DOCTOR OF PHILOSOPHY

Early Applied Behaviour Analytic Interventions for Children Diagnosed with Autism Spectrum Disorder: A cross-national study of the UK and China

Liao, Yini

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Early Applied Behaviour Analytic Interventions for Children Diagnosed with Autism Spectrum Disorder:

A cross-national study of the UK and China

By

Yini Liao MRes, B.L.

A thesis submitted in fulfilment of the requirements for the

Degree of Doctor of Philosophy

Queen’s University Belfast

School of Social Sciences, Education and Social Work

20 February 2017
### Table of Contents

List of figures ........................................................................................................ VII
List of tables ........................................................................................................ IX
Abstract ................................................................................................................. XI
Acknowledgements ................................................................................................ XII
Abbreviations ......................................................................................................... XIII

**Chapter 1. Introduction** .................................................................................. 1
  1.1 Overview ........................................................................................................ 1
  1.2 Background .................................................................................................... 1
    1.2.1 Definition of ABA .................................................................................. 2
    1.2.2 Definition of EIBI .................................................................................. 2
    1.2.3 Definition of ASD .................................................................................. 2
  1.3 Research aims, objectives and questions ...................................................... 3
    1.3.1 Central research question and aims of study ........................................ 3
    1.3.2 Research objectives ............................................................................. 3
    1.3.3 Research questions for each study ....................................................... 4
  1.4 Comparative research ................................................................................... 4
    1.4.1 Theoretical framework ......................................................................... 5
    1.4.2 Practical reasons - Understanding the differences ................................ 11
  1.5 Thesis layout .................................................................................................. 13

**Chapter 2. Autism spectrum disorder** .............................................................. 15
  2.1 Chapter overview ......................................................................................... 15
  2.2 History of autism research ......................................................................... 15
  2.3 Diagnosis criteria and screening instruments .......................................... 17
    2.3.1 Diagnostic and Statistical Manual (DSM) ............................................ 17
    2.3.2 International Classification of Disease (ICD) ...................................... 18
    2.3.3 Screening and diagnosis .................................................................... 19
  2.4 Prevalence of autism spectrum disorder .................................................... 22
    2.4.1 Prevalence of ASD in the UK ............................................................... 23
    2.4.2 Prevalence of ASD in China ................................................................. 23
  2.5 Aetiology and treatment ........................................................................... 24
    2.5.1 Aetiology ............................................................................................... 24
    2.5.2 Medical treatment and interventions .................................................. 25
  2.6 Children with ASD and the context of policy .......................................... 29
    2.6.1 Policy background in the UK ............................................................... 29
    2.6.2 Policy background in China ................................................................. 32
  2.7 Children with ASD and the context of society and culture ...................... 36
2.7.1 Autism awareness and knowledge .............................................. 36
2.7.2 Family culture ........................................................................... 37
2.7.3 Mass media ............................................................................... 38
2.8 Chapter summary .......................................................................... 39

Chapter 3. Applied behaviour analysis ............................................. 40
3.1 Chapter overview .......................................................................... 40
3.2 Behaviourism ................................................................................ 40
3.3 The experimental analysis of behaviour ......................................... 41
3.4 Applied behaviour analysis ........................................................... 43
3.5 Early intensive behavioural intervention ....................................... 47
  3.5.1 School-, centre- or community-based behavioural intervention ... 49
  3.5.2 Home-based behavioural intervention ..................................... 49
  3.5.3 Core components of EIBI ......................................................... 50
3.6 ABA-based intervention in the UK ................................................ 52
  3.6.1 Rapid reviews of ABA-based interventions in the UK ............. 52
3.7 ABA-based intervention in China ................................................. 62
  3.7.1 Rapid reviews of ABA-based interventions in China ............. 62
3.8 The Census study in Victoria, Australia .......................................... 70
3.9 Chapter summary .......................................................................... 71

Chapter 4. Methodology ................................................................. 72
4.1 Overview ....................................................................................... 72
4.2 Methods of data collection ........................................................... 72
  4.2.1 Ethical considerations ............................................................. 73
  4.2.2 Main sample sites ................................................................. 74
4.3 Pilot study ..................................................................................... 81
4.4 Study 1: Surveys .......................................................................... 83
  4.4.1 Rationales for the surveys ....................................................... 83
  4.4.2 Participants ............................................................................. 83
  4.4.3 Instruments ............................................................................. 96
  4.4.4 Research procedures ............................................................... 101
  4.4.5 Data analysis ......................................................................... 104
4.5 Study 2: Semi-structured interviews ........................................... 106
  4.5.1 Rationales for semi-structured interviews ............................. 106
  4.5.2 Participants ............................................................................. 106
  4.5.3 Instruments ............................................................................. 114
  4.5.4 Research procedures ............................................................... 116
  4.5.5 Data analysis ......................................................................... 119
4.6 Study 3: Direct observations ....................................................... 123
Chapter 5. Results of surveys ................................................................. 137

5.1 Overview .................................................................................. 137

5.2 Children’s diagnosis, length of wait and hours of care ............... 137
  5.2.1 Children’s diagnosis .......................................................... 137
  5.2.2 Children on the wait-list for ABA programme ..................... 140
  5.2.3 Length of time of parental care/support for the child ............ 142

5.3 ABA-based behaviour intervention programmes ...................... 142
  5.3.1 Way to find about ABA-based interventions ....................... 142
  5.3.2 Recommendation on ABA services .................................... 143
  5.3.3 Number of supervision hours that parents received .............. 143
  5.3.4 Parents’ cost and payment methods on the ABA-based programme .................. 144
  5.3.5 Mode of service delivery of the ABA-based programme .......... 146
  5.3.6 Areas addressed in the ABA-based programme .................... 156
  5.3.7 Skills generalised to daily life .......................................... 156
  5.3.8 Programme inclusion ....................................................... 157
  5.3.9 Programme’s involvement of overseas organisations or professionals .... 160
  5.3.10 Other types of services accessed by children ................. 161

5.4 EIBI programmes .................................................................... 162
  5.4.1 Age of beginning the intervention ..................................... 163
  5.4.2 Intensity ........................................................................ 163
  5.4.3 Duration ......................................................................... 163
  5.4.4 Cost of the EIBI programme ........................................... 164

5.5 Data collection of the programme ........................................... 166

5.6 Professionals’ working status and self-evaluation .................... 168
  5.6.1 Number of children worked with ..................................... 168
  5.6.2 Length of time working in the area of ABA ....................... 169
  5.6.3 Training undertaken ....................................................... 169
  5.6.4 Self-evaluation of the skills and techniques ....................... 170
  5.6.5 Frequency of accessing research evidence on ABA .......... 172
  5.6.6 Parents’ perception of professionals’ support ................... 172

5.7 Parents who worked as ABA therapists .................................. 173
  5.7.1 Reasons for being an ABA therapist ................................. 173
  5.7.2 Types of training received .............................................. 174
Chapter 7. Results of direct observations ...................................................... 249
  7.1 Overview .................................................................................................. 249
  7.2 Parents ...................................................................................................... 249
    7.2.1 UK parents ......................................................................................... 249
    7.2.2 Chinese parents ................................................................................. 261
  7.3 Professionals ............................................................................................. 275

Chapter 6. Results of qualitative interviews .................................................... 178
  6.1 Overview .................................................................................................. 178
  6.2 Children’s diagnosis .................................................................................. 178
    6.2.1 Pre-diagnosis ..................................................................................... 178
    6.2.2 Diagnosis and the health service ....................................................... 181
    6.2.3 Post-diagnosis ................................................................................. 185
    6.2.4 Accessing ABA-based intervention .................................................. 188
  6.3 ABA-based behaviour intervention programmes ....................................... 191
    6.3.1 UK ABA-based programme ............................................................... 191
    6.3.2 Chinese ABA-based intervention programme ................................... 196
    6.3.3 EIBI programmes ............................................................................. 206
    6.3.4 Professionals’ skills and qualifications ............................................... 211
    6.3.5 Parents who worked as ABA therapists ............................................. 213
    6.3.6 Co-operation among professionals and parents ................................. 218
    6.3.7 Children’s changes ........................................................................... 221
  6.4 ABA and the school ................................................................................. 225
    6.4.1 UK: ABA and schools ....................................................................... 225
    6.4.2 China: ASD, school and ABA ............................................................. 229
    6.4.3 UK and China: A ‘battle’ with the school .......................................... 231
  6.5 ABA and policy context ............................................................................ 232
    6.5.1 UK: ABA and policy support ............................................................. 232
    6.5.2 China: ABA and policy support ........................................................ 234
  6.6 ASD, ABA, and societal and cultural contexts .......................................... 237
    6.6.1 Acceptance by the society ................................................................. 237
    6.6.2 Eclectic approach ............................................................................. 240
    6.6.3 Different development of ABA .......................................................... 242
  6.7 Chapter summary ..................................................................................... 247

Chapter 5. Results of quantitative interviews .................................................... 176
  5.1 Overview .................................................................................................. 176
  5.2 Barriers experienced by parents ............................................................... 176
  5.3 Professionals ............................................................................................. 176
  5.4 Changes after starting the programme ..................................................... 178
    5.4.1 Changes of children’s quality of life .................................................. 178
    5.4.2 Reasons for changes of child’s quality of life ...................................... 179
  5.5 Chapter summary ..................................................................................... 179

IV
<table>
<thead>
<tr>
<th>Appendix</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 7</td>
<td>UK parents’ questionnaire</td>
<td>370</td>
</tr>
<tr>
<td>Appendix 8</td>
<td>Chinese parents’ questionnaire</td>
<td>390</td>
</tr>
<tr>
<td>Appendix 9</td>
<td>UK therapists’ questionnaire</td>
<td>406</td>
</tr>
<tr>
<td>Appendix 10</td>
<td>UK supervisors’ questionnaire</td>
<td>418</td>
</tr>
<tr>
<td>Appendix 11</td>
<td>Chinese professionals’ questionnaire</td>
<td>434</td>
</tr>
<tr>
<td>Appendix 12</td>
<td>Participant Call poster</td>
<td>444</td>
</tr>
<tr>
<td>Appendix 13</td>
<td>UK parents’ interview schedule</td>
<td>445</td>
</tr>
<tr>
<td>Appendix 14</td>
<td>UK professionals’ interview schedule</td>
<td>448</td>
</tr>
<tr>
<td>Appendix 15</td>
<td>Chinese parents’ interview schedule</td>
<td>451</td>
</tr>
<tr>
<td>Appendix 16</td>
<td>Chinese professionals’ interview schedule</td>
<td>455</td>
</tr>
<tr>
<td>Appendix 17</td>
<td>Excerpts of quotations from Chinese interviewees</td>
<td>459</td>
</tr>
<tr>
<td>Appendix 18</td>
<td>Excerpts of one UK interviewee transcription</td>
<td>462</td>
</tr>
<tr>
<td>Appendix 19</td>
<td>Data recording sheet of direct observations</td>
<td>466</td>
</tr>
<tr>
<td>Appendix 20</td>
<td>Invitation letter from a Chinese sample site</td>
<td>467</td>
</tr>
<tr>
<td>Appendix 21</td>
<td>Reasons for the change of child’s quality of life</td>
<td>468</td>
</tr>
<tr>
<td>Appendix 22</td>
<td>Barriers experienced while accessing ABA services</td>
<td>469</td>
</tr>
</tbody>
</table>
List of figures

Figure 1.1: Inside and outside view of living history .................................................. 9
Figure 1.2: Inside and outside view of research experience ........................................ 10
Figure 1.3: Layout of the thesis .................................................................................. 13
Figure 3.1: Prisma chart of rapid reviews of ABA-based interventions in the UK ...54
Figure 3.2: Prisma chart of rapid reviews on ABA-based interventions in China
(English articles) ....................................................................................................... 64
Figure 3.3: Prisma chart of rapid reviews on ABA-based interventions in China
(Chinese articles) ....................................................................................................... 66
Figure 4.1: The structure of data collection approach .................................................. 72
Figure 4.2: Home training between a mother and her son .......................................... 75
Figure 4.3: Playday ...................................................................................................... 76
Figure 4.4: Parents’ practice session in small classroom .............................................. 77
Figure 4.5: Outdoor activities .................................................................................. 79
Figure 4.6: Afternoon exercise .................................................................................. 80
Figure 4.7: Homework .................................................................................................. 81
Figure 4.8: UK participants’ country of residence ...................................................... 84
Figure 4.9: UK participants’ national identity .............................................................. 85
Figure 4.10: Chinese participants’ place of residence ............................................... 85
Figure 4.11: Participants’ distribution by regional geography ....................................... 86
Figure 4.12: Urban and rural residence of participants .............................................. 86
Figure 4.13: Chinese professional participants’ place of residence ......................... 93
Figure 4.14: Chinese professional participants’ current work location ...................... 93
Figure 4.15: Role of UK supervisor participants ....................................................... 95
Figure 4.16: Role of UK therapist participants ......................................................... 95
Figure 4.17: Role of Chinese professional participants .............................................. 96
Figure 4.18: Workshop in China facilitated by the researcher .................................... 103
Figure 4.19: Sample data output .............................................................................. 135
Figure 5.1: Payment methods for ABA-based programme ....................................... 146
Figure 5.2: Reasons for taking non-intensive programmes ....................................... 150
Figure 5.3: Specific approaches in the service delivery ............................................ 151
Figure 5.4: Other services provided by UK supervisor participants .......................... 152
Figure 5.5: Guidelines/training manuals that were followed in the programme ...... 153
Figure 5.6: Skills generalised to child's daily life .......................................................... 157
Figure 5.7: Child’s special interests incorporated into the programme ....................... 159
Figure 5.8: Family’s concern incorporated into the programme .............................. 160
Figure 5.9: Changes of child’s quality of life ................................................................ 175
Figure 7.1: Accuracy levels during discrete trials for Daisy ...................................... 254
Figure 7.2: Submarines captured from the internet (AZ Colouring, 2012) ................. 256
Figure 7.3: Mark’s drawing generalisation procedure ............................................... 257
Figure 7.4: Example of 24 alphabet blocks (My Wooden Toys, 2016) ........................ 258
Figure 7.5: Accuracy levels during discrete trials for Mary ...................................... 260
Figure 7.6: Accuracy levels during discrete trials for Ling ........................................ 265
Figure 7.7: Accuracy levels during discrete trials for Meimei ................................. 269
Figure 7.8: Accuracy levels during discrete trials for Wangjun ............................... 274
Figure 7.9: Accuracy levels during discrete trials for Jane ....................................... 278
Figure 7.10: Accuracy level of discrete trials for Xiaohong (Session 1) ................... 280
Figure 7.11: Accuracy level of discrete trials for Xiaohong (Session 2) .................... 282
Figure 7.12: Individualised training at Hebei GC School ......................................... 283
Figure 7.13: Accuracy level of discrete trials for Liumei ........................................ 284
Figure 9.1: A model of relationship for children with ASD ...................................... 320
List of tables

Table 2.1: Prevalence of ASD reported by CDC (2002-2010) .................................22
Table 3.1: Methods of the 36 empirical studies in the UK.......................................55
Table 4.1: Class schedule example for one of the classes .....................................78
Table 4.2: Demographic information of survey participants .................................87
Table 4.3: Parents’ working/employment status ..................................................88
Table 4.4: Participants’ highest education qualifications ........................................89
Table 4.5: Participants’ family annual income ......................................................90
Table 4.6: National identify and country of work ..................................................92
Table 4.7: Professional participants’ highest education qualifications ...................94
Table 4.8: Professional participants’ employment ...............................................94
Table 4.9: Example of content analysis for open-ended questions .........................105
Table 4.10: A summary of UK parent interviewees ............................................108
Table 4.11: A summary of UK professional interviewees .....................................110
Table 4.12: A summary of Chinese parent interviewees ......................................112
Table 4.13: A summary of Chinese professional interviewees ............................114
Table 4.14: Sample of codes ...........................................................................121
Table 4.15: Metrics for assessing the application of DTT .................................130
Table 5.1: Children’s diagnoses for survey sample .............................................138
Table 5.2: Diagnosticians of the children with ASD ...........................................139
Table 5.3: Children’s age of diagnosis (in year) ..................................................140
Table 5.4: Children’s age of starting ABA-based programmes ............................141
Table 5.5: Number of hours per week providing help or care for the child ..........142
Table 5.6: Amount of supervision received per month (in hours) .......................144
Table 5.7: Team meetings with therapists/supervisors in the UK .........................144
Table 5.8: Cost reported on ABA-based programmes .......................................145
Table 5.9: Mode of service delivery reported by parents .....................................147
Table 5.10: Mode of service delivery reported by professionals .........................148
Table 5.11: Characteristics of current ABA programmes ...................................149
Table 5.12: Services undertaken by Chinese participants ...................................155
Table 5.13: Areas addressed in child’s ABA-based programmes .......................156
Table 5.14: Professionals’ co-operation into the programme (1) .......................158
Table 5.15: Professionals’ co-operation into the programme (2) .......................158
Table 5.16: The involvement of overseas organisations ........................................... 161
Table 5.17: Other types of services accessed by children ............................................. 162
Table 5.18: Cost of undertaking EIBI programme ................................................... 164
Table 5.19: Techniques utilised in the EIBI programme ............................................. 165
Table 5.20: Features of the EIBI programme ............................................................ 166
Table 5.21: Data collection in ABA-based programmes reported by parents ............ 167
Table 5.22: Data collection in ABA-based programmes reported by professionals 167
Table 5.23: Training undertaken by professionals ................................................... 170
Table 5.24: Participants’ self-evaluation of skills relating to children with ASD ....... 171
Table 5.25: Participants’ self-evaluation of applying ABA techniques ..................... 171
Table 5.26: Frequency in accessing ABA research evidence .................................... 172
Table 5.27: Parents’ perception of the extent of professionals’ supportiveness ...... 173
Table 5.28: Reasons for working as an ABA therapist ............................................. 173
Table 5.29: Types of training received ........................................................................ 174
Table 6.1: Age of child when parents identified developmental delay (in months) 179
Table 6.2: Children’s age when diagnosed (in month) ............................................ 182
Table 7.1: Summary of accurate trials instructed by Daisy ..................................... 250
Table 7.2: Summary of accurate trials instructed by Mary ...................................... 255
Table 7.3: Summary of accurate trials instructed by Ling ...................................... 261
Table 7.4: Summary of accurate trials instructed by Meimei .................................. 266
Table 7.5: Summary of accurate trials instructed by Wangjun ............................... 270
Table 7.6: Summary of accurate trials instructed by Jane ..................................... 275
Table 7.7: Summary of accurate trials instructed by Xiaohong ............................. 279
Table 7.8: Summary of accurate trials instructed by Liumei ................................. 283
Abstract

This study explores the application of behaviour analytic practices for children with autism in two geographical and culturally diverse regions, the UK and China, through a mixed method research approach. A survey was conducted with 97 parent respondents, consisting of 12 UK parents, and 85 Chinese parents and with 90 professional respondents, consisting of 24 UK professionals (10 supervisors and 14 therapists) and 66 Chinese professionals. Semi-structured interviews were conducted with 18 UK and 18 Chinese participants. A total of 8 cases were considered, consisting of 5 observations on parents (2 from Northern Ireland and 3 from Northern China) and 3 observations on professionals (1 therapist from Northern Ireland and 2 teachers from Northern China).

There were substantial differences in types of service delivery between the UK and China. Specifically, in the UK, professionals played a leading role, while in China, parents took a more active role than professionals. Home-based programmes were the most common mode of service delivery in the UK while in China, the majority of which were organized through autism organisations. Chinese parents tended to move away from home temporarily to access good quality programmes. The wide-spread application of high calibre Early Intensive Behavioural Intervention (EIBI) was not yet established in statutory sectors of the UK and China.

However, there were important similarities between the two regions despite culture, population, policy, economy and societal differences. Parents of both countries reported that their child’s quality of life improved after the ABA-based programme. An eclectic approach was reported by participants from each country. A number of parents ran ABA-based training sessions for their child as a parent therapist. Professionals and many parents indicated their willingness to advance professional levels.

Data from the cross-national comparisons provided for discussion on the reasons for different types of service delivery of ABA in their respective environments. Recommendations are outlined for future practice in international contexts.

**Key words:** Autism; ABA; service delivery; comparative research
Acknowledgements

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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ABA</td>
<td>Applied Behaviour Analysis</td>
</tr>
<tr>
<td>ABC</td>
<td>Autism Behaviour Checklist</td>
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<tr>
<td>ABIA</td>
<td>Autism Behavioural Intervention Association</td>
</tr>
<tr>
<td>ABC</td>
<td>Antecedent, Behaviour and Consequence</td>
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<tr>
<td>ADI</td>
<td>Autism Diagnostic Interview</td>
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<td>ADOS</td>
<td>Autism Diagnostic Observation Schedule</td>
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<tr>
<td>APA</td>
<td>American Psychiatric Association</td>
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<tr>
<td>AS</td>
<td>Asperger Syndrome</td>
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<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<td>BACB</td>
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<td>BHNMU</td>
<td>Brain Hospital of Nanjing Medical University</td>
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<td>CAM</td>
<td>Complementary and Alternative Medicine</td>
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<td>ICD</td>
<td>International Classification of Disease</td>
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<td>CDC</td>
<td>Centre for Disease Control</td>
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<td>CDPF</td>
<td>China Disabled Persons’ Federation</td>
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<td>CHAT</td>
<td>Checklist for Autism in Toddlers</td>
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<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
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<td>DTT</td>
<td>Discrete Trial Teaching</td>
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<td>EAB</td>
<td>Experimental Analysis of Behaviour</td>
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<td>EHCP</td>
<td>Education, Health and Care Plan</td>
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<td>EIBI</td>
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</tr>
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<td>Journal of Applied Behaviour Analysis</td>
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</tr>
<tr>
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</tr>
<tr>
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</tr>
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</tr>
<tr>
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<td>National Institute for Health and Care Excellence</td>
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<tr>
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<td>Occupational Therapy</td>
</tr>
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<td>People’s Republic of China</td>
</tr>
<tr>
<td>PBCMA</td>
<td>Psychosis Branch of Chinese Medical Association</td>
</tr>
<tr>
<td>PDD</td>
<td>Pervasive Developmental Disorder</td>
</tr>
<tr>
<td>PDD-NOS</td>
<td>Pervasive Developmental Disorder-Not Otherwise Specified</td>
</tr>
<tr>
<td>PDDST</td>
<td>Pervasive Developmental Disorders Screening Test</td>
</tr>
<tr>
<td>PECS</td>
<td>Picture Exchange Communication System</td>
</tr>
<tr>
<td>RBT</td>
<td>Registered Behaviour Technician</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Control Trial</td>
</tr>
<tr>
<td>SALT</td>
<td>Speech and Language Therapist</td>
</tr>
<tr>
<td>SAS</td>
<td>Shenzheng Autism Society</td>
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<td>SCD</td>
<td>Social Communication Disorder</td>
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<tr>
<td>SEN</td>
<td>Special Educational Needs</td>
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<tr>
<td>STAT</td>
<td>Screening Tool for Autism in Toddlers and Young Children</td>
</tr>
<tr>
<td>TCM</td>
<td>Traditional Chinese Medicine</td>
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<tr>
<td>TEACCH</td>
<td>Treatment and Education of Autistic and Related Communication Handicapped Children</td>
</tr>
<tr>
<td>UCLA YAP</td>
<td>University of California-Los Angeles Young Autism Project</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<td>UN</td>
<td>United Nations</td>
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<tr>
<td>UPIAS</td>
<td>Union of Physically Impaired Against Segregation</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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Chapter 1. Introduction

1.1 Overview

Applied Behaviour Analysis (ABA)-based interventions have proved to be an effective approach for children\(^1\) diagnosed with Autism Spectrum Disorder (ASD). It is reported that the prevalence of people diagnosed with ASD increases year by year but causes of ASD are still unknown. Early Intensive Behavioural Intervention (EIBI) falls under the umbrella of ABA and proves to be effective in improving the majority of children’s IQ, language, life skills, cognitive and functional behaviours (Lovaas, 1987; Fein et al., 2013).

However, most of the research is conducted in the USA and Canada, with some data from the UK. There is virtually no research on this topic from China and there is little research that covers a comparison between countries of practices in early applied behaviour analytic interventions for children diagnosed with ASD.

Unlike in many of the experiments of ABA-based interventions, quantitative and qualitative techniques were combined to study the current provision of early applied behaviour analytic interventions for children with ASD. The field work generated 187 completed questionnaires, 36 taped semi-structured interviews and 8 completed direct observation cases. The focus of the present study is to establish a comprehensive and nuanced understanding of the similarities and differences in ABA-based intervention programmes for children with ASD in the UK and China\(^2\).

1.2 Background

The researcher’s Master’s dissertation at University of York (Liao, 2013) explored ABA-based interventions for children diagnosed with ASD between England and China, in which qualitative interviews were conducted with 7 participants (5 professionals and 2 parents) from England and 8 participants (5 professionals and 3 parents) from China. Findings indicated cultural and policy differences in the delivery of ABA-based early interventions for children with autism in UK and China.

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\(^1\) Child is defined as a person who is below 18 years of age (UN Convention on the Rights of the Child, 1989), but for this article, children under 16 years of age (16 inclusive) are included for the study.

\(^2\) For this article, UK is defined as the United Kingdom; China is defined as the People’s Republic of China, while the study focused on mainland China.
(Liao, Dillenburger & Buchanan, 2016). In this Master’s research, questions about EIBI were also asked but few participants reported having heard about it or utilised it. It is probable that such a small number of qualitative interviews could not reflect the true extent of EIBI use in each country. Nevertheless, the Master’s research can be regarded as a pilot study of the present research.

In order to understand the real reason for the popularity of EIBI in the UK and China, mixed methods were used and targeted at a larger population. In addition, confining the topic to EIBI is overly restrictive and will not be representative of the views on ABA-based intervention. Hence the topic was broadened to ‘Early applied behaviour analytic interventions for children with ASD’.

1.2.1 Definition of ABA
‘Applied Behaviour Analysis (ABA) is the science in which tactics derived from the principles of behaviour are applied systematically to improve socially significant behaviour where experimentation is used to identify the variables responsible for behaviour changes’ (Cooper, Heron, & Heward, 2007).

1.2.2 Definition of EIBI
Early Intensive Behavioural Intervention (EIBI) falls under the umbrella of ABA-based interventions and commonly includes Discrete Trial Teaching (DTT) and Natural Environment Training (NET) (Lovaas, 1987). EIBI was proven to be effective to improve the IQ, language, daily life skills, cognitive and functional behaviours for the majority who underwent intervention (Lovaas, 1987; Fein et al., 2013).

1.2.3 Definition of ASD
Autism Spectrum Disorder (ASD) is considered to be a neurodevelopmental disorder. People diagnosed with ASD displayed difficulties in social communication and interaction, along with restricted or ritualised behaviours and sensory issues (WHO, 2011; APA, 2013).
1.3 Research aims, objectives and questions

1.3.1 Central research question and aims of study
The central research question is: What are the similarities and differences in ABA-based intervention programmes for children diagnosed with ASD in the UK and China?

More specifically the study aims:

- To understand current provision of health care for children with ASD.
- To identify the categories of service delivery of ABA-based intervention programmes in each country and the associated cost, support, access, and perceived effectiveness.
- To explore the extent to which children with ASD have access to the ABA-based interventions (specifically EIBI).
- To understand changes observed in the child’s behaviour and the relationship with other professionals during or after involvement in programmes.
- To explore parents’ and professionals’ experiences with local ABA provisions in both countries.
- To explore difficulties faced and to understand intrinsic reasons and to put forward recommendations.

1.3.2 Research objectives
In order to address these research aims, a mixed methods approach was used to collect data in three distinct studies.

- Study 1: Surveys were carried out, including parents, professionals and provider organisations, in both countries to establish the practice and policies related to ABA-based interventions (specifically EIBI). A similar survey was completed in Australia in 2014, which allowing for further international comparisons.
- Study 2: A number of in-depth interviews were carried out, including parents, professionals and provider organisations, in both countries to establish personal experiences in the practices related to ABA-based interventions (specifically EIBI).
• Study 3: Detailed direct observations were carried out, including parents, professionals and provider organisations, in both countries to establish differences and similarities in the practice of ABA-based interventions (specifically DTT).

1.3.3 Research questions for each study
The specific research questions addressed in each of the three distinctive studies were as follows:

1.3.3.1 Research questions addressed in Study 1- Surveys
1. What is the current situation and mode of delivery of ABA-based intervention programmes for children diagnosed with ASD in the UK and China?
2. To what extent is EIBI used for children with ASD in the UK and China?
3. How do professionals and parents work as ABA therapists?
4. What kind of changes do parents and children have after the ABA-based intervention programmes and what are the barriers experienced?

1.3.3.2 Research questions addressed in Study 2- Semi-structured interviews
1. What other popular therapies are also used in addition to ABA?
2. What is participants’ understanding towards the children diagnosed with ASD?
3. What categories of the ABA-based intervention programme are used in each country and how do culture, policy and society impact service delivery?
4. To what extent are EIBI services used in the UK and China and why?
5. What are the challenges faced by families?

1.3.3.3 Research questions of Study 3- Direct observations
Is the application of Discrete Trial Training (DTT) the same across cultural divides?

1.4 Comparative research
The concept of comparative research includes a theoretical as well as a practical framework. These are important for the present comparison between ABA-based practices in the UK and China.
### 1.4.1 Theoretical framework

#### 1.4.1.1 Comparative research

The comparative research encompassed many topics, such as comparative politics (e.g., Lijphart, 1971; Turgeon, Papillon, Wallner & White, 2014), comparative social policy (e.g., Turgeon et al., 2014), comparative study of society and history (e.g., Confino, 2011), cross-cultural comparative study (e.g., Brislin, 1976) and cross-national study (e.g., Merritt & Rokkan, 1966). The theoretical framework of comparative research is broad and varied, including emphasizing specific subjects like Lor (2010), studying the comparative librarianship, or more generally, the comparative study of international social research (e.g., Øyen, 1990). The key in comparative research is that specific topics are not isolated from one another, but are viewed as interrelated. For example, Belfiore (2004) compared cultural policy between Britain and Italy; Confino (2011) compared history and culture between Russia and other European countries.

As such, the comparative method is a basic scientific approach or research strategy with a clear focus, an exploration of the relationship among a number of different variables (Lijphart, 1971). Lijphart’s early contribution to comparative methods is widely regarded as one of the most influential and has inspired many scholars to undertake comparative research since the 1970s (Enli, 2010). Comparative research is particularly prevalent in social research (Vallier & Apter, 1973; Caramani, 2008), as it reflects an important part in people’s lives: ‘the novelty in the social sciences today is not comparative research but the primary reasons for undertaking it’ (Swanson, 1971, p145).

However, comparative methods are not without limitations. For example, Confino (2011) noted from a historian’s perspective that comparative research usually assumes that events or individuals are in the same category. This assumption neglects the fact that each event or each individual is unique and therefore the comparison of two events/people does not have a common starting point.

In addition, the post-modernist Rosenau (1992, p105) denied the possibility of representative comparisons and questioned ‘the very act of comparing, in an effort to uncover differences and similarities, a meaningless activity because postmodern
epistemology holds it impossible ever to define adequately the elements to be contrasted or likened’. However, Confino (2011) argued that the historical events or processes at different times across different countries are comparable and implied that they can contain common features, either structural or functional. In fact, he argued, these differences can be helpful in the process of evaluating the significance of similarities.

These seemingly diametrically opposed perspectives provide different conceptualisations of comparative research. The focus of the central research question in the present study lies in cross-national research.

Cross-national research is a subset of comparative research (Kohn, 1987). Slomczynski, Miller and Kohn (1981) indicated that if a difference is apparently identified in social structure and personality across countries, it is necessary to emphasize the heterogeneity from country to country, so as to better and more easily interpret the social phenomenon. Against this background, there are obvious differences in social structures and peoples between a Western country, in this case the UK, and an Eastern country, in this case China, which demands an acknowledgement of the heterogeneity in culture, policy, economy and history between these two countries (Slomczynski et al., 1981). However, Kohn (1987) argued that issues cannot be simply characterised as similar or dissimilar but rather exist on a continuum of likeness. The crucial part of the comparative research is to focus on explaining or interpreting findings rather than directly comparing in a binary manner (Przeworski, 1987).

In the present study, mixed methods were employed in the UK and China to gain a comprehensive understanding of a spectrum of similarities and differences (Kohn, 1987) about early ABA-based interventions in culturally and historically grounded, socially mediated, and politically applied experiences and events. The research methods included surveys, interviews, and direct observations.

1.4.1.2 Cross-national study

Verba (1973, p309) claimed that: ‘If survey research is to be useful in understanding nations it must be cross-national.’ However, it is not easy to conduct cross-national surveys, and the common problems are the ‘many variables [and] small number of
cases’ (Lijphart, 1971, p685). The most challenging problem faced by comparative research is identifying and defining variables that are comparable (Lijphart, 1971; Verba, 1973). Ragin (1987), a statistical sociologist, admitted that often the greatest difficulty is to identify large enough sample sizes and thus strengthen the comparability of variables in the statistical world of quantitative research. Therefore it is recommended to merge similar variables into one, using acceptable similarity in the variables to establish relationship among them and bypass questions of minor importance but to focus on key points (Lijphart, 1971). In addition, Verba (1973) indicated that the measurements of variables in two different regions rendered cross-national surveys unable to compare while considering the societal and cultural difference.

In order to increase the comparability in the cross-national survey research, Verba (1973) suggested considering the structure and cultural factors in the research design. Ragin (1987) and Macinnes (2006) suggested that combining the variable-oriented quantitative study and the case-oriented qualitative study can increase comparability. On this basis, the research design in the present study included quantitative as well as qualitative methods (see Chapter 4-Methodology).

1.4.1.3 Inside and outside perspective

The theoretical framework of Study 2, which contains qualitative interviews with parents and professionals, is based on the inside and outside perspective. The inside and outside perspective had been traditionally linked with *emic* and *etic* in cultural research respectively (Morris, Leung, Ames & Lickel, 1999).

The terms *emic* and *etic* were coined by Pike (1954), a linguist, from the words phonemic (i.e., being able to distinguish the smallest units of sounds, such as the individual sounds of a word) and phonetic (i.e., a direct correspondence between symbols and sounds). The inside view, *emic*, focused on taking a native point of view, while the outside view or objective observation, *etic*, focused on taking a culturally neutral perspective.

Culture is a set of *behaviour, attitudes* and *symbols* that is shared by a large group of people from one generation to another (Shiraev & Levy, 2015). *Behaviour* denotes ‘norms, roles, customs, traditions, habits, practices and fashions’ (Shiraev & Levy,
Attitude involves traditional ideas, knowledge, beliefs, opinions and their attached values (Brislin, 1976; Shiraev & Levy, 2015) and symbol is a mark or character representing something or someone (Martin & McIntyre, 1994; Shiraev & Levy, 2015). By acknowledging the impact of the past experience of the researcher in the research process, Pike’s work steered a popular trend from the analysis of language to the analysis that emanates from an understanding of the behaviour stream (Harris, 1976).

The inside and outside perspectives are widely used in cross-cultural research (Triandis et al., 1986; Morris et al., 1999; Shiraev & Levy, 2015; Cheng, Shu, Zhou, & Lam, 2016). Brislin (1976) demonstrated the emic-etic dimension in cross-cultural psychology research and Morris et al. (1999) integrated the inside and outside view with emic and etic insights. Here, the inside (emic) perspective was used to describe the social behaviour and local people’s values which leads the researcher to understand the local people’s language, culture and their daily lives, ‘including their attitudes, motives, interests and personality’ (Berry, 1999, p167). It denotes the in-group (Brislin, 1976). Then, the outside (etic) perspective is used to illustrate from an external perspective and generalise across cultures considering all human behaviour. It denotes the out-group (Brislin, 1976) and provides an overall perspective for the researcher to explore the similarities and differences across cultural events (Berry, 1999).

Based on these theories, the researcher developed two figures to describe the outside view and inside view for this research. These could be reflected in terms of the researcher’s living history (Figure 1.1) and her research experience (Figure 1.2).

First, the living history in each country denotes her different understating of world view, thought pattern and ideology (Figure 1.1). As the researcher had lived in China for more than 20 years, there has been a deep understanding of the indigenous Chinese culture, way of thinking, language and lifestyle. The researcher understands the social norms and culture in social communication and social interaction. This advantage was reflected in the field work: the researcher did not need lengthy explanations because of the sense of belonging. In addition, the researcher lived near the school and participants’ home. As a Chinese proverb goes: ‘A far-off relative is
not as helpful as a near neighbour\textsuperscript{3}, the neighbourhood community made the researcher part of the ‘in-group’.

![Diagram of UK and China]

**Figure 1.1**: Inside and outside view of living history

Though the researcher has been living in the UK for more than 4 years, in reality, she was considered to be an outsider to the UK because of the immigration policies. In addition, the researcher had a relatively lower understanding of UK cultural and social norms compared to local people. Nevertheless, it should be noted that being an outsider does not necessarily have to be a disadvantage in research because, for example, in the field work participants might be more willing to explain something which was regarded as normal to a researcher not familiar with the in-group norms or culture. Furthermore, because of her outside status, people might be more open to her without sensitivity issues. This was reflected when participants freely described their experiences with the health care system and the local authority.

Second, the research experiences changes her position (Figure 1.2). Though the researcher was born in China and lived there for more than 20 years, she had little knowledge and understanding of children with ASD and ABA before coming to the UK. Under this circumstance, the researcher could be viewed as an outsider, which provided an objective and neutral perspective for this topic. The researcher began systematic training in ABA and practised the ABA-based intervention with children with ASD at a UK university and a local autism charity as well as becoming certified as a Registered Behaviour Technician (RBT) by the Behaviour Analyst Certification

\textsuperscript{3} In Chinese: 远亲不如近邻
Board (BACB) in March 2015. The field work in the UK made the researcher stand as an insider with regards to ABA and ASD and then, generalising the research across to China, as an outsider.

![Figure 1.2: Inside and outside view of research experience](image)

In fact, the inside and outside perspective could not be separated because the emic and etic should never be dichotomised. They offer two different perspectives in the interpretation of the same contextual information. As Pike (1954, p41) stated:

*Through the etic ‘lens’ the analyst views the data in tacit reference to a perspective oriented to all comparable events (whether sounds, ceremonies, activities), of all people, of all parts on earth; through the other lens, the emic one, he views the same events in that particular culture, as it and it alone is structured. The result is a kind of ‘tri-dimensional understanding’ of human behaviour instead of a ‘flat’ etic one.*

1.4.1.4 Comparative case study

The comparative case study offers a detailed look at the minutiae of life in different cultures (Lijphart, 1971). The debate about the value and definition of comparative case study in social science is not new (Thomas, 2011), as it has been challenged by empirical-oriented scientist (Ragin, 1987). However, case study is a recognised tool for empirical inquiry particularly because it recognises that the boundaries between a phenomenon and the real life context are often not clear (Yin, 1981, 2003). Ragin (1987) indicated that a case study can provide a detailed portrait of a particular
phenomenon. Arguably, the case study cannot represent a large population and usually cannot be replicated (McLeod, 2008; Murphy, 2014). Yin (1981) argued that case study should not be only considered as a product of interpretivism, such as the participant observation; instead, Kaarbo and Beasley (1999, p372) defined the comparative case study as ‘the systematic comparison of two or more data points (case) obtained through use of the case study method’, which indicated comparative case study applies to both the quantitative research methods such as survey, and the qualitative research methods, such as interviews.

The Study 3 of the present research was a case study in exploring the application of ABA-based interventions, specifically Discrete Trial Training, in the UK and China, while the other two studies focussed on more general comparisons of service delivery and lived experiences (Yin, 1981; Kaarbo & Beasley, 1999).

1.4.2 Practical reasons - Understanding the differences

There were several differences in the recognition of autism, developing and introducing effective approaches, autism awareness and public policies between the UK and China, which motivated the researcher to do this comparative research.

There are different stages in the recognition of autism. In the English speaking countries, autism was first diagnosed and then reported by Leo Kanner in 1938 (Kanner, 1943). Hans Asperger’s work, published in 1944, was not known until translated by Frith (1991). However, in China, people first came to recognize autism in 1982 (Tao, 1987). Officially, it was not until 1980 that the diagnosis and classification of autism was defined, in the third edition of Diagnostic and Statistical Manual (DSM-3, APA, 1980). At that time, the criteria for diagnosis were based on the ‘triad of impairments’ (Wing & Gould, 1979), although since then the definitions have changed considerably in the recent DSM-5 (APA, 2013). However, it was not until 1995 that people in China became familiar with autism when ASD was included in the second edition of the Chinese Category of Mental Disease (CCMD-2, Psychosis Branch of Chinese Medical Association & Brain Hospital of Nanjing Medical University, 1995).

There were also differences between the two countries in terms of the timing of developing and introducing effective approaches for children and families, either in practice or in research. In the UK, parental pressure for the recognition (Department
of Health, 2011) and adoption of policies and interventions to help children with autism has grown since the 1960s (Wolff, 2004). In China, since the 1990s, parental concerns increased as they were not able to help their child and interventions were all but non-existent (Wang, 2011). Compared with China, there has been a lot of research about autism in the UK. Many of the articles published in China are based on the introduction of knowledge and techniques developed in the Western, English-speaking countries (Wang, 2011), which indicated a lack of Chinese indigenous research.

Another motivation for this comparative research stems from the fact that both the UK and China imported the basic tenets of ABA-based interventions from the USA. The researcher conducted three rapid reviews of ABA-based interventions in the UK and in China (using both English and Chinese databases). The rapid review of the UK found out 36 empirical studies and the rapid review of China found 12 empirical studies, i.e., 4 English articles and 8 Chinese articles. The present literature was summarised, identifying features and gaps in the ABA-based intervention research (See Chapter 3). The focus therefore, was on how procedures and techniques were culturally adapted to these contexts in relation to historical development, practice and research, and policy awareness.

The different levels of autism awareness, to some extent, manifested themselves in the different stages at which autism was introduced in public policy. In the UK, public service care and treatment from the NHS, across various settings for people with disability, had been introduced since 1948. In 2009, the Welsh Assembly Government (2009) published the first UK autism strategy, *Autism spectrum disorder strategic action plan*. In England, the *2009 Autism Act* (National Archives, 2009) and *the Autism strategy fulfilling and rewarding lives* (Department of Health, 2010), have largely promoted public autism awareness and aimed to improve the lives of people with ASD. However, in mainland China, there was a lack of specific legislative acts for children with autism. Policies for children with autism were stated under the context of people with disability. In 2008, the Central Committee of the Communist Party of China and State Council issued the *Viewpoints on promoting the career development of the disabled* (The Central People’s Government of the P. R. C., 2008), in which children with autism were included in the educational and medical support plan. In 2011, national special funds were made available for poor
children with autism through the *Colourful dream action plan: Implementation scheme on helping children with disability* (The Central People’s Government of the P. R. C., 2011). It is necessary for the Chinese government to learn from the UK and other developed Northern European countries about autism-specific medical, educational, community support and professional development systems (Xun, Yang, Ji, Xu & Wang, 2014).

These issues are reflected in the title of the thesis in which the term ‘cross-national’ is used in the sense of Kohn (1987, p725).

*I use the term cross-national mainly because nation has a relatively unambiguous meaning. Cross-cultural can mean anything from comparing subcultures within a single nation.*

**1.5 Thesis layout**

This thesis has nine chapters. Figure 1.3 shows the layout of the thesis.

![Figure 1.3: Layout of the thesis](image)

Chapter 1 introduced the topic, research aims, research objectives, research questions and why doing a comparative research, i.e., theoretical and practical framework.

Along with ‘why do a comparative research’, there are also ‘what to compare’, ‘who to compare’ and ‘how to compare’ to consider. Chapter 2 and Chapter 3 are
Literature Review chapters, in which questions of ‘what to compare’ and ‘who to compare’ are illustrated in detail. Specifically, Chapter 2 is a literature review on ASD and Chapter 3 is a literature review on ABA.

Chapter 4 is a methodology chapter, which answers the question of ‘how to compare’. This chapter presents three studies in the UK and China. Study 1 is surveys; Study 2 is qualitative interviews and Study 3 is direct observations.

Chapter 5, Chapter 6 and Chapter 7 are results chapters, in which Chapter 5 presents findings from Study 1 - surveys; Chapter 6 presents findings from Study 2 - semi-structured interviews; and Chapter 7 presents findings from Study 3 - direct observations.

Chapter 8 discusses findings from the results chapters and combining with literature review chapters, puts forward recommendations and indicates contributions and limitations of the study.

Chapter 9 is the conclusion chapter, which starts by revisiting the original topic, restates research aims, limitations and implications for future research, and summarises findings of the thesis.
Chapter 2. Autism spectrum disorder

2.1 Chapter overview
This chapter presents the history of autism research, the diagnosis, prevalence, possible causes and aetiology and treatment approaches of autism. In addition, the context surrounding policy, society and culture towards children with ASD will be illustrated.

2.2 History of autism research
The history of autism study was thought to be dated back to 1799 when an early report described a 10 or 11 year-old boy named Victor, the so-called ‘Wild boy of Aveyron’, who displayed symptoms similar to autism and lived in the woods near Southern France (Trevarthen, Aitken, Papoudi, & Robarts, 1998). He was taken care of and educated by a young French physician, Jean Itard (Wolff, 2004). The boy Victor exhibited features of autism, i.e., impairments in intelligence, sensory attention, social interaction and social imagination and also displayed stereotyped behaviour (Frith, 2003). Itard developed a behavioural programme starting with waking up his senses, then building the knowledge of social structure and language (Wolff, 2004). Results showed Victor learnt to imitate, speak, distinguish emotional feelings and even learnt social values (Frith, 2003; Wolff, 2004).

At the beginning of the 20th Century, Eugen Bleuler (1857-1939), a Swiss psychiatrist, coined the term ‘autism’ and it referred to a group of people who exhibited schizophrenia (Frith, 1991; Trevarthen et al., 1998). The word autism is originated from Greece: ‘Aut-’ refers to ‘self’ and ‘-ism’ underpins the meaning of ‘orientation or state’ (Happé, 1995; Trevarthen et al., 1998). Happé (1995) indicated that autism refers to those who introvert themselves from the outside environment, which failed to describe people on the autism spectrum.

Leo Kanner (1894-1981), an American psychiatrist, was seen as the pioneer of autism research. Kanner (1943) described 11 children with early infantile autism who exhibited disturbance of affective contact. Specifically, he identified children with autism disorder having socialisation problems; they preferred to live in their own world and displayed communication and language barriers, but excelled at rote memory, repeating words or sentences; but unable to use them in the right situation.
and sensitive to outside noise. In addition, repetitive or obsessive behaviours were also found in these children and a change of routine, behaviour or order would make some of the children feel depressed or scream. Kanner (1943) claimed that physically, these children look like typical children, but some of them showed some inborn differences, such as having a large head or clumsiness in walking. In addition, most of their parents were highly educated. Eisenberg and Kanner (1958) summarised the main features of children with autism as self-isolation and self-absorption; other symptoms were mostly secondary to, or a result of, these two features.

Hans Asperger (1906-1980), an Austrian psychiatrist, published *autistic psychopathy in childhood* in 1944, but this work was not widely known until its translation into English by Frith (1991). Asperger discovered that children with autism lacked eye contact and displayed stereotype behaviours, and it might be a developmental disability so symptoms varied in age and ability (Frith, 1991). Frith (2008) said that the research by Asperger was different from Kanner, because of Asperger’s description of symptoms happening at children’s later life or even at their adulthood age, and people with Asperger might also display an odd appearance (Frith, 1991). Kanner and Asperger are considered to be pioneers in autism research. Interestingly, they were born in the same country - Austria, used the same mother language - German, and illustrated the same type of children in 1943 (Lyons & Fitzgerald, 2007).

Wing and Gould (1979) conducted an epidemiological survey among 35,000 children less than 15 years of age, to clarify the classification of autistic symptoms, known as autism spectrum. Wing and Gould’s breakthrough understanding was that autism is on a spectrum with two or more syndromes that might co-occur with untypical ones rather than separate disorders. The triad of impairments, i.e., social interaction impairment, social communication impairment and the lack of imagination and understanding, along with repetitive/ritualised behaviours, featured across the spectrum of autism. The triad of impairments introduced by Wing and Gould (1979) offered diagnosis criteria for autism identification and classification.
2.3 Diagnosis criteria and screening instruments

2.3.1 Diagnostic and Statistical Manual (DSM)

The Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychiatric Association (APA) provides clinicians and researchers with diagnostic criteria and classifications on mental disorder. DSM was first published in 1952 (APA, 2017). It was in 1980 that APA began to define the classification for autism in DSM-3 (APA, 1980). Based on the clinical practice and research (Taheri & Perry, 2012), DSM-3-R (APA, 1987), DSM-4 (APA, 1994) and DSM-4-TR (APA, 2000) were subsequently released. In DSM-4-TR, ASD includes autistic disorder, Asperger’s disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). ASD, along with Rett’s Disorder and Childhood Disintegrative Disorder (CDD), falls under Pervasive Developmental Disorders (APA, 2000).

The DSM-5 was released in May 2013 (APA, 2013). The diagnosis criteria on ASD were among the most important changes in DSM-5, in which autistic disorder, Asperger’s syndrome, childhood disintegrated disorder, or the catch-all diagnosis of PDD-NOS were clearly identified (APA, 2013). A new diagnosis called Social Communication Disorder (SCD) was added under ASD (APA, 2013). The triad of impairments (difficulties in social communication, social interaction and lack of imagination and understanding) described by Wing and Gould (1979) is no longer used under the DSM-5; instead, social communication and interaction, restricted and repetitive behaviour were used as indicators (Barton, Robins, Jashar, Brennan, & Fein, 2013). The diagnostic criteria for ASD (APA, 2013) mainly include:

A. Persistent deficits in social communication and social interaction across multiple contexts;
B. Restricted, repetitive patterns of behaviour, interests or activities;
C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life);
D. Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning;
E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder), or global developmental delay.
In DSM-5, dimensional elements were introduced as indicators to evaluate the level of disorder (Weitlauf, Gotham, Vehorn, & Warren, 2014), which are specified as Level 1: requiring support, Level 2: requiring substantial support, and Level 3: requiring very substantial support (APA, 2013). Some researchers reported the diagnostic consistency of DSM-4 and DSM-5 for the diagnosis of ASD (e.g., Mazefsky et al., 2013), including Asian countries (e.g., Kim et al., 2014). However, critics noted that the population which were diagnosed under DSM-5 decreased, especially for the Asperger’s or PDD-NOS subgroup given that these diagnoses were no longer available (Kulage, Smaldone, & Cohn, 2014; Smith, Reichow, & Volkmar, 2015) and that DSM-5 failed to represent the more functionally impaired group of children (Turygin, Matson, Beighley, & Adams, 2013). Hence, some children with developmental disorders remained undiagnosed and no longer received public service, educational or other medical support (Kulage et al., 2014).

2.3.2 International Classification of Disease (ICD)

The World Health Organisation’s International Classification of Disease (ICD) is another standard dialogistic tool (WHO, 1992). ICD is used as a main categorisation for clinical diagnosis across most of Europe. The ICD-10 (WHO, 1992, p10) criteria about autism can be summarised as follows:

A. Qualitative impairments in reciprocal social interaction;
B. Qualitative impairments in communication;
C. Restricted repetitive and stereotyped patterns of behaviour, interests and activities;
D. Developmental abnormalities must be present before 3-years-old for making diagnosis;
E. Clinical criteria not applied to: PDD, specific developmental disorders of receptive language with secondary socio-memorial problems; reactive attachment disorder or disinhibited attachment disorder, mental retardation with some associated emotional/behavioural disorder, schizophrenia of unusually early onset; and Rett’s syndrome.

The ICD and DSM were considered to be very similar (APA, 2009). However, the ICD emphasizes classifications of mental behavioural disorders for global use, while the DSM serves as a diagnostic system by an American psychiatry professionals’ association (Doernberg & Hollander, 2016).
The Chinese Classification of Mental Disorders (CCMD) is developed largely based on the ICD and DSM (Psychosis Branch of Chinese Medical Association & Brain Hospital of Nanjing Medical University, 1995). It was not until 1995 that ASD was formally included in the second edition of the Chinese Category of Mental Disease (Clark & Zhou, 2005). The CCMD-3 is considered to be the common diagnosis tool in mainland China (Zou et al., 2008; Sun et al., 2015), though Dai et al. (2014) found, in a survey with 211 participants, which nearly half of Chinese participants (48.8%) used ICD-10, nearly two fifths of participants (39.3%) used CCMD-3 and around ten percent of participants (11.4%) used DSM-4.

2.3.3 Screening and diagnosis

2.3.3.1 A brief summary of instruments

The development of screening and diagnostic instruments is beneficial, because early identification and detection of autism allows children with autism and their families to look for effective intervention and training (Bryson, Rogers, & Fombonne, 2003; Baron-Cohen et al., 2009; Barton, Dumont-Mathieu, & Fein, 2012). There are a number of screening instruments designed for children with autism (e.g., Baron-Cohen, Allen, & Gillberg, 1992; Baron-Cohen et al., 1996; Baron-Cohen et al., 2000).

The Checklist for Autism in Toddlers (CHAT) method is aimed at children 18 months of age and it focuses on pretend play and joint-attention (Baron-Cohen et al., 1992; Baron-Cohen et al., 1996; Baron-Cohen et al., 2000; Dumont-Mathieu & Fein, 2005). Specifically, pretend play normally happens by 12-15 months, which is defined as the ability to make substitution and/or attribution of objects to what is physically absent (Baron-Cohen et al., 1992; 1996). Joint-attention happens by 9-14 months, including gaze-monitoring and protodeclarative pointing (Baron-Cohen et al., 1992; 1996). The study by Baron-Cohen, Allen and Gilberg (1996) showed children who did not pass the three key items, i.e., protodeclarative pointing, gaze-monitoring and pretend play, at the age of 18 months, had around 80% of risk of being diagnosed with autism. However, the study by Baron-Cohen et al. (1992, 1996 & 2000) on the CHAT method did not include children with severe autism (Stone, Coonrod, & Ousley, 2000).
The Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R)™ is a modified version of CHAT and was released in December 2013. M-CHAT enables children at 24 months of age to be screened and was proved to be a promising tool for early detection (Robins, Fein, Barton, & Green, 2001; Kleinman et al., 2008). In addition, children with PDD-NOS are also included. The CHAT-23 method is an integration of the M-CHAT (23 questions) and the observational session of the CHAT, which is used to diagnose children aged 18 to 24 months old (Barton et al., 2012). Particularly in China, Wong et al. (2004) stated that CHAT-23 is more sensitive and appropriate, and easier to manipulate.

The Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview (ADI, Lord et al., 1989; Lord, Rutter, & Couteur, 1994) were regarded as the gold standard assessment instruments for children with ASD (Levy, Mandell, & Schultz, 2009). Sun et al., (2015) validated the consistency of the application of ADOS and ADI-R on a Chinese sample.

Pervasive Developmental Disorders Screening Test-stage I (PDDST-I) is a clinical instrument aimed at children from new-borns to 36 months old (Siegel, 2013). PDDST-II allows parents to fill in the questionnaires based on stereotypical repetitive behaviour, communication and social skills (Siegel, 2004). The PDDST-II is similar to stage I, but focused on the period between birth and 18 months. It has a special clinical section to assess the severity of autism. However, critics argued that PDDST-II lacked significant statistic sensitivity or specificity data from a large-scale unselected sample (Dumont-Mathieu & Fein, 2005).

Screening Tool for Autism in Toddlers and Young Children (STAT) is designed by community service providers to screen children (between 24 months and 36 months) who are suspected to have developmental disorders, such as autism (Stone, Coonrod, Turner, & Pozdol, 2004). STAT is developed as a Stage 2 screener in a referral environment, which allows the child and the examiner to interact in a fun and playful setting. Observations and evaluations are taken during activity performance (Stone, McMahon, & Henderson, 2008).

In addition to commonly used early screening instruments, parental questionnaires and other evaluation checklists were also developed. Childhood Autism Rating Scale (CARS) is used by clinicians to distinguish children (aged older than 2 years old)
with autism from other developmental disorders (Schopler, Reichler, DeVellis, & Daly, 1980). CARS is often used to gauge effectiveness of intervention or treatment (Perry, Condillac, Freeman, Dunn-Geier, & Belair, 2005). Autism Behaviour Checklist (ABC) is used by teachers or clinicians to assess children’s (older than 3 years old) ability in 5 sections: sensory, relating, body and object, language, and social and self-help (Krug, Arick, & Almond, 1980).

It is noticeable that there are a range of diagnostic and screening instruments for parents and clinical professionals. Nevertheless, the diagnostic criteria and tools should be validated across cultural settings (Zhang, Wheeler, & Richey, 2006). For example, Sun, Allison, Auyeung, Matthews, Baron-Cohen and Brayne (2013) found that the identification instruments by Chinese clinics were adopted from western countries for at least two decades.

### 2.3.3.2 Diagnosis in each country

Predictive signs of autism can be seen at 6-9 months (Rogers et al., 2014). This makes early diagnosis not only an ethical and practical imperative, but also economically important during a time of austerity (Dillenburger, 2014).

In the UK, the average age of diagnosis was 3.6 years of age (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010) with many children being much older before they receive diagnosis; and there was an average of 3.5 years’ delay between parents first reporting concerns to a health professional about their child and the diagnosis (Crane, Chester, Goddard, Henry, & Hill, 2016). A report showed that 254 children in North Yorkshire, England were waiting to be assessed and 180 of these children had exceeded the statutory waiting time of three months (BBC, 2013). In Northern Ireland, more than 2,000 children were waiting for a diagnosis, with over 200 new referrals per month (Dillenburger, McKerr, & Jordan, 2016). In a survey involving 1,047 parents by Crane et al. (2016), more than half of the participants were not satisfied with the diagnostic process, information, manner of health care professionals and the post-diagnostic support.

In China, only 15% of parents raised first concerns before the child was 2 years old and most parents raised first concerns when the child was aged 3 or older (Yu, 2011). Only 4% of Chinese children received their diagnosis before the age of 2 and
65% of the children were older than 3 years old before they were diagnosed (Yu, 2011). In Beijing alone, around 300 children were waiting to be enrolled in training programmes (SINA, 2013).

Some children were diagnosed by psychiatrists as ‘tendency autism’ in China (Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013). Zhou et al. (2014) reported that of a sample 22,000 children, around half of them were diagnosed in municipalities, such as Beijing, Guangzhou and Nanjing. In addition, the diagnosis of autism was attached with social stigma, which to some extent delayed the child’s intervention (Sun, Allison, Auyeung, Matthews, Baron-Cohen, et al., 2013).

2.4 Prevalence of autism spectrum disorder

The number of children diagnosed with ASD around the world is increasing each year. Table 2.1 shows the prevalence of ASD as reported by Centre for Disease Control (CDC). The prevalence of ASD increased approximately 123% from 2002 to 2010 in the US (CDC, 2016).

<table>
<thead>
<tr>
<th>Year</th>
<th>Prevalence</th>
<th>Report</th>
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<tbody>
<tr>
<td>2002</td>
<td>1 in 150</td>
<td>2007</td>
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<td>2006</td>
<td>1 in 110</td>
<td>2009</td>
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<td>2008</td>
<td>1 in 88</td>
<td>2012</td>
</tr>
<tr>
<td>2010</td>
<td>1 in 68</td>
<td>2014</td>
</tr>
</tbody>
</table>

In addition, more boys are affected than girls (Developmental Disabilities Monitoring Network & Centre for Disease Control, 2014). Kanner (1943) found that boys were four times more likely to be on the spectrum. CDC (2016) showed a ratio of boys (1 per 42 individuals) 4.5 times higher than girls (1 per 189 individuals).

In addition to a true prevalence, possible reasons for the increase might be a wider clinical phenotypes being identified and increased knowledge of autism clinical diagnosis (Nicholas et al., 2008). The changing diagnostic criteria had led to significant variations in the reported prevalence rates. This can be observed in both UK and Chinese literature.
2.4.1 Prevalence of ASD in the UK

In the UK, Wing and Gould (1979) reported approximately a 5/10,000 prevalence of ASD in children whose IQ was under 70 and 15/10,000 on children who displayed difficulties in social interaction, communication and imagination, along with repetitive behaviours. In 2004, the Office of National Statistics conducted a survey among 12,294 families on the mental health of children and young people in Britain between 1999 and 2004. Results showed that approximately 90/10,000 children and young people displayed a less common disorder. This estimation not only included autism, but also included other disorders such as tics, eating disorders and mutism (Green, McGinnity, Meltzer, Ford, & Goodman, 2005). In 2006, Baird and his colleagues conducted a cohort study among 56,946 children (aged 9-10 years-old) in the South Thames region. It was reported that the prevalence of ASD is 116.1/10,000, in which 38.9/10,000 were children with autism and 77.2/10,000 were other autistic spectrum disorders (Baird et al., 2006). In a school-based population study conducted by Baron-Cohen et al. (2009), a 157/10,000 prevalence was estimated among children aged 5-9 years old. Russell, Rodgers, Ukoumunne and Ford (2014) reported 170/10,000 children having ASD in the Millennium Cohort Study. In the Millennium Cohort Study in the UK, 350/10,000 of 11 year-olds born in the year 2000 were reported by parents to have ASD (Dillenburger, Jordan, McKerr, & Keenan, 2015).

2.4.2 Prevalence of ASD in China

Little cohort data are available showing the prevalence of children diagnosed with ASD in China. In the Second China National Sample Survey on Disability in 2006 (State Statistics Bureau, 2007), there were 70.5 million households with disability (making up 17.80% of all households nationwide), in which 8.76 million households had more than two people with disability (12.43%). There were 2.46 million children (aged between 6 to 14 years old) with disability and they made up 2.96% of the total population, in which roughly 60,000 were children with mental disability.

In Asia, the prevalence of ASD is increasing and is more prevalent than previously predicted (Sun & Allison, 2010). Sun and Allison (2010) indicated that the average prevalence of ASD in Asia was 1.9/10,000 before 1980, while the prevalence was reported to be 14.8/10,000 after 1980. In mainland China, Guo (2004) conducted a study including 3,606 children (2-6 years old) in Tianjin (one of the four direct-
controlled municipalities in China) and reported 5 children (2-4 years old) as having autism spectrum disorder and displaying intellectual disability. Zhang and Ji (2005) reported a prevalence of 11.0/10,000 in a survey among 7,345 children (2 to 6 years of age) in Tianjin. Yang, Hu and Han (2007) surveyed a random sample of 10,412 children, in which 6 children were identified with ASD: an estimation of 5.6/10,000 prevalence rate was reported. In a systematic review and meta-analysis by Sun et al. (2013), a prevalence of 11.8/10,000 people was reported in mainland China and 26.6/10,000 people for mainland China, Hong Kong and Taiwan combined. Wan et al. (2013) reported a prevalence of autism to be 12.8/10,000 in a meta-analysis of 18 studies in mainland China. Kim et al. (2011) indicated the prevalence of ASD in South Korea to be 264/10,000.

The prevalence in China was lower than other developed countries (1%) and the UK. This might be due to limitations in research methods’ utilise and sample selection in China, which made prevalence estimation not consistent with the West (Sun et al., 2013; Wan et al., 2013).

2.5 Aetiology and treatment

2.5.1 Aetiology

Insofar as the cause of autism is unknown, some speculations have been put forward. Some people believed that a possible cause might be a combined involvement of genetic disorders, environmental factors and immune system dysfunctions (Freitag, 2007; Frith, 2008; Ratajczak, 2011). ASD is thought to be a genetically determined disorder, although no specific gene has been identified (Ratajczak, 2011). Glasson et al. (2004) demonstrated older parents have a higher risk of giving birth to a child with autism and these children are generally firstborn. Monozygotic identical twins are believed to have high risk of developing ASD than dizygotic con-identical twins. If autism occurs in family members or relatives, the child has a higher risk of autism incidence (Howlin, 2009). It should be noted that the causes of autism may be not only because of obstetric factors, but also combined actions by genetic and environmental factors (Glasson et al., 2004). Individuals having ASD were reported to have had possible exposure to toxins or infections during pregnancy (Lathe, 2006; Randall & Parker, 1999) or immune system dysfunction in the child caused by
maternal conditions (Bailey et al., 1995; Durkin et al., 2008). In addition, psychological factors are sometimes cited as causes because of children with autism’s susceptibility to stress and associated links to birth trauma (Finegan & Quarrington, 1979). In the UK, parents, organisations and the press were influenced by studies (since retracted and discredited) that MMR (measles, mumps and rubella) vaccination would result in bowel disorder and might cause autism (Wolff, 2004). There is no evidence to show that there is a correlation among autism, bowel disorder and the MMR vaccine (Krause, He, Gershwin, & Shoenfeld, 2002; British Psychological Society & Royal College of Psychiatrists, 2012).

2.5.2 Medical treatment and interventions

There are few established medical treatments for children diagnosed with ASD (McPheeters et al., 2011; Lofthouse, Hendren, Hurt, Arnold, & Butter, 2012). Children at an older age with lower adaptive skills and social skills were most likely to be given more medications (Witwer & Lecavalier, 2005).

In the first survey on younger population (3-21) in the US, the use of psychotropic medicine was reported to be as high as 46.7%; 17.3% of participants used vitamin or supplement; 15.5% of participants used specific diets; 11.9% of participants had psychotropic medication and an alternative treatment combined and 4.8% of them had anticonvulsant (Witwer & Lecavalier, 2005). However, in a systematic review by McPheeters et al. (2011) on medical treatments, which included antipsychotic, serotonin-reuptake inhibitor (SRI) and stimulant medications, it was found that of the antipsychotic medications, risperidone and aripiprazole were reported to be most helpful in improving the child’s (5-16 year-old) challenging and repetitive behaviours despite the associated adverse side effect. A similar result was reported by Sawyer, Lake, Lunsky, Liu and Desarkar (2014) that risperidone and fluvoxamine were beneficial in treating challenging behaviour. Nevertheless, there was little evidence to prove whether SRI and stimulant medication are effective (McPheeters et al., 2011). In a systematic review by Krishnaswami, McPheeters, and Veenstra-VanderWeel, (2011), secretin was reported to have no significant effect in improving language, repetitive behaviour, social skills and other autistic symptoms.

Traditional Chinese Medicine (TCM) is believed to be more gentle on the patient and better at eliminating the root cause of issues, while western medicine is faster
acting but may have significant side effects (Lam, 2001; Poon, Goyal, Cheng, &
Poon, 2014). TCM is used privately rather than being the standard practice in the UK.
NHS Choices (2016) suggested acupunctures can be used to alleviate headache or
body pains. In China, the study of autism is characterised by the combination of
TCM, such as acupuncture and massage with behaviour treatments (Yuan, Li, Liu,
Wu, & Jin, 2007; Yuan et al., 2009; Zhang et al., 2012; Choi, Lee, Moon, & Cho,
2013). For example, Ma, Yuan, and Jin (2006) examined the effect of combining
acupuncture with behaviour intervention on children with autism. Three groups were
selected to examine efficacy of ‘Jin’s three-needling’ method4. There were 29 cases
in the combination group (Group 1); 15 cases in the acupuncture group (Group 2)
and 10 cases in the behaviour intervention group (Group 3). Results showed that the
combination group achieved the best outcome, i.e., significant improvement was
identified in children’s problematic behaviours, language expression and social
communication (P<0.01). However, no significant changes were observed in sense
factors and daily life skills (P>0.05). Yuan et al. (2009) proved that Jin’s 3-needling
therapy is also effective for children with severe autism. In their study, 35 children in
Jin’s 3-needling group were compared to 34 children in the behaviour intervention
group. After 2 therapeutic courses (240 sessions), the experiment group showed
higher significance (85.7% effectiveness) than the behaviour intervention group
(64.7% effectiveness).

However, it should be noted that those researchers who utilised behaviour
interventions on the control group lacked detailed description in their research
procedures. In addition, those interventions were eclectic with some non-evidence-
based approaches, such as sensory integration, and some evidence proved
approaches like those based on ABA (Clark & Zhou, 2005). Hence, it is hard to
examine whether the two groups really had the stated statistical significance.

Because of the uncertainty in medical treatments, a number of families adopted
Complementary and Alternative Medicine (CAM), which encompasses medical
products and various unproven interventions and practices. CAM is not accepted as
conventional in mainstream healthcare (Salomone, Charman, McConachie, &

4 Professor Jin developed this method and the method is named after him. It includes the Four-Shen
needling, Zhi-Three needling and Nao-three needling (See (Yuan, Li, Liu, Wu, & Jin, 2007) for a
review about the needling method)
Warreyn, 2015). Salomone, Charman, McConachie and Warreyn (2015) examined the use of CAM on children with ASD (under 7 years of age) in 1,690 families across 18 European countries and showed that 25% of the sample areas used diets and supplements; 25% of parents used the unconventional treatments; 24% of the sample areas used mind-body practices and 2% of parents tried unsafe approaches.

In a worldwide survey of 111 listed treatments for children with autism developed by Green et al. (2006), 552 parent respondents indicated the top 5 treatments were speech therapy (70.0% currently using, 23.2% have used in past), visual schedules (43.2% current and 18.6% past), sensory integration (38.2% current and 33.2% past), ABA (36.4% current and 22.7% past) and social stories (36.1% current and 18.0% past). In addition, 52% of parents mentioned they were using at least one medication to treat their child; 27% of parents were using special diets and 43% of them were using vitamin supplements.

In the US, Lofthouse et al. (2012) reported that conventional therapies and CAM were often used together by parents. Goin-Kochel, Myers and Mackintosh (2007) surveyed parents on their children’s therapies including pharmacological (drug), diet, and behavioural/educational/alternative therapies. On average, children with ASD had tried 7-9 therapies before and were using 4-6 therapies at the time of being surveyed. In addition, children with autism or PDD-NOS tried more behavioural and educational therapies, while children with Asperger’s tried more pharmacological treatments (Goin-Kochel et al., 2007). Hess, Morrier, Heflin and Ivey (2008) surveyed 185 teachers’ reports on 226 children with ASD (preschool to 12th) and found that gentle teaching (McGee, Menousek, & Menolascino, 1988), sensory integration, cognition behaviour modification, assistive technology and social stories were the top five approaches reported.

Salomone et al. (2016) surveyed a number of 1,680 parents of children with ASD (under 7 years of age) across 18 European countries and reported 64% of children received speech and language therapy, 55% of children received behaviour, developmental and relationship-based interventions, and 20% of children did not receive any interventions.

In the UK, the very recent survey by Denne, Hastings and Hughes (2017) with 160 parents, who found that the most popular approaches were currently (at the time of
survey) using were visual schedules (46.2%, n=74), speech and language therapy (45.0%, n=72), ABA (31.3%, n=50), VB (19.4%, n=31) and PECS (19.4%, n=31).

In China, in 2012, Shenzhen Autism Society (SAS, 2013) surveyed 56 of organisations’ founders/principals, 510 professionals and 988 parents. Results found that 68.86% of parents reported they did not take their child for medical treatments after formal diagnosis and 57.37% of parent chose to take their child for training or intervention. It can be concluded that sensory integration, ABA, play therapy and TEACCH were most commonly used by the three types of participants in China.

Parents reported the top 5 therapies used were sensory integration (73.89%), speech and language therapy (61.74%), play therapy (53.69%), ABA (40.56%) and music therapy (36.78%). Founders/principals reported the top therapies they provided for children and families were ABA (88.89%), sensory integration (86.11%), play therapy (86.11%), Treatment and Education of Autistic and related Communication handicapped Children (TEACCH, 86.11%), speech and language therapy (86.11%), music therapy (80.56%), PECS (75.00%), social story (69.44%) and mind reading (58.33%). In addition, 70.41% of professionals had received in-job special education training and 34.02% of participants had received pre-career training and 7.69% of them did not receive any training. Professionals reported the top five treatments they received training on were sensory integration (85.94%), ABA (84.38%), TEACCH (69.06%), play therapy (50.63%) and PECS (46.88%).

In 2013, Deng, Huang, Yan and Guan (2014) surveyed 738 SEN teachers at 9 provinces of China, who reported the top five training method provided by autism organisations were sensory integration (68.9%, n=262), play therapy (54.7%, n=208), speech therapy (48.7%, n=185), music therapy (46.3%, n=176) and ABA (45%, n=171, 45).

There is no doubt that parents need guidance about which treatments to use. Researchers showed that parents tried or currently use different kinds of treatments, even those without any empirical evidence (Green et al., 2006; Salomone et al., 2016). In contrast, with early screening in a group of infants (7-15 months), Rogers et al. (2014) achieved optimal outcomes for children receiving parent-implemented ABA-based developmental intervention before 12 months.
2.6 Children with ASD and the context of policy

The United Nations (UN) Declaration on Human Rights (United Nations, 1948) stated that everyone has a right to a good living (Article 25), education (Article 26) and to freely participate in the community (Article 27). The Convention of the Rights of the Child (1989) stated that each child has survival rights, development rights, protection rights and participation rights. The United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006) stated that a child with mental or physical disability should have the right to live a good life, receive special care, service and education (Article 23). The majority of governments have enacted legislation and made policies corresponding to the Convention of the Rights of Persons with Disabilities (CRPD, 2006), but there are differences in the implementation worldwide (Dillenburger, Jordan, & McKerr, 2014).

2.6.1 Policy background in the UK

The liberation movements in Western countries in the 1960s led to the promulgation of the Union of Physically Impaired Against Segregation (UPIAS) which outlined the rights of people with physical disability and claimed their involvement in financial, medical, technical and educational programmes (UPIAS, 1976).

The political position taken by disability activists is that people are disabled by society (the social model), not by their impairments (the medical model), and this has been a driving force in disability reforms in the UK that have affected all parts of society (Oliver, 2004). The UK’s first Disability Discrimination Act (National Archives, 1995) followed a campaign of civil disobedience by large numbers of disability activists (Barnes, 1995). The Disability Discrimination Act in 2005 (HM Government, 2009) acknowledged the social model’s influence on policy in its preamble.

There are a number of legal acts and government strategies to improve the lives of people with ASD in the UK. In February 2008, the National Autistic Society (NAS) launched the “I Exist” campaign to meet the needs of adults with autism; and later, in May, the Department of Health made its announcement on funding and support strategies for adults with autism (National Autistic Society, 2008). In April 2009, Welsh Assembly Government (2009) published the first UK autism strategy Autism
Spectrum Disorder Strategic Action Plan which was aimed at five key areas: diagnosis, access to services, community and monitoring support, employment and related issues and housing. In November 2009, the Autism Act 2009 was passed, the first legislation specifically addressing autism spectrum in England (National Archives, 2009). This Act created autism strategy and guidance for the local authorities and National Health Service (NHS) bodies to work with for adults with autism (National Archives, 2009). In England, Department of Health (2010) issued Implementation Fulfilling Rewarding Lives to secure the running of the 2009 Autism Act and to promote autism awareness, addressing fundamental changes and implications for public services. A year later, the Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England was released for adults to promote employment and independent living (Department of Health, 2011). There were also other strategies released for other regions of the UK. For example, Scottish Government (2011) put forward the Scottish Strategy for Autism to address the needs of individuals with ASD and their families over the next decade. The Autism Act Northern Ireland 2011 was passed to include people with ASD in the Discrimination Act and to mandate for a cross-departmental strategic approach to autism policies, practices and procedures, led by the Department of Health (National Archives, 2011).

These Autism strategies have produced a significant influence on people diagnosed with ASD and the development of service organisations. However, debate arose over whether it was outcome-focused or process-oriented (Walsh & Hall, 2012). It remained unclear how to achieve these aims and the application of this Act mostly depended on existing legislation. Moreover, it paid more attention to the context of accessing mainstream services, and to some extent would restrict developing specialist interventions under the current economic background.

The UK government maintains a comprehensive system of health, social support, income maintenance and free education in its welfare programme. The modern welfare state is delivered through national organisations like the NHS and local authorities (LAs). For instance, in England, Local Authority Social Services Act 1970 (National Archives, 1970) had been made for organisation, management and administration for each local government area, and later, Better Services for the Mentally Ill (Department of Health, 1975) was introduced to offer community-based
social care provisions rather than care at large mental hospitals. The NHS was set up on 5 July 1948 and also provided public care services and treatments across various settings for people with mental disability (Boardman, 2005).

The UK guidance from the National Institute for Health and Care Excellence (NICE, 2013) was set out for the identification and diagnosis of people with ASD up to 19 years of age. The guidance for the management of children with autism from NICE (2016) summarised the most recent evidence for interventions; behavioural interventions were recommended and functional analysis was mandated to deal with people with challenging behaviours (NICE, 2015).

In Northern Ireland, Health and Social Care Trusts (HSC) provide services for families. For example, the Belfast Autism Assessment and Intervention Service was delivered by HSC professionals to provide assessment and interventions for families and children (Health and Social Care Trust, 2017).

In relation to the education of children with autism, schools receive funds according to the number of pupils that they have. Local Education Authorities (LEAs) do not control schools directly but they continue to support the system of special needs education, which has, since the Education Act 1981 (National Archives, 1981), developed a system of assessing pupils’ special needs and producing a statement of the educational supports that a pupil requires. The LEA provides funding to schools to pay for this support, usually provided within mainstream schools. Many LEAs offer full or partial training funding for additional services for children with autism, such as personal teaching assistants. Children with ASD are also covered under the Special Educational Needs (SEN) Code of Practice (Department for Education and Skills, 2001), in which necessary duties were delegated to the LEA for children’s special needs education. This code required mainstream schools, early educational and other relevant educational bodies to make decisions based on inclusion principles but did not include individual test cases. In England, a Statement of Special Educational Needs is an official document detailing a child's learning difficulties and extra help would be provided if the school could not meet the child’s needs (BBC, 2016). As the Children and Families Act took effect in 2014 (National Archives, 2014), the Education, Health and Care Plan (EHCP) replaced the Statement of SEN and Learning Difficulties Assessment (LDA), which means all
health issues are covered by the EHCP which can support people up until 25 years of age (Ambitious about Autism, 2015).

**2.6.2 Policy background in China**

In stark contrast to the UK system, the Chinese government system can be described as a ‘central-local relationship’, which means the Central People’s Government has the highest power and directs the political regulations and executive decisions made by provincial governments (Dong, 2007).

In China, the 1987 Reform and Opening-up policy\(^5\) has significantly promoted policy development for children with autism. Deng Xiao-ping is regarded as China’s contemporary economic architect and he introduced the *Reform and Opening-up* policy, which boosted China’s economy and brought in foreign investment. In 2001, China joined the World Trade Organization (WTO), which has further increased China’s interaction and co-operation with the rest of the world (Grivoyannis, 2012). Since then, internal reforms and learning from Western countries have been promoted by the central government. The process of the *Reform and Opening-up* policy was very often described as ‘groping for stones to cross the river’\(^6\), in which metaphorically each step depends on the previous one, a step at a time, and it refers to taking the heuristic approach regarding the uncertainty of facing new problems (McCabe, 2013). The same principle guides the policy-making and exploration of treatments for people diagnosed with ASD. Chinese people began to learn from the West, taking in developed techniques and knowledge on autism\(^7\) (McCabe, 2007; 2013).

On 28 December 1990, the 17th Meeting of the Standing Committee of the Seventh National People’s Congress (1990) publicized the *Law of People’s Republic of China (P.R.C.) on the Protection of Disabled Persons*, in which the rights of people with disability were protected. In this statement, people with disability are categorized into seven types, i.e., impairment, hearing disorder, language impairment, intellectual disability, mental disability, physical disability and multiple disabilities\(^8\).

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\(^5\) In Chinese 改革开放 (Gaige Kaifang)

\(^6\) In Chinese 摸着石头过河 (Mozhe Shitou Guohe)

\(^7\) In China, national policy or statement all use the word autism instead of autism spectrum disorder. This will be illustrated in detail in the following context.

\(^8\) Multiple disabilities refer to being disabled with two or more than two categories.
The Disability Certificate, issued by the central government, assesses disabilities based on various criteria, in which mental disability was categorised into three scales from mild to severe (China Disabled Persons’ Federation, CDPF, 2006). This law was further revised in 2008, to ensure people with disability have the same educational rights, rehabilitation services, employment opportunities, social security and cultural life as a typical person. It also started to build a disability-friendly environment (National People’s Congress, 2008).

In 2006, the Second China National Sample Survey on Disability first formally included children with autism as one of the mental disability groups (State Statistics Bureau, 2007). On 4 June 2006, the State Council of the P.R.C. issued the Outline of the Work for Persons with Disabilities during the 11th Five-year Development Programme Period, formally outlining nationwide training for people with autism (Xinhua News Agency, 2006).

On 16 January, 2007, the China Disabled Persons’ Federation (CDPF) held a conference on Rehabilitation Work for Children with Autism during the 11th Five-year Development Programme Period (Guangzhou Autism Website, 2006). It acknowledged that children with autism had constituted a major proportion of the children with mental disability. 31 cities were selected around the country as pilot locations to implement these policies, i.e., maternal and children health care, building a special needs education network and social resources to help people with ASD. Systems for early childhood screening, early diagnosis and early rehabilitative intervention were subsequently implemented.

On 23 January 2007, CDPF (2007) issued the Implementation Strategy on Mental Disorder Prevention and Rehabilitation during the 11th Five-year Development Programme Period (2006-2011). It aimed to cover 800 million people nationwide and build a community-based, comprehensive and open environment for the 4.8 million people with severe mental conditions, and provide access to medical treatments for the 100,000 impoverished people with disability (CDPF, 2007).

In 2008, the Central Committee of the Communist Party of China and State Council (2008) issued the Viewpoints of the Central Committee of the Communist Party of

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9 This survey focused only on the family unit of mainland China. The survey was based on the seven categories of the Chinese Disability Criteria.
China Central Committee and State Council on Promoting the Development of Undertakings for People with Disabilities, which reported more than 83 million people with disability, affecting 260 million people (family population\textsuperscript{10}) in mainland China. In this statement, people with disability, alongside selected medical rehabilitation programmes, were included in the national medical care insurance system. Priority treatment and therapy training were given to children with disability, and children with autism were clearly stated in the education development strategy.

Families of children with mental disability were allowed to have a second child if their disability levels were assessed to be moderate or above (Department of National Health and Family Planning Commission, 2008). The One-child Policy (family planning policy) was introduced in the late 1970s to curb population growth, alleviate poverty and aide economy growth (Ding & Hesketh, 2006; Potts, 2006). It is a family planning programme encouraging fewer children (Zhu, 2003). However, in 2013, the One-child policy was relaxed for families where either husband or wife was from a single child family (Department of National Health and Family Planning Commission, 2013) and in 2015, the universal Two-Child policy was released (Xinhuanet, 2015).

In 2009, the State Council issued the Advice on Further Accelerating the Development of Special Needs Education (Central People’s Government of the People’s Republic of China, 2009). It further clarified that the local authority should actively create conditions for children with autism to receive compulsory education.

In 2010, the Guidance about Accelerating the Social Security System and Service Construction for the Disabled set out free compulsory education provisions for children with disability (Central People’s Government of the People’s Republic of China, 2010). Professional rehabilitation organisations were established at the province-, city- and county-level\textsuperscript{11} for children with autism. Early intervention, early education and rehabilitation were also emphasised in the guidance.

\textsuperscript{10} This data was stated as family population, which means within the same household.
\textsuperscript{11} Chinese administrative division is classified into province level region, autonomous region and municipalities regions (directly under the Central government administration), cities (with districts) and counties (automatic counties, townships and rural towns); Hong Kong & Macao are two special administrative municipalities (Laurence & MaCui, 1987).
In 2011, national special funds were made for children with autism from low socio-economic backgrounds through the “Colourful Dream Action Plan” Implementation Scheme on Helping Children with Disability to ensure the implementation of the 2008 Viewpoints on Promoting the Career Development of the Disabled (Central People’s Government of the People’s Republic of China, 2011). In this statement, the specific implementation scheme had been outlined for children with autism. A sum of ¥12,000 (around £1,419)\textsuperscript{12} was provided annually for poor children with autism (aged 3- to 6-year-old) to receive service in designated autism organisations. It aimed to provide rehabilitation training services for 36,000 poor children with autism during 2011 to 2015, beginning with 6,000 children from 2011 to 2012 and expanding to 10,000 children annually from 2013 to 2015. This policy had prioritised resources for low income families. Individualised educational plans and parents’ training were also included in this policy.

In 2015, CDPF (2015) issued the first Handbook of rehabilitation and scientific knowledge about children with autism, which provided practitioners and parents with basic information about autism, diagnosis and treatments. In 2016, the diagnosis and assessment was covered by the medical insurance, in which the Autism Diagnostic Interview (ADI) assessment was freely provided for children with ASD under 6 years of age (National Health and Family Planning Commission of the P.R.C., 2016). However, the economic status of different regions led to different levels of support. For example, based on the Central Government’s 2008 Viewpoints on Promoting the Career Development of the Disabled, financial aid was available for children with autism who are under 6 years of age nationally, Jiangsu province issued Protection Guidelines of the Disabled People at Jiangsu Province, which increased the coverage to children from 7 to 14 years of age (Jiangsu Province Department of Public Information, 2013). In Shanghai, children with autism who are under 7 years of age can receive a ¥3000 (around £355) allowance per year for living expenses (Xu, Ding, Shi, & Liu, 2013).

\textsuperscript{12} Currency on 25 Jan. 2017
2.7 Children with ASD and the context of society and culture

2.7.1 Autism awareness and knowledge
The increasing prevalence of ASD has raised awareness around the world. In December 2007, the UN General Assembly recognised 2 April as World Autism Awareness Day and April as Autism Awareness month. The initiative of ‘light up blue’, in which internationally buildings are lit with blue light during the month of April, helped raise autism awareness and highlight the necessity in improving the lives of individuals with ASD and their families (UN General Assembly, 2008). The Autism Awareness Day was also adopted by many countries (Autism Europe, 2016). In the UK, the World Autism Awareness Week was organised in public, social media and school settings (National Autistic Society, 2016c). Similarly, in China, autism awareness activities, such as ‘10K Autism Genome Project’, were organised by NGOs in China (Autism Speaks, 2012) and many regional Disabled People’s Federations (DPF) organised autism themed activities to raise autism awareness in public (e.g., Disabled Persons’ Federation of Chongqing city, 2016; Disabled Persons’ Federation of Autonomous region, 2016).

People’s knowledge on autism has been growing in past years, but there is a shortage of knowledge relating to the awareness of treatment approaches in both the UK and China (Wang, 2011; Xu, Yang, Ji, Xu, & Wang, 2014; Dillenburger, McKerr, Jordan, Devine, & Keenan, 2015; Liu et al., 2016). In the 2012 Northern Ireland Life and Times (NILT) survey, which involved a sample of 1,204 people, it was reported that 82% (n=989) of the respondents were aware of autism and a vast majority of participants indicated their acceptance in living, working and learning with individuals with autism (Dillenburger et al., 2015). In China, there has been a growing advocacy for care and education for children with autism, but substantial improvement should be made to promote knowledge of treatments. For example, in a survey of 471 preschool teachers in Guangzhou and Foshan of China the reported majority of participants were not aware of ASD-specific organisations (>70%) and treatment approaches (>60%) (Liu et al., 2016), while more than three quarters (77%) of UK participants were aware of the effectiveness of behavioural interventions (Dillenburger et al., 2015).
2.7.2 Family culture

Children with ASD require family care and support. There is a big difference in family culture between the Western culture (e.g., UK) and the Eastern culture (e.g., China) (Liu, 1992; Liu, 2008; Clayton, 2011; Huo & Yuan, 2015).

Western culture emphasized individualism, which mainly includes the separation from in-groups\(^\text{13}\) and self-reliance with hedonism (Triandis et al., 1986). Individualists emphasize independence, self-reliance and self-autonomy and consider achieving their own goals, calculating the relations with others by gains and losses and doing things based on his/her own interests (Hofstede, 1984; Triandis et al., 1986; Triandis, 1995). In contrast, Chinese culture emphasizes collectivism (Gu, 1992; Ho & Chiu, 1994; Clayton, 2011), which mainly includes family integrity and independence with sociability (Triandis et al., 1986). Collectivists consider individuals as an aspect of the group and the priority is given to in-groups (Triandis, 2001). The conceptualisation of individualism and collectivism has significantly influenced child rearing. In the self-oriented individualism, parents expected children to be independent, to have self-esteem and become self-autonomous (Carteret, 2013), while the collectivism is group-oriented and parents have the responsibility to take care of their children and expect their children to obey them (Tseng & Wu, 2013).

Confucianism, established by Kung Chiu (Kung Fu-tse or Confucius, 551-479 BC) and his students, has more than 2,000 years’ influence on Chinese family culture (Huang & Gove, 2012) as well as in many east Asian countries, such as Korea and Japan (Park & Cho, 1995). Confucianism, unlike the Western Christianity which is a religious belief, is a philosophical and ethical system impacting people’s way of life, thoughts, values and ideology. It endogenously creates instructions and rules on education, society and even national governance (Slote & Vos, 1998; Huang & Gove, 2012; Ebrey, 2014).

In particular, family is viewed as a very important part in Confucianism. The Western family culture emphasized the relation between wife and husband, but the Chinese culture emphasized the relation between parents and children (Liu, 2008). Hierarchy is emphasised in Confucianism and collectivism (Liu, 2008; Liu, 1992;

\(^{13}\text{In-group means a social group to which a person belongs/identifies and outgroup is a social group to which a person does not belongs/identifies (Tajfel, Billig, Bundy, & Flament, 1971).}\)
Tseng & Wu, 2013), in which five basic elements are summarised about human relations, i.e., ‘father - son, emperor - subject, husband - wife, elder - younger, friend - friend’ (Huang & Gove, 2012, p.11). Hence, parents hold the authority in Chinese family culture. In addition, there is a widely known sentence from the Three Character Classics saying that ‘a son not taught, is the father’s fault’\(^{14}\), which emphasises parents’ responsibility on children’s education (Tseng & Wu, 2013).

Several studies showed that family culture impacted on children with ASD. Mandell and Novak (2005) believed that culture influence people’s decision during autism diagnosis and treatment. Liao, Dillenburger and Buchanan (2016) found that family culture impacted different types of service delivery of ABA-based intervention programmes in the UK and China.

2.7.3 Mass media

In China, children with autism are widely known as ‘children of stars’ (Wiki, 2007). In the Western countries, ‘rain man’, the movie with Dustin Hoffman, is often used to typify autism (Wiki, 2016), although there are arguments about its conflict with the real autism definition (Autism Speaks, 2017).

The terms ‘autistic disorder’ ‘autism spectrum disorder (ASD)’ and ‘autism spectrum condition (ASC)’ are largely used in the Western countries (e.g., Kanner, 1943; Sun, et al, 2013). According to the summary by Trevarthen et al. (1998), terms such as ‘early infantile disorder’ (Kanner, 1943), ‘autism infantile psychosis’ (Mahler, 1965) and ‘early childhood autism’ (Wing & Gould, 1979) were used in the past. Kenny et al. (2016) surveyed 3,470 UK residents and results showed there is no consistent way of describing autism in the UK, i.e., a large number of people with autism and their families and friends prefer to use the term ‘autistic people’ to illustrate that autism is part of who they are, while the majority of the professionals prefer to use the term ‘person with autism’, to illustrate that they see the person first, before the diagnosis.

In China, the majority of the mass media and the public prefer to use the term autism rather than ASD (e.g., Huang, 2003). In addition, the word autism was translated in

\(^{14}\) In Chinese: 子不教父之过（zi bu jiao, fu zhi guo）
two ways: ‘zibi zheng’\textsuperscript{15} and ‘gudu zheng’\textsuperscript{16}, and both of them were widely used in public. It should be noted that the two translated words have different meanings in Chinese. Literally, ‘zibi’ ostensibly underpins a meaning of self-enclosure, while ‘gudu’ underpins a meaning of loneliness or aloneness (What’s on Weibo, 2016). Neither of the two underlying meanings could fully explain autism spectrum disorder. According to an official document from the Chinese Disabled People’s Federation (2015), the two words ‘guduzheng’ and ‘zibizheng’ are the same and translated from the English term ‘autism’. The word ‘guduzheng’ is mainly used in the medical field or areas of SNE in mainland China, while the word ‘zibizheng’ is mainly adopted in Hong Kong, Macau, Taiwan, Japan, Singapore, Malaysia and other countries that use Chinese language. However, there is no consistency in the use of ‘zubizheng’ or ‘guduzheng’ in the Chinese social media (Feinstein, 2011).

In both UK and Chinese movies or News reports, there have been many individuals who have a special talent (i.e., savants) such as a good memory, excellence in music, painting or calculation are on the spectrum. Examples include movies such as Ocean Heaven from China (Wiki, 2010) and Rain Man from the USA (Wiki, 2016). On the other hand, Bie and Tang (2015) found that some social media often reported a singular feature of children with ASD, such as self-harm or hurting other people, to attract the public’s attention. In China, the stigma from society and social media has, to some extent, made parents fear disclosure of their child’s diagnosis of autism and as a result, exclusion from mainstream education (Bie & Tang, 2015; Du, 2011).

2.8 Chapter summary

This chapter on children with ASD in the UK and China discussed the two important questions of ‘what to compare’ and ‘who to compare’. The illustration of the different historical research background, diagnosis, prevalence, and aetiology as well as treatment approaches of autism forms the background to the present study. The overview of the policy, culture and society context in the UK and China illustrated the backdrop against which this research was conducted.

\textsuperscript{15} In Chinese characters 自闭症
\textsuperscript{16} In Chinese characters 孤独症
Chapter 3. Applied behaviour analysis

3.1 Chapter overview

Applied Behaviour Analysis (ABA) is the application of the science of behaviour analysis (Baer, Wolf, & Risley, 1968). Applied behaviour analysis aims to enhance socially significant behaviour on the basis of a good understanding of the interaction of the organism with the environment (Baer et al., 1968; Cooper et al., 2007). Behaviour analysis is based on three distinct yet interdependent branches (Baer et al., 1968; Keenan, Kerr, & Dillenburger, 1999; Cooper et al., 2007), i.e., the philosophy of behaviourism; the experimental analysis of behaviour (EAB), which focuses on implementation of experimental methods to understand and analyse the basic principles and processes of behaviour; and applied behaviour analysis (ABA), which uses experimentally validated techniques to enhance socially significant behaviours.

3.2 Behaviourism

Behaviourism is a philosophical underpinning of the science of behaviour. Skinner (1974, p9) questioned the validity of ‘following the ancient principle of post hoc, ergo propter hoc (after this, therefore because of this)’ to explain the cause of behaviour. He exposed mentalism as pseudo-explanation used to ‘explain’ behaviour with reference to supposedly causal events, such as feelings, psychic, spiritual, assumed or internal dimensions rather than by behavioural dimensions (Moore, 2003). Mentalism presumes that phenomena in these dimensions wholly or partly caused the behaviour.

The term ‘behaviourism’ was coined by John Watson in his early publications (Schneider & Morris, 1987). In Watson’s famous work ‘Psychology as the behaviourist views it’ (1913), Watson pointed out that psychology is the science of observable behaviour rather than states of mind or psychological process.

*Psychology as the behaviourist views it is a purely objective experimental branch of natural science. Its theoretical goal is the prediction and control of behaviour. Introspection forms no essential part of its methods, nor is the*
scientific value of its data dependent upon the readiness with which they lend themselves to interpretation in terms of consciousness. (Watson, 1913)

Watsonian behaviourism viewed the science of behaviour from a stimulus (S) and response (R) paradigm. Watson believed that S-R psychology can explain behaviour and help to improve people’s performance in a wide range of settings, such as education, business and law (Cooper et al., 2007). Skinner extended Watson’s methodological behaviourism by introducing the concept of behaviour ‘being contingencies of survival, reinforcement or social evolution’ (Day, 1983, p101).

Skinner’s (1974) radical behaviourism goes beyond methodological behaviourism and is the philosophical foundation of the science of behaviour, which covers all human behaviours, including innate behaviours (e.g., thoughts, thinking and feelings). The word ‘radical’ stems from the Latin term radix (genitive radicis) meaning ‘root’, thus referring to a science that is going to the root and affecting the fundamental nature of something (Schneider & Morris, 1987). Skinner (1953) believed that overt (public) as well as covert (private) behaviour are dependent variables in the study of behaviour. As such, behaviour analysis goes beyond methodological behaviourism and views all behaviour as its subject matter. This sets behaviour analysis apart from cognitive psychologists, who view hypothetical private constructs as causing public behaviours. In contrast, the philosophy of behaviour analysis, i.e., radical behaviourism, defines behaviour as the interaction of the organisms and the environments (Cooper et al., 2007).

3.3 The experimental analysis of behaviour

By providing basic scientific knowledge, the experimental analysis of behaviour forms the core of the discipline. Many basic behavioural principles have been discovered in behaviour analytic laboratories across the world.

Watson and Pavlov were two pioneers putting forward S-R (Stimuli-Response) theories (Wittrock, 1979). Ivan Pavlov (1849-1936) was a Russian physiologist who won a Nobel Prize for his research on digestive systems and was famous for discovering the process called ‘classical conditioning’. In Pavlov’s experiment (Pavlov, 1927), a dog salivated when given food and presented with a bell at the same time. As this was repeated for several times, the dog began to salivate at the
signal-ring bell alone. Therefore, in classical conditioning (Pavlov conditioning/respondent conditioning), learning occurs when unconditioned stimulus (US) is paired with a conditioned stimulus (CS) that elicits the previously unconditioned responses (UR). Following repeated pairing of the US and the CS, the UR becomes a conditioned response (CR).

Watson developed the now infamous experiment which is known as the Little Albert study. In this study (Waston & Rayner, 1920), he explored whether classical conditioning worked on a human being. Results showed that Little Albert demonstrated fright responses (UR) when a small and white furry rat (CS) was repeatedly paired with a loud noise (US). Thereafter, the fear (CR) was generalised to other white and furry objects (Cooper et al., 2007). Obviously, such experiments would breach modern day ethics. However, highly effective therapies, such as systematic desensitisation, were developed from the knowledge gained in the Little Albert experiments (Wolpe, 1969).

B. F. Skinner laid the foundation for experiment-based studies in behaviour analysis that took S-R experiments one step further. He discovered that consequences have differential effects on behaviour, which is known as operant conditioning (Skinner, 1974). In operant conditioning (instrumental conditioning), the contingencies of behaviour are formulated as three-term contingency (ABC): an environmental antecedent (A) elicits a behavioural response (B) that is followed by a consequent stimulus (C), in other words, an antecedent discriminate stimulus (SD) is followed by a specific behavioural response (R) contingent upon a consequent stimulus (S+). The behaviour is a function of the S+, in other words, the S+ can either reinforce and thus enhance the probability of the behaviour or decrease or punish the probability of the behaviour occurring again (Pryor, 1997).

Reinforcement can be positive (a stimulus is added) or negative (a stimulus is removed): in both cases the probability of the behaviours occurring increases. Similarly, punishment can be positive (a stimulus is added) or negative (a stimulus is removed), in both cases a decrease in the occurrence of behaviours is observed (Skinner, 1953; 1974).

Skinner and his team conducted many laboratory-based experiments from the 1930s to the 1950s, in which they discovered and tested the basic principles of behaviour
analysis (Cooper et al., 2007). The Skinner Box provided a new tool to control experimental variables and to record data by various devices (Slater, 2005). Skinner experimented with simple organisms such as rats and pigeons that allowed for clear measurements of simple responses, for example, being placed in various schedules of reinforcement. In general, the experimental analysis of behaviour (EAB) introduced by Skinner is regarded as the basic scientific methodology in the science of behaviour analysis (Cooper et al., 2007). Most importantly for the applied scientist, EAB offered a clear and systematic way of describing the functional relations between behaviour and various environmental factors (Cooper et al., 2007).

3.4 Applied behaviour analysis

Behaviourism and EAB form the basis for the development of ABA. Fuller (1949) carried out the first study on the application of the principles of operant conditioning. He conducted a study with an 18 year-old boy, whose behaviour was considered to be ‘vegetative idiot’ (Fuller, 1949, p588), which means he could only lie on his back and was not able to roll over. However, he was able to open his mouth and slightly move his limbs and trunks. Fuller (1949) injected warm milk as the reinforcing stimulus into his mouth each time he lifted his arms and results found that the boy was able to move his arm 3 times per minute after only 4 sessions.

A substantial amount of experimental behaviour analysis, to explore whether the principles of behaviour can be used on human beings throughout the 1950s to the early 1960s (Hake, 1982). For instance, Bijou was one of the first developmental behaviour analysts to conduct laboratory-based experiments to examine ‘Pavlovian type of experimental neurosis’ (Bijou, 1942) and to explore conditioned response on rats (Bijou 1943). He also designed laboratory experiments with young children as participants to explore the principles of behaviour (Bijou, 1955, 1957, 1958). Baer conducted a series of studies with preschool children to explore the principles of behaviour, such as schedules of reinforcement, punishment and extinction (Baer, 1960; 1961; 1962). Ferster and DeMyer (1961) reported a study of two children with autism using a teaching machine, in which reinforcers such as food and candy were provided. This experiment examined the effect of schedules of reinforcement and generalisation. Ferster and DeMyer (1961) claimed that the operant reinforcement
facilitated children with autism to sustain and develop a socially relevant behaviour repertoire.

ABA was formalised when Ayllon and Michael (1959) published ‘the psychiatric nurse as a behavioural engineer’, in which they reported a study at a psychiatric hospital where nurses were trained with a systematic approach for 19 patients, of which 14 were diagnosed with schizophrenia and 5 with mental disability. Participants were first observed, and reinforcement was applied on a fixed-interval schedule. Results showed improvements and changes in the problematic behaviours. This study led to a new thinking in how ABA principles can change the people with mental disability and psychiatric disorder behaviour.

The flagship publication of ABA, the Journal of Applied Behaviour Analysis (JABA), was first published in 1968 (Cooper et al., 2007). JABA is a cornerstone for the development of ABA as it provides researchers with a platform to publish their findings. In the inaugural issue, Baer et al. (1968, p92-97) published an article that defined the dimensions of ABA: ‘applied, behavioural, analytic, technological, conceptual systems, effective, and capable of appropriately generalised outcomes’. In addition, these dimensions were further refined in their paper in 1987 (Baer, Wolf, & Risley, 1987).

1. **Applied** means researchers, practitioners and service users or their parents (if they are not able to decide for themselves) are supposed to select behaviours for modification or a change from the perspective of the social importance and social relevance so as to improve clients’ and their families’ lives (Baer et al., 1968, 1987);

2. **Behavioural** emphasized three forms in ABA (Baer et al., 1968, 1987): First, the behaviour analyst studying what the subjects do instead of what they say (this does not include the subject’s verbal response). The selected behaviour for study must be of social importance. Furthermore, the objective behaviour should allow for reliable and valid quantitative measurements. Third, it is essential to ask whose behaviour is changed, as change happens during an observation and data recording process. The directly observed behaviours are always considered as dependent variables;
3. Analytic refers to ‘a convincing experiment design’ (Baer, Wolf & Risley, 1987, p318). It is necessary to establish a functional relation between instrumental treatments and the change of behaviour to allow for further application;

4. Technological refers to the notion that definitions should be precisely described and the practice process can be replicated;

5. Conceptual systematic means that the process of changing behaviour and explanations of the way to these changes are supposed to be systematically defined on the principles of which theories were initially developed;

6. Generality suggests that treatments can be not only used in one setting but also applied in other settings and across different people. ‘If the application of behavioural techniques does not produce large enough effects for practical value, then application has failed’ (Baer, Wolf & Risley, 1968, p96).

The dimensions introduced by Baer et al. (1968; 1987) are regarded as the foundation of ABA and are often used as a set of guidance principles in the application of behavioural treatments (Cooper et al., 2007; Morris, Altus, & Smith, 2013). In short, the principles and approaches of ABA are implemented as part of the scientific discipline of behaviour and it aims at modifying socially relevant behaviours. Behaviour is considered as dependent variable, while environmental events are considered independent variables (Cooper et al., 2007). The resultant change of behaviour should be socially accepted and of social significance (Sarafino, 2012). Finally, the methodology which causes these changes must be experimentally measured and empirically proven to be practical and socially valid (Schloss & Schloss, 1997).

ABA involves a combination of basic research and applied research (Morris et al., 2013) and substantial evidence supports the effectiveness of ABA for people with developmental disabilities (e.g., Smith, Buch, & Gamby, 2000; Lovaas, 2003), including autism (Matson, Tureck, Turygin, Beighley, & Rieske, 2012). ABA is applicable to a range of other mental disabilities. For example, Doughty, Anderson, Doughty, Williams and Saunders (2007) performed an experiment on three adults with mental disability to examine the antecedent stimulus by using different punishments and had shown induced significant changes in the targeted behaviour. Furthermore, the use of ABA techniques and principles, such as behavioural
approaches, can help to improve play skills (Stahmer, Ingersoll, & Carter, 2003) and to reduce aggressive behaviours (Brosnan & Healy, 2011). In addition, ABA-based interventions had been endorsed by the United States Surgeon General in 1999 (1999).

The principles, strategies and techniques of ABA-based intervention had provided the theoretical foundation for many important applications, such as Picture Exchange Communication System (PECS; e.g., Frost & Bondy, 1996), Discrete Trial Teaching (DTT; e.g., Lovaas, 1987; Smith, 2001), Social Skill Treatments (e.g., Matson, Matson, & Rivet, 2007), Pivotal Response Treatment (PRT; e.g., Koegel & Koegal, 2006), Verbal Behaviour (VB; e.g., Sundberg, 2008) and Early Intensive Behaviour Intervention (EIBI; e.g., Lovaas, 1987). ABA also served as a basis for a number of assessments scales and tools, such as assessing the EIBI curriculum (e.g., Gould, Dixon, Najdowski, Smith, & Tarbox, 2011), psychometric scales of challenging behaviours for children with ASD, Asperger’s syndrome and PDD-NOS (e.g., Matson, Gonzalez, & Rivet, 2008), parents’ education as a behaviour therapist (e.g., Keenan et al., 1999) and evaluation of the effectiveness of eLearning on behavioural therapists (e.g., Granpeesheh et al., 2010).

Behaviour analysts are professionals who deliver the ABA-based intervention services. The Behaviour Analyst Certification Board (BACB) is a non-profit organisation established in 1998, which offers professional qualification assessment for behaviour analysts (BACB, 2017a). The BACB provides credentials for behaviour analysts at four levels: Board Certified Behaviour Analyst-Doctoral (BCBA-D), Board Certified Behaviour Analyst (BCBA), Board Certified Assistant Behaviour Analyst (BCaBA) and Registered Behaviour Technician (RBT). The BCBA-D, BCBA and BCaBA level have coursework, experience and supervisory requirements as well as the corresponding examinations (BACB, 2017a). The RBT level can be attained with a minimum of high school diploma, completing 40 hours of training and a competency assessment as well as passing the RBT exam (BACB, 2017c). Most importantly, all professionals accredited by the BACB are required to follow the professional and ethical compliance code (BACB, 2016b). According to the latest release by (BACB, 2017a), there were 2,000 BCBA-Ds, 20,274 BCBAs, 2,439 BCaBAs and 25,279 RBTs (as of 7 November 2016). The formal accreditation
process ensures that these professionals deliver consistent and effective behaviour analytic services for the public, including children with ASD and their families.

3.5 Early intensive behavioural intervention

Early Intensive Behavioural Intervention (EIBI) is an intensive (long hours) programme which incorporates a number of ABA-based methods, commonly Discrete Trial Teaching (DTT) and Natural Environment Training (NET), that are used with young children on the autism spectrum. It is accepted as the ‘well-established’ treatment for children diagnosed with ASD (Lovaas, 1987; Jacobson, 2000; Green, Brennan, & Fein, 2002; Carr & Firth, 2005; Cohen, Amerine-Dickens, & Smith, 2006; Dawson, 2008; Reichow, Barton, Boyd, & Hume, 2012).

EIBI is sometimes referred to as the Lovaas approach, University of California-Los Angeles Young Autism Project (UCLA YAP model), intensive behaviour intervention (IBI), or early behaviour treatment (Reichow, 2012). In 1970, Lovaas and his team carried out a UCLA YAP project to generalise behavioural treatments from one teaching environment to other settings, such as community or school (Lovaas, 1987). In this project, children with autism, who were under 4 years of age were targeted as they were deemed to be able to gain and maintain new skills more easily. Participants were assigned into three groups. The experiment group (n=19) included children diagnosed with autism, who were treated by therapists. These children received one-to-one treatment for 40 hours per week and the programme lasted for at least 2 years. The experimental group was compared with two control groups. Control Group 1 (n=19) received the same one-to-one treatments as the experiment group but was only treated for less than 10 hours per week. Control Group 2 (n=21) received other programme treatment methods (Treatment as Usual, TAU). Results showed that of the 19 children in the experiment group, 9 children (47%) completed regular first grade, gained language and academic skills and achieved average or above IQ scores (94-120; Mean=107); 8 children (42%) completed their first grade in aphasic classes and their IQ, on average, were in the mild range of the intellectual retardation (IQ score= 56-95, Mean= 70), and 2 children (10%) were placed in classes for children with autism or intellectual disability, with a low IQ score (IQ<30, Mean= 30). In the follow-up study by (McEachin, Smith, & Lovaas, 1993), the 9 children from the UCLA YAP model’s
experiment groups were re-assessed at an average of 11.5 years of age. Results showed that their gains were maintained and their IQs were significantly higher than those in the control groups.

The features of EIBI are summarized below (Green et al., 2002; Eldevik et al., 2009):

A. Treatment is comprehensive and targeted at all skill domains. Intervention is individualized and focuses on improving children’s deficits and exploits advantages to the full;

B. Many behaviour analytic procedures (e.g., differential reinforcement, prompting, discrete-trial instruction, incidental teaching, activity-embedded trials, task analysis and others) are used to build new repertoires and reduce interfering behaviours;

C. One or more individuals with advanced training in ABA and experiences with young children with autism directs the intervention;

D. Normal developmental sequences guide the selected intervention goals and short-term targets;

E. Parents work closely together with therapists. Parents play an active part in the whole process and are required to know basic skills;

F. Initially one-to-one intervention, with gradual transitions from small-group to large-group formats when warranted; tasks slowly increasing in complexity to match improving competency; and,

G. Intervention typically begins at home and will be generalised to other settings, such as the community. If children with autism have developed required skills, they will be able to transition to preschools, kindergarten or elementary school.

Many studies examined and replicated the UCLA treatment model and produced abundant evidence for the effectiveness of EIBI (Birnbrauer & Leach, 1993; Smith, Groen, & Wynn, 2000; Davis, Smith, & Donahoe, 2002; Beglinger & Smith, 2005; Eldevik et al., 2009; Hayward, Gale, & Eikeseth, 2009). Several empirical studies showed that there is a statistically significant relationship between the skills and abilities of children with ASD and their participation in EIBI (e.g., Fein et al., 2013; Orinstein et al., 2014). Fava et al. (2011) noted that EIBI should be generalised
across settings. EIBI can be delivered in community-based programmes (e.g., Perry et al., 2008), home-based programmes (e.g., Anderson, Avery, DiPietro, Edwards, & Christian, 1987), or within autism specialist nurseries (e.g., Green et al., 2002).

3.5.1 School-, centre- or community-based behavioural intervention

EIBI programmes have been assessed in school- and centre-based environments (e.g., Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris & Handleman, 2000).

Fenske et al. (1985) launched the Princeton Child Development Institute (PCDI) ABA model programmes for children with ASD and their families. In their study, 18 children from two groups received treatment for 27.5 hours per week. They received 11 months of treatment per year, delivered by trained ABA teachers and therapists over a period of at least 24 months. Group 1 consisted of 9 children (8 male and 1 female), who enrolled before they were 60 months of age (Mean = 48.9 months), while Group 2 consisted of 9 children, who enrolled at over 60 months of age (Mean = 101.2 months). This study showed that early entry age into school-based intervention yielded a more positive outcome.

Harris and Handleman (2000) conducted a study on 27 children (31-65 months), who enrolled at the Douglass Developmental Disabilities Centre (DDDC). The IQ of these children ranged from 35 to 109 upon entry into the programme and they all received 35-45 hours of instruction per week for a full calendar year. The programme includes 5.3 hours of intervention per school day and 5 school days per week, with an extra 10-15 hours per week of home-based instruction. Results showed that children who enrolled at a younger age (Mean age = 46 months) or had a comparatively higher IQ (Mean IQ = 78) at intake were more likely to be able to enrol in regular classes, while those who were older (Mean age = 54 months) or had a lower IQ (Mean IQ = 46) at intake were more likely to enrol in a special education class.

3.5.2 Home-based behavioural intervention

The UCLA YAP model developed by Lovaas (1987) has been replicated and modified to be used within the home settings (e.g., Anderson et al., 1987; Johnson & Hastings, 2002). Birnbrauer and Leach (1993) conducted the Murdoch Early Intervention Program, which aimed at replicating the UCLA YAP model. This study
involved 9 children (Mean age = 39 months) with autism and severe developmental disability. They received an average of 18.72 hours of intervention per week in a two-year treatment programme. Results showed that four of the nine children made significant gains and four of the remaining five children achieved a moderate improvement. This study also reported that parents’ stress decreased with on-going treatments.

Anderson et al. (1987) conducted a home-based educational programme for preschool children with ASD. These children’s average age was 43 months and they received 15-25 hours per week of home-based intervention from parents and therapist. Results indicated children showed positive outcome in language, self-independence and skills development, and mal-adaptive behaviours decreased.

The service delivery of EIBI programmes in the UK is usually in a community setting (Magiati, Charman, & Howlin, 2007), whereas in the US, EIBI programmes are generally managed by clinic or university. This is due to differences between the US and the UK educational systems and health care systems.

In sum, EIBI can be conducted across different settings, even within the same programme. Centre- or school- based programmes are often combined with home-based training or community-based interventions (e.g., Reichow, et al., 2012; Strauss et al., 2013). Regardless of the different settings, the literature is in consensus that EIBI is an effective way to improving skills and behaviour for children with ASD.

### 3.5.3 Core components of EIBI

The key characteristics of EIBI programmes with respect to the child’s age, programme intensity, duration, cost and outcomes are outlined below.

#### 3.5.3.1 Age of intervention

Early entry into a programme improves the final outcome. EIBI usually begins before the age of 5, i.e, at 1 to 4 years of age (Green et al., 2002; Reichow, et al., 2012). However, the majority of the children start programmes when they are 3-4 years old (Eldevik et al., 2009). The best age for starting behaviour intervention is between the ages of 2 or 3 years old (Fenske et al., 1985; Howlin, Magiati, & Charman, 2009). In addition, children with higher IQ at intake, who began at a
younger age, they are most likely to be able to enrol in regular classroom (Harris & Handleman, 2000).

3.5.3.2 Intensity

Lovaas (1987) found that the most effective EIBI programmes has an intensity of 20-40 hours per week, in structured sessions (Howlin et al., 2009; Reichow, et al., 2012). Weekly supervision of therapists was recommended. EIBI programmes usually involve informal instructions and practice during child’s remaining waking period (Green et al., 2002; Eldevik et al., 2009). Reichow et al. (2012) reported in a systematic review that the average intensity of EIBI was calculated to be more than 24 hours per week. Overall, intensive supervision of therapists and intensive intervention for the child is most likely to lead to optimal outcome for children with ASD (Eikeseth, Hayward, Gale, Gitlesen, & Eldevik, 2009).

3.5.3.3 Duration

EIBI programmes generally last for at least 2 years (Green et al., 2002; Howlin et al., 2009). Reichow et al. (2012) reported that the duration of EIBI programmes ranged from 14 months to 36 months with an average duration of 26.3 months.

3.5.3.4 Effectiveness

EIBI is considered to be a well-established treatment method for children diagnosed with ASD (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Fein et al., 2013; Tonge, Bull, Brereton, & Wilson, 2014). However, some have argued that EIBI is not effective for all children and some children show modest or no changes (Howlin et al., 2009; Fernell, Eriksson, & Gillberg, 2013). Magiati et al. (2007) were amongst the few researchers who found that progress of children on EIBI home-based programmes were not significantly different from those in autism specialist nursery and both groups showed great improvement after two years.

In contrast, a significant number of researches showed that EIBI can produce considerable improvements across different settings (Fava et al., 2011). On these programmes, children diagnosed with ASD show improvement in IQ, adaptive behaviours, expressive and receptive language, communication skills, socialisation and daily living skills (e.g., Green et al., 2002; Symes, 2005; Trudgeon & Carr, 2007;
Hayward et al., 2009; Dawson & Burner, 2011; Reichow, Barton, Boyd, & Hume, 2012; Klintwall & Eikeseth, 2015). Generally, no other intervention consistently performs as well and hence EIBI had become the accepted treatment option.

The involvement of the parents in the decision-making, treatment and intervention plans (e.g., Strauss, Mancini, SPC Group, & Fava, 2013) provides a chance to generalise newly learnt skills into a child’s daily life (e.g., Keenan et al., 1999). Sibling involvement can also produce more positive outcomes for children with autism (e.g., Cebula, 2012). However, it should be noted that parents face many challenges (Grindle, Kovshoff, Hastings, & Remington, 2009). Hastings and Johnson (2001) reported parents’ lack of energy and time to execute the programmes. Moreover, funding from the authority is required for these programmes as the cost is too high for most families (Howlin et al., 2009).

3.6 ABA-based intervention in the UK

Since the 1960s, parents have been the motivators for increased recognition and adoption of interventions to help their child with autism (Wolff, 2004). In the mid-1990s, the UCLA YAP model was introduced into the UK (Hastings & Johnson, 2001) and adopted into the UK YAP model (UK YAP, 1994). Hastings and Johnson (2001) reported that 250 EIBI programmes were established in the UK since 1999. In a national census study by Griffith, Fletcher and Hastings (2012), 14 ABA schools and classes were identified in the UK.

3.6.1 Rapid reviews of ABA-based interventions in the UK

Systematic review and meta-analysis of ABA-based intervention have been completed by many researchers (e.g., Eldevik et al., 2009; Howlin, Magiati, & Charman, 2009; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Warren et al., 2011; Reichow, 2012). However, few researchers synthesized empirical studies of ABA-based interventions of the UK. A rapid review was conducted with the aim to describe the status quo of the practices of ABA-based interventions in the UK.

Rapid reviews are accelerated or streamlined methods to develop evidence summaries (Khangura, Konnyu, Cushman, Grimshaw, & Moher, 2012). The Cochrane Rapid Reviews Methods Group (RRMG) is one of the 17 Cochrane Method Groups and consists of global researchers who focus on systematic reviews.
The traditional systematic review is regarded as the ‘gold standard’ in gathering information for evidence-based research, but it usually takes 6 months to 2 years to complete (The Cochrane Collaboration, 2011). A rapid review can be completed in less than 5 weeks and is suitable for the reporting of social issues, clinical effectiveness and economic factors in a timely manner (National Collaborating Centre for Methods and Tools, 1996). A rapid review describes and summarises the available literature and does not provide statistical information.

Ten databases were searched in this rapid review conducted on ABA-based interventions in the UK, including British Education Index, Child Development & Adolescent Studies, Directory of Open Access Journals (DOAJ), Education Abstracts, ERIC, International Bibliography of the Social Sciences (IBSS), ProQuest Education Journals, PsychINFO, SCOPUS and Web of Science, on 16-21 January 2017.

The key words for the search were: ABA, ASD and UK. The wildcard (*) and double quotation marks (“”) were used for inclusion purposes. The combination of search terms for each database can be found in Appendix 1.

All studies included in this review meet the following selection criteria:

1. They included children with ASD, who met recognised diagnostic criteria, such as DSM-4 (APA, 1994) or ICD-10 (WHO, 1992);

2. They focussed on interventions that were behaviour analytic in nature (Baer et al., 1968, 1987), including EIBI, that has to follow the guidance as set out by Green et al. (2002);

3. They were empirical studies conducted in the UK;

4. They were published in peer-reviewed journals between 1980 and 2017.

These selection criteria were based on the research aims and research questions of the present study, which means participants included in this rapid review were children, parents or professionals. In addition, empirical studies consisted of experimental studies, such as single-system design studies, and non-experimental studies, such as surveys, interviews, and census.
Finally, geographically, the review area was limited to the UK. Studies where UK participants constituted less than 10% of the whole sample (Mackintosh, Goin-Kochel, & Myers, 2012) were excluded.

Figure 3.1 is the Prisma chart of this rapid review. The search produced 589 records which were filtered down to 36 studies for inclusion in the analysis.

![Prisma chart](image)

**Figure 3.1: Prisma chart of rapid reviews of ABA-based interventions in the UK**

The detail of each journal paper can be found in Appendix 2. A total of 36 empirical studies were identified through the rapid reviews of literature on ABA-based interventions of the UK. Table 3.1 shows the breakdown of the methods used in the included studies.
Table 3.1: Methods of the 36 empirical studies in the UK

<table>
<thead>
<tr>
<th>Methods</th>
<th>Records</th>
</tr>
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<tbody>
<tr>
<td>Experiment/experiment-based</td>
<td>16</td>
</tr>
<tr>
<td>Survey/ census/ measurement/cohort</td>
<td>13</td>
</tr>
<tr>
<td>Interview</td>
<td>7</td>
</tr>
<tr>
<td><strong>Sum</strong></td>
<td><strong>36</strong></td>
</tr>
</tbody>
</table>

The experimental studies include replication of the Lovaas studies in the UK population (Eikeseth, Smith, Jahr, & Eldevik, 2007; Eikeseth et al., 2009; Kovshoff, Hastings, & Remington, 2011), studies exploring low-intensity ABA-based interventions within the existing UK educational system (Foran et al., 2015; Grindle et al., 2009; Lambert-Lee et al., 2015), and studies of specific behaviour analytic techniques (Elliott & Dillenburger, 2016; Sowden, Perkins, & Clegg, 2011). Non-experimental studies included overviews of the status quo of ABA-based interventions (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2012; Griffith et al., 2012), studies related to the working status of therapists (Symes, Remington, Brown, & Hastings, 2006; Griffith, Barbakou, & Hastings, 2014), and studies focussing on psychological issues affecting parents and siblings (Hastings & Johnson, 2001; Hastings, 2003). The status quo of ABA-based interventions in the UK were described below.

### 3.6.1.1 How do parents find out about ABA-based interventions

The internet was the main source of information of ABA-based intervention for most parents. For example, by searching key words such as ‘effective treatments for ASD’ in the search engine (Tzanakaki et al., 2012; McPhilemy & Dillenburger, 2013). Some parents discovered ABA through peer recommendation and published literature (Tzanakaki et al., 2012). Statutory services did not fulfil their role of recommending this evidence-based approach, which led to many parents trying the eclectic approach (Dillenburger et al., 2012; McPhilemy & Dillenburger, 2013). Some parents did not wait for a final diagnosis before commencing ABA-based programmes (McPhilemy & Dillenburger, 2013). In addition, Tzanakaki et al. (2012) reported that some mothers misunderstood EIBI because they expected their child to be ‘cured’.
3.6.1.2 Characteristics of the ABA-based programme

Home-based programme was the main mode of service delivery for ABA-based programmes in the UK, which meant that parents were hiring and paying for ABA professionals privately (Dillenburger et al., 2012; Foran et al., 2015). Dillenburger et al. (2012) surveyed 95 parent respondents and over half of them (53%) mentioned that their child was involved in an ABA-based home tuition programme. In an earlier study in Northern Ireland, 50 families were engaged in home-based ABA programmes (Dillenburger, Keenan, Gallagher, & McElhinney, 2004).

The average age of children with ASD at commencement of ABA-based programme was 38 months and the average length of programmes was 42 months (McPhilemy & Dillenburger, 2013). Dillenburger et al. (2012) reported an average age of 63 months at commencement.

Mudford, Martin, Eikeseth and Bibby (2001) replicated the Lovaas model by conducting a study on parent-managed EIBI programmes of 75 children in England: 43% of these children (n=32) started the programme between 40-45 months of age and 71% of the children (n=53) started the programme by 4 years of age. Hastings and Symes (2002) reported the average starting age of children in ABA-based programmes to be 45.52 months and the average length of the programme was 14.18 months.

The intensity of the ABA-based programmes in the UK was reported to be low compared to the ‘well-established’ EIBI model in the US. Symes, Remington, Brown and Hastings (2006) indicated a therapist provided an average 20.2 hours of EIBI per week. Remington et al. (2007) reported children (n=23) who participated in a home-based early intervention received an average of 25.6 hours per week (Min. =18.4 hrs; Max. =34.0 hrs) from therapists/parents. Mudford, Martin, Eikeseth and Bibby (2001) reported the average intensity of EIBI programmes to be 32.0 hours per week. Of the 75 children studied, 71 children received more than 20 hours per week and 35 children received more than 35 hours per week (Mudford et al., 2001). Hastings and Symes (2002) found an average intensity of 6.79 hours per week for mothers who worked as a therapist on their child. The average length of intervention received for clinic-based interventions was 37.4 hours per week and 34.2 hours per
week for parent-managed programmes (Hayward et al., 2009). Eldevik, Hastings, Jahr and Hughes (2012) reported a lower intensity of 13.6 hours per week on average.

The frequency of the programme supervision was studied by Mudford et al. (2001). In a sample of 75 children, 66 programmes were supervised twice a year; 45 were supervised every 3 months or more; 15 were supervised for every two months or more, and 5 received supervision twice a week.

The travelling time for children to reach clinic-based services was usually 1-2 hours, with a travel distance ranging between 60 to 120 miles (Hayward et al., 2009).

3.6.1.3 Competence of professionals and parent therapists

The level of competence in ABA of professional therapists or parent therapists is very important for intervention outcomes. Symes et al. (2006) indicated that the delivery of ABA-based interventions is influenced by the characteristics of the therapist, such as the therapists’ theoretical and practical training in ABA, supervision levels and the techniques utilisation in the intervention. In addition, Hastings and Symes (2002) suggested that, apart from the severity of the child’s autism, the competence and support levels of ABA programme teams played a key role in the level of maternal stress. In addition, professional competence influences therapeutic efficacy of the ABA-based programme, especially when the parent worked as a therapist for their own child.

Staffing levels are also important. Foran et al. (2015) found the staff-to-child ratio at SEN schools to be 0.56:1. Lambert-Lee et al. (2015) reported on 6 students in an autism-specific school, where the staffing ratio was 1:1, which was attended to by a multidisciplinary team composed of an ABA tutor, an ABA supervisor, an experienced teacher, an ABA consultant (BCBA level), a speech and language therapist (occupational therapist and subject specialist teachers, where needed) and vocational specialists.

Symes et al. (2006) found that the average therapist delivered home-based interventions to a total of 3 children (Min. =1, Max. =12); at the time of the study, the average therapist typically worked with 2 children (Min. =1, Max. =4). Poorly trained staff reduced the efficacy of the intervention (Johnson & Hastings, 2002). According to Eikeseth, Hayward, Gale, Gitlesen and Eldevik (2009), supervision
meetings for intensive home-based programmes generally involve parents, therapists, consultants and, sometimes, professionals from the child’s school. After the meeting, the consultants usually provided a written report to describe the matters discussed and outline intervention strategies for the next targets (Svein Eikeseth et al., 2009). Of a sample of 141 parents, 75.9% indicated the service they received was supportive and the team had a strong commitment (Johnson & Hastings, 2002).

Parents often hired private tutors to work with the child, however, generally, parents found recruiting professionals was challenging. For example, in a sample of 141 parents, 70.9% reported difficulty in recruiting therapists and hiring training supervisors (Johnson & Hastings, 2002). Hence, a number of parents worked as parent therapists for their own child. According to Hastings and Symes (2002), of the 141 parents surveyed, 66.67% of parents (n=94) worked as a parent therapist for their own child. Hayward et al. (2009) noted that in an intensive home-based, parent-managed programme, parents were supported by ABA supervisors/consultants for 6 hours in a 6-week period.

**3.6.1.4 ABA-based interventions in the educational system**

There were several studies exploring low-intensity ABA-based interventions within the existing UK educational system. These included an SEN school (e.g., Foran et al., 2015), mainstream education (e.g., Grindle et al., 2012), and an autism-specific educational organisation (e.g., Lambert-Lee et al., 2015).

Foran et al. (2015) put forth a cost-effective model of applying ABA-based interventions in an SEN school in North Wales. In this model, behaviour analysts worked closely with school teachers. This model had two major components. The first is, individualised early behavioural intervention programme that was carried out with younger children with the purpose of building communication, self-management, independent living and academic skills with the view of integration into mainstream education. Since group teaching is an essential part of the SEN school, some skills, such as listening to the classroom instructions was also taught. The principles and techniques, such as task analysis, DTT, NET, errorless teaching, reinforcement, and prompting were utilised by teachers in both the individualised programme and group teaching. The second component of the North Wales programme component is function-based behaviour intervention which was
conducted with older students with the purpose of decreasing challenging behaviours. This was a low intensity ABA-based intervention environment (around 7 hours per week individualised intervention), which was integrated into the nominal 30 hours per week school programme mainly using functional analysis. This model led to great improvements with regards to IQ, learning skills, language skills, and social/play, self-motor and motor skills. In addition, the functional analysis designed by behaviour analysts helped reduce older children’s challenging behaviours.

Grindle et al. (2012) studied the integration of low-intensity ABA-based intervention in a state-funded public mainstream school (30 hours per week in school) via the delivery of an ABA class for children with ASD, i.e., individualised intervention sessions, for up to 18.75 hours per week of therapist to child intervention. In addition, children in this ABA class were also arranged into small-group activities, either with their classmates within the ABA class or within a mainstream class with typically developed students, with the assistance of a therapist. Results showed that the 11 children who were put into this ABA class had positive outcomes after two years (Grindle et al., 2012). Eldevik et al. (2012) also reported optimal outcome for children who received a low-intensity of behavioural intervention for two years.

Lambert-Lee et al. (2015) described the use of a comprehensive ABA-based educational model at an autism specific special school. The service delivery happened at London Treehouse School, which accommodated children and young people with ASD from 3 to 19 years of age. The curriculum content was individualised and used the principles, strategies and techniques of ABA with the aim of enabling all learners to achieve their own potential, to live independently and safely, and become a responsible citizen in their communities. For example, one of the children (aged 7) had a personalised curriculum to teach life skills (e.g., toilet training) and social communication in groups; another child (aged 17) was taught vocational skills because he had one year left before graduation. Similarly, Reed, Osborne and Corness (2012) indicated an autism specialist nursery placements is helpful for nurturing children’s adaptive behaviour.

3.6.1.5 Cost and financial support

The expense of the ABA-based interventions was mostly born by the family. Many parents wanted their child to receive the evidence-based approach but could not
afford it (McPhilemy & Dillenburger, 2013). The majority of parents reported the Local Education Authorities (LEAs) did not provide EIBI services because of cost and other practical reasons, such as children in special needs school being easier to manage and administer (Grindle et al., 2009). Grindle et al. (2009) also indicated that: ‘LEAs held outdated and incorrect views about EIBI’.

According to Hastings and Johnson (2001), of the 250 Lovaas model programmes in the UK, 109 were involved in tribunal dispute with the local educational board to access funding. Johnson and Hastings (2002) said that 17.7% of the parents held negative views about or had issues with the local authority. Similarly, Tzanakaki et al. (2012) said some parents received funding from the local authority, but others had to challenge the educational authority to receive funding.

In contrast, speech and language therapy was the most commonly funded approach by the health care system (McPhilemy & Dillenburger, 2013). In 1996, UK parents set up a support group called Parents for the Early intervention of Autism in Children (PEACH), which made a substantial impact on helping parents get financial support from the local authority (Hastings & Johnson, 2001).

The level of support for ABA based services in the UK differs significantly by region. Magiati, Charman and Howlin (2007) reported that within 3 hours travel of Central London, of the 28 children who were on an EIBI home-based programme, 21 were funded by the Local Educational Authorities (LEAs). In the South-East of England, the local educational authority developed a home-based programme for preschool children with ASD, in which parent training, individualised intervention and relevant supervision, and support sessions from a psychologist, were included (Reed et al., 2012).

3.6.1.6 Changes to children and family

There are many empirical studies demonstrating the effectiveness of ABA-based interventions with the UK population. Empirical studies, such as Elliott and Dillenburger (2016) utilised single system research designs to examine whether choice on motivation affected the effectiveness of an educational procedure; Sowden, Perkins and Clegg (2011) explored a context and communication strategies in naturalistic behavioural intervention; Cebula (2012) explored the benefit of sibling
involvement in the intervention programme. Generally, optimal outcome was considered as transitioning of the child from specialist setting to mainstream school (Reed et al., 2012).

Remington et al. (2007) conducted a Randomised Control Trial (RCT) study on an intervention group (23 preschool children with ASD) who were engaging in an EIBI programme and were compared them against the control group (21 children) who received treatment as usual in the UK. Results showed young children with ASD in the intensive and applied behaviour analytic intervention group had a significant improvement in IQ, language, daily life skills and social communication skills compared to the control group. A similar result was obtained in an experiment-based study by Eikeseth, Smith, Jahr and Eldevik (2007).

There are many non-experimental studies as well. McPhilemy and Dillenburger (2013) and Liao et al. (2016) described parents reporting changes in social skills, social communication, gross and fine motor skills, and independent skills in their child. In a survey involved 59 parents by Grindle, Kovshoff, Hastings and Remington (2009), respondents also reported changes in the child’s language and communication skills, social skills and play skills.

ABA-based intervention also significantly impacted the family. McPhilemy and Dillenburger (2013) reported ABA-based intervention having a positive impact on the family. Some researchers studied coping strategies for parents (Hastings et al., 2005). Trudgeon and Carr (2007) conducted semi-structured qualitative interviews with 16 parents who had experience of home-based EIBI programmes. Results indicated that parents had mixed reactions to the child’s EIBI programme, i.e., parents’ demand for the programme was accompanied with anxiety and stress due to disruption of their personal lives, financial pressure, and shortage of resources. In addition, parents of children with ASD experienced higher pressure than parents whose child was diagnosed with other developmental disabilities (Hastings & Johnson, 2001; Johnson & Hastings, 2002).

Some research focused on stress and general health of therapists. The study by Griffith, Barbakou and Hastings (2014) reported the psychological impact on ABA staff members and recommended support for ABA professionals, who carried out a questionnaire survey of 45 ABA therapists across 6 ABA schools in the UK. Results
showed that 42% of participants reported a low sense of achievement in their job, 13% of participants felt tiredness and 40% of participants experienced stress (Griffith, Barbakou, & Hastings, 2014).

This rapid review outlined various aspects of the application of ABA-based interventions in the UK and provided a backdrop to the present study. The next section reports on a similar rapid review with regards to the situation in China.

3.7 ABA-based intervention in China

Increasing concern from Chinese parents, whose child were diagnosed with autism, led a number of autism organisations being established in the 1990s (McCabe & Tian, 2001). Zhou et al. (2014) reported that there were approximately 1,000 autism training centres in China.

*Beijing Stars and Rain* is considered to be the first autism organisation to introduce the evidence-based approach of ABA-based interventions to their autism specific programme (McCabe & Tian, 2001; Guo, 2006; Wen, 2014; Zhou et al., 2014). It is an NGO founded in 1993 by a mother whose son was diagnosed with ASD.

In contrast to the typical ABA-based intervention service of the West, the service delivery mode at Beijing Stars and Rain is parent-focused and delivered through a three-month residential course, for which at least one of the parents moves with their child to Beijing for the duration of the course (Guo, 2006). Parents rent a flat, often sharing with other parent and children dyads, who also attend Stars and Rain (Liao et al., 2016). Parents and children attend Stars and Rain together, in other words, the child is never at school without the parent also attending. As such, parents are trained at the school, while working with their own child.

In 2005, Stars and Rain started the Heart Alliance, a network comprising 230 autism NGOs to share resources and knowledge to provide quality services for children with ASD and families (Zhou et al., 2014).

3.7.1 Rapid reviews of ABA-based interventions in China

The empirical research on children with intellectual disability in China is in its infancy (Wang, 2010). Few researchers specifically studied ABA-based interventions in China (Clark & Zhou, 2005; Huang, Jia, & Wheeler, 2013). Some
researchers living in the West had also studied autism in China. For example, the American researcher McCabe explored the current practices in autism intervention (McCabe, 2013), the situation faced by families and parents whose children were diagnosed with ASD (McCabe, 2007), the parent-to-parent support structure (McCabe, 2008a), and inclusive education (McCabe, 2003).

Some Chinese researchers collaborated with international scholars and studied the prevalence of autism in the epidemiological manner (e.g., Sun et al., 2013), reviewed Chinese traditional medicine such as acupuncture and ABA-based intervention (Clark & Zhou, 2005), and described the diagnostic process and legislative issues in China (Huang, Jia, & Wheeler, 2013).

Of these studies, most were not solely focussed on ABA and were lacking in detail. Two rapid reviews were conducted with the aim of describing the status quo of the research on practices of ABA-based interventions in China.

### 3.7.1.1 English databases

Six English databases were searched for this review, including Education Abstracts, ERIC, Web of Science, ProQuest Education Journals, SCOPUS and PubMed between 22-25 January 2017. The key words for the search were: ABA, ASD and mainland China. The method of the review was similar to the UK rapid review (see Section 3.6). The combination of search terms for each database can be found in Appendix 3.

All studies met the following selection criteria:

1. They included children with ASD, who met the diagnostic criteria, such as DSM-4 (APA, 1994), ICD-10 (WHO, 1992) or CCMD-3 (Psychosis Branch of Chinese Medical Association, 2001);
2. Intervention had to be behaviour analytic in nature (Baer et al., 1968, 1987) and EIBI had to follow the guidance as set out by Green et al. (2002);
3. They had to be empirical studies conducted on Mainland China;
4. The studies had to be peer-reviewed journals and written in English.
Figure 3.2 is the prisma chart showing the procedures of this rapid review. The review produced 66 records, which were filtered down to 4 studies for inclusion in the analysis.

Figure 3.2: Prisma chart of rapid reviews on ABA-based interventions in China (English articles)

The detail of the four journal papers that were included in the review can be found in Appendix 4.

There were two qualitative semi-structured interview studies: Zhang and Spencer (2015) talked about the needs of students with ASD and Liao et al. (2016) explored cultural differences impacted the service delivery of ABA-based interventions in the UK and China. Zhou et al. (2014) conducted a statistical analysis on the students’ data at Stars and Rains over a twenty year period (1993 to 2012) and surveyed 100 member centres of Heart Alliance. Wang (2008) explored the effects of a parent
training programme (20 hrs of training per day) on the interactive skills of parents of
children with autism.

3.7.1.2 Chinese databases

Another rapid review was conducted for ABA-based interventions in China in
Chinese databases. Two databases were searched for this review, including CNKI
and VIP\textsuperscript{17}, which are considered to be the most frequently used Chinese academic
databases (e.g., Sun et al., 2013). The key words for this search were: autism and
ABA. The method of the review was the same as the above reviews. The
combination of search terms for each database can be found in Appendix 5. Articles
from CNKI were searched on 26-28 January 2017 and articles from VIP were search
on 4-5 February 2017.

The selection criteria were the same as the above rapid reviews of ABA-based
interventions in China in English databases. A slight differences were children with
autism could be diagnosed by (APA, 1980) and all of these articles were written in
Chinese.

Figure 3.3 is the prisma chart showing the procedures of this rapid review. The
review produced 194 records, which were filtered down to 8 studies for inclusion in
the analysis.

\textsuperscript{17} CNKI (China National Knowledge Infrastructure) in Chinese: 中国知网; VIP (Weipu) in Chinese: 维普
As can be seen from Figure 3.3, a large body of Chinese literatures were excluded in the abstract level. In addition to those articles that were not about ABA (n=25), a number of articles were non-empirical studies (n=29). Specifically, Chinese researchers mostly reviewed or described theories and practices of ABA-based interventions of the West, for example, describing theoretical introductions of autism diagnosis and intervention in Western publications (e.g., You & Yang, 2006), outlining what ABA intervention is and how it can be implemented (e.g., Liu & Li, 2007), offering an overview of PRT (e.g., Huang, Chen, & Li, 2010), and reviewing EIBI usage in the West (e.g., Wang & Kang, 2011). Most interestingly, 29 articles reviewed eclectic methods, which meant that ABA was regarded as a type of intervention and mixed with approaches, such as sensory integration, auditory integration, TEACCH, music therapy and medical therapy. For example, researchers explored the effectiveness of combining specific ABA-based procedures with music therapy (Zhang, 2005) or with sensory integration and auditory integration therapies (Wang et al., 2011). However, they did not differentiate to which
intervention approach the effectiveness of the overall intervention was attributable (McCabe, 2013), and there was little information on how control groups were managed (Clark & Zhou, 2005). There were some single system design studies, but there was a shortage of well-designed experimental studies in the Chinese literature. Common limitations included the lack of a baseline or lack of description of explicit research procedure (e.g., Yu & Chen, 2011).

The detail of the eight journal papers that were included in the review can be found in Appendix 6. Five out of the eight articles were single subject design. For example, researchers explored PECS on child’s communication skills (Shao, Xu, & Zhang, 2014; Hu & Fan, 2015); Hu and Fan (2014) reported children with autism’s immediate learning, generalization and maintaining effects for interventions that were based on the principles of ABA. Zhong (2016) reported decreases in a child’s problematic behaviour through a case study; Dong (2015) conducted a task analysis on a child’s vocational skills. The remaining three articles were using assessment evaluation to test the effectiveness before and after the ABA-based training. For example, Ding, Zhong, Cheng and Jiang (2015) assessed the outcome of 66 children with autism and Xiong et al. (2010) assessed the quality of life of 76 children and their mother’s psychological level after they received 3 months training; Liu and Chen (2012) assessed the speech and language skills of 41 children before and after ABA-based intervention.

As far as the researcher is aware, there is no RCT study on EIBI or ABA-based interventions in China, and few professionals in China have studied behaviour analysis in depth (Clark & Zhou, 2005; Huang et al., 2013). The status quo of ABA-based interventions in China were described below.

**Parental involvement**

ABA-based intervention programmes in China typically involve parents (McCabe, 2007; Zhang & Spencer, 2015). Parents are also involved in the discussion of their child’s IEP with teachers (Zhang & Spencer, 2015). Over half (56%) the founders of organisations delivering autism interventions are parents of children diagnosed with autism, who wanted to help their own child and those like them (Shenzhen Autism Society, 2013). Of the 100 autism NGOs surveyed by Zhou et al. (2014), 73
organisations provided both children and parent training, 24 organisations solely provided children intervention, and 3 organisations solely provided parent training.

The effectiveness of parent training is demonstrated by Wang (2008), who demonstrated improvements in interaction between the parent and the child with ASD after the parents-focused training. Parents were more accepting of their child, clearer about their child’s interests, more able to appropriately deal with the child’s behaviour, and able to better interact and communicate with their child (Wang, 2008). In addition, parent training provided parents of a child with autism a forum to share their emotional feelings, to support each other, to accept their child, and to some extent, to relieve their psychological pressure (McCabe, 2008b; Xiong et al., 2010).

**Different intervention models used for children with autism**

Zhou et al. (2014) found that the number of professionals working at each organisation ranged widely from 3 to 75, with a median staff to child ratio of 1: 2.77 and many different models and approaches are used to support children with autism in China, both in practice and in research. Zhang and Spencer (2015) reported teachers used a ‘life and experimental model’, which dealt with life skills, and ‘recovery model’, which dealt with the emotional or physical difficulties. In 2013, Zhou et al. (2014) surveyed 100 autism NGOs of the Heart Alliance, of which 99 organisations provided ABA-based interventions, 73 provided sensory integrations intervention and 36 provided TEACCH. A total of 87 organisations provided more than two approaches (Zhou et al., 2014).

The duration of programme were mostly reported to be around three moths (Xiong et al., 2010; Ding et al., 2015)

**Lack of knowledge and limited training**

The public has little knowledge of evidence-based approaches in China. Liu et al. (2016) surveyed 471 preschool teachers in Foshan, Southern China and reported that more than 60 % of respondents had not heard about ABA-based interventions, while the majority of participants had heard of sensory integration therapy (76%), or auditory integration therapy (71%). However, Shenzhen Autism Society (SAS, 2013) reported 88.89% of the 56 autism service providers in South China offered ABA-based interventions.
There is a lack of knowledge on ABA and limited training opportunities in evidence-based approaches (Zhang & Spencer, 2015). Most teachers (91.5%) feel that they need more training to improve their skills (SAS, 2013).

**Financial issues**

Families of children with autism usually carry the largest financial burden (¥19582.4 per year ≈ £19582.418) as a result of having a child with autism, compared to having children with physical disability (¥16410.1 per year ≈ £1888) and intellectual disability (¥6391.0 per year ≈ £735), as reported in the survey on 225 parents (Xiong et al., 2011). Many parents, who travelled from their home to one of the major cities to access quality parent training, chose to leave their job (McCabe, 2010). Parents had to self-finance their child if he/she was receiving services or training outside their province, as reimbursement from the local authority is limited to services within their local province (Liao et al., 2016).

**Changes to children**

Chinese researchers also reported optimal outcomes after undertaking ABA-based interventions. Xiong et al. (2010) had an assessment on 76 mothers after three months intervention at a parent-focused ABA training programme, where the parent-child dyad was practised under teacher’s supervision. Results showed children with autism had a great improvement in sense ability, social ability, movement ability, speech ability and self-care ability. In addition, girls had a greater improvement than boys in terms social ability and independanta skills; older children had a better outcome than younger ones in self-care ability (Xiong et al., 2010). Ding, Zhong, Cheng and Jiang (2015) assessed 66 children with autism after they received 3 moths training in ABA programme. Results showed children with ausim improved quality of life (physical functioning), but not much improvied in emotial and social communication compared with typical children. A number of resaerchers reported child’s language and communication skills improved (Liu & Chen, 2012; Shao et al., 2014; Hu & Fan, 2015). Child’s probmatic behaviour decreased (Zhong, 2016). In addition, Hu and Fan (2014) reported children’s theory of mind ability significantly improved.

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18Currency on 25 Jan. 2017
In summary, the rapid review of ABA and autism literature in China yielded limited reading. 4 English literatures and 8 Chinese literatures were found, although a small number of non-empirical papers were available. Generally, quality ABA-based services in China are only available in large cities and parents have to move to the city, with their child and at their own expense for lengthy training periods. Yet, data that are available evidence that these processes appear effective.

3.8 The Census study in Victoria, Australia

Study 1 of thepresent research part-replicated the original census study, ‘Early behavioural intervention practice for children with autism’ in Victoria, Australia (Autism Behavioural Intervention Association; ABIA, 2013). The ABIA census project investigated the status of behavioural intervention practice for children on the autistic spectrum between 20th and 27th of November, 2013 (Horiguchi, 2014). The study was conducted through three types of online questionnaires, i.e., a parents’ questionnaire, a therapists’ questionnaire, and a supervisors’ questionnaire. A total of 38 therapists, 15 supervisors and 72 parents completed the survey and yielded the following results (Autism Behavioural Intervention Association, 2013; Horiguchi, 2014):

(a) Around 39 organisations provided behaviour analytic services for 585 children in Victoria. The ratio of girl to boy was 1:6. The ratio of families living in metropolitan to rural areas was 10.8:1;
(b) The most common mode of service delivery was the Lovaas model and this was reported by 60% of supervisor participants (n=9). One-to-one training (55%) was one of the most common service delivery mode;
(c) The average age at commencement of the programmes was 3.3 years (Min. =1.5, Max=13.41). A total of 65 parents (90.27%) reported their child receiving an average of 16.79 hours (Min. =4, Max. =38) of individualised training per week. In addition, 12 supervisors (80%) indicated the duration of the programmes was at least two years, and only 3 supervisors (20%) indicated a duration between one to two years;
(d) The supervisor respondents reported an average experience of 10.87 years (Min. =3, Max. =18) and therapist respondents reported an average experience of 2.67 years (Min. =0.3, Max. =6.5);
(e) The majority of the parents (94%) believed that their child’s quality of life was improved after the ABA-based programme while only a small percentage of parents (5%) believed their child’s quality of life was the same or lower.

This study was the first census study in Victoria on autism intervention (Autism Behavioural Intervention Association, 2013). It provided an overview of ABA-based services of the local area and offered data for comparison or replication in future research. Further details of the part-replication of the ABIA census are included under Study 1 in the Methodology Chapter.

3.9 Chapter summary

This chapter reviewed the literature regarding ABA-based interventions in the UK and China to allow for the development of the question of ‘What to compare’. It also identified gaps in the research literature. The chapter offered a very brief outline of the fundamental philosophy of behaviourism and the experimental analysis of behaviour. It outlined how ABA evolved and subsequently reviewed in some more detail what EIBI is and how it is used to tackling some of the main challenges experienced by children with ASD.

Most importantly, in order to identify gaps in the knowledge, this chapter conducted three rapid reviews on ABA-based interventions; one for the UK and two for China (one for studies published in English and one for studies published in Chinese). The rapid review in the UK yielded 36 empirical studies that highlighted the key characteristics and features of ABA-based interventions. It also outlined how ABA-based interventions were adapted to the UK educational system. The rapid reviews on ABA-based interventions in China summarised the status of ABA in research and in practice in China (n=12). A widely use of eclectic method and lack of well-designed experimental studies were discussed. The Chinese ABA-based programmes were featured by the parental involvement. The present study covered some of the gaps identified in these reviews. The following chapter details the methodology used in the present studies.
Chapter 4. Methodology

4.1 Overview
A comparative study in the context of applied behaviour analysis (ABA)-based interventions for children with ASD was carried out between the UK and China, comprising three related studies. Study 1 was a quantitative questionnaire-based survey presented in Section 4.4. Study 2 included a number of in-depth interviews with parents and professionals presented in Section 4.5. Study 3, presented in Section 4.6 and was a direct participant observation of the use of one specific ABA-based procedure, Discrete Trial Teaching (DTT), by parents and professionals working with a child. These three studies did not include any additional direct work with children with ASD or their siblings other than that carried out in their usual intervention setting.

4.2 Methods of data collection
A mixed methods approach was used to maximise advantages, utilising the strength of each method to complement the shortcomings of the other and allowing for triangulation of results (Creswell, 2002; Neuman, 2013). A combination of quantitative and qualitative techniques was employed in this project to provide a comprehensive view of the social reality of the use of ABA-based interventions in the two countries. The structure of the data collection approach is described at Figure 4.1.

Figure 4.1: The structure of data collection approach
The quantitative surveys (Study 1) provided a wide-ranging look at the sample population, exploring the relationship between variables or their influencing factors, but did not allow for contextual interpretation or explanation of individual differences in behaviours, perceptions or feelings under different socioeconomic circumstances. Specifically, a survey questionnaire may constrain respondents if they would like to explain their circumstances in more detail. The qualitative interviews (Study 2) allowed for an in-depth analysis of the views of service users and practitioners and an exploration of each of the respondent's lived experiences. Direct observations (Study 3) offered opportunities for a detailed understanding of the applications of one specific ABA-based procedure in each country (Creswell, 2002; Corbetta, 2003; Bryman, 2015).

The selection criteria for all participants were that they either lived/worked in UK or China, regardless of their own nationality. Parents had to have at least one child that was diagnosed with ASD and was involved in an ABA-based programme. Professionals had to work with children diagnosed with ASD and be involved in ABA-based programmes.

The analysis and triangulation of the data gathered throughout all three studies provided new insights into the conceptualisation and application of behaviour analytic practice in these two geographical and culturally diverse regions and led to recommendations for future practice in international contexts.

4.2.1 Ethical considerations

The research reported here was approved by the Ethics Committee, School of Social Sciences, Education and Social Work, Queen’s University Belfast (QUB) and conducted within the Research Governance procedures of QUB. Participation in this study was purely voluntary and discontinuation did not have adverse effects on service provision for any of the participants. Information and consent forms were sent to all participants. All data were stored securely and confidentially in accordance with QUB data protection guidelines. All materials were stored appropriately in a locked cabinet and a password protected computer. In order to avoid identification of any participants, pseudonyms were given. After the study was completed, the electronic data were stored securely for 5 years, in line with School of
Social Sciences, Education and Social Work data storage policy; any hard copies were destroyed.

4.2.2 Main sample sites
In this study, the main sample site was the location for the major part of the data collection, especially direct observations (Study 3) in each country. The main sample site in the UK was located in Belfast, Northern Ireland. In China, the main sample site was located in Beijing, Northern China. These two organisations had been established at similar times, i.e., NIU charity in the UK was founded in 1997 and Beijing AC School, the Chinese sample site, was founded in 1993. Thus, their experience is historically similar and differences can be attributed to their local environment and culture.

4.2.2.1 The UK main sample sites
In the UK, the study was conducted at NIU charity (anonymised name). NIU charity was a parent-led charity founded in 1997 by parents in Northern Ireland. The charity employed 4 BCBAs and provided services for families in home settings. This organisation also trained parents and other caregivers of young children with ASD to implement ABA-based interventions and skills. NIU charity was based on research showing that parent-implemented interventions, aimed to help children with ASD, can be effective in the long-term (McConachie & Diggle, 2007).

Home settings
Referrals to the NIU charity came from parents, schools, and health and social care trusts. Programmes were home-based and regularly supervised by BCBAs. At the beginning of the programme, parents took part in a 4-week parent training class and children were assessed by a BCBA in order to draw up an Individualised Educational Plan (IEP). During the assessment parents observed the professionals working with the child. Once the programme was in place, families took part in monthly training sessions (i.e., so-called ‘playdays’ were convened on one Saturday per month, where the children joined supervised social skills groups, while the parents took part in training workshops conducted by the BCBAs). NIU charity also collaborated with a local university to organise further workshops that were regularly delivered by a BCBA.
In this sample organisation, some parents hired a therapist to deliver the ABA-based training for their children and some parents trained their child themselves, integrating therapy into their daily lives (often using Natural Environment Training procedures); some of the families combed therapist and parent-led interventions (Figure 4.2). In addition, a BCBA supervised the therapist’s or parent’s work and ensured progress was made with the child. These consultations generally occurred once a month and parents and therapists received detailed feedback from the BCBA.

![Home training between a mother and her son](image)

Figure 4.2: Home training between a mother and her son

(Permission was granted for the use of this photo)

**Playday workshops**

In addition to supervising interventions in the home settings, NIU charity held playday workshops at the end of each month (Figure 4.3). At playdays, parents and children were offered separate activities. Parents attended parent-training workshops to learn about ABA-based interventions. At times external speakers were invited while at other times the BCBA led the training. While the parents attended workshops, children were engaged in social skills training and play activities in a safe venue with volunteers and therapists supervising and engaging with the children.
4.2.2 The Chinese main sample site

The main sample site in China was at AC School (anonymised name). It was a leading autism Non-government Organisation (NGO) in China. This NGO was founded by a mother in 1993, whose son was diagnosed with ASD. AC School had been delivering parent-focused training since 1998. Parents accompanied their child to the centre for ABA-based interventions. Specifically, parents were taught ABA theories, and practical skills were demonstrated in the classroom. Centre-based parent training was used, as parents were considered the persons who spent the most time with children with autism and therefore were the best to ensure generalisation and maintenance of behavioural gains.

There were two sectors at AC school, pre-school sector and teenage sector, located at different campuses (around 5 minutes’ walk away). Only the pre-school sector was used as the sample site in the present study.

Classroom

There were 5 class groups at the preschool sector. In each class, there were 10 children, i.e., students, accompanied with 10 parents. Student/parent dyads were grouped by the child’s ability level, which was assessed by experienced teachers at
the beginning of the term. One term lasted for 11 weeks. School opened from Monday to Friday.

Table 4.1 shows an example schedule of one of the classes. There were 5 classrooms at the preschool sector, 1 large classroom and 4 small classrooms. The large classroom was designed for independent practice (1st column), where parents and children sat together. There were 10 small tables in the room allowing a parent to work with their child in a one-to-one intervention setting. Each table was isolated by movable barriers or ‘shelters’ (approx. one metre high) to avoid distractions and thus enhance concentration, i.e., students-parent dyads were not able to see each other while sited, so the child and parent were focussed on the task during independent one-to-one practice. The 5 class groups took turns to use the large classroom. During the break time, parents and children moved between classrooms. The 4 small classrooms also were equipped with 10 small tables and each table had two chairs, one for a child and one for a parent to sit behind, however there were no movable barriers (e.g., Figure 4.4).

Figure 4.4: Parents’ practice session in small classroom

(Permission was granted for the use of this photo)
Table 4.1: Class schedule example for one of the classes

<table>
<thead>
<tr>
<th>Time</th>
<th>Courses</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.30-9.15</td>
<td>Independent practice</td>
</tr>
<tr>
<td></td>
<td>15 minutes break time</td>
</tr>
<tr>
<td>9.30-10.15</td>
<td>Teacher-led theory introduction &amp; practice demonstration</td>
</tr>
<tr>
<td></td>
<td>5 minutes short break</td>
</tr>
<tr>
<td>10.20-10.40</td>
<td>Snack time</td>
</tr>
<tr>
<td></td>
<td>5 minutes break time</td>
</tr>
<tr>
<td>10.45-11.30</td>
<td>Parent-led practice session 1</td>
</tr>
<tr>
<td>11.30-14.30</td>
<td>Lunch &amp; long break</td>
</tr>
<tr>
<td>14.30-15.15</td>
<td>Music instrument &amp; outdoor activities</td>
</tr>
<tr>
<td>15.15-15.45</td>
<td>Afternoon exercise</td>
</tr>
<tr>
<td>15.45-16.30</td>
<td>Parent-led practice session 2</td>
</tr>
</tbody>
</table>

In Table 4.1, there were 3 sections and a snack time in the morning. Classes began at 9.30 am and finished at 11.30 am. Each class lasted for 45 minutes, with break/snack time in between classes.

The 1st session included independent practice, which took place in the big classroom. In this session, parents were first given a task by the leading teacher and independently conducted the training with their child. An assistant was standing by in case parents needed support.

The 2nd session focussed on theory introduction and practice demonstration, in which teachers were standing in front of the whole class to demonstrate theories and techniques of ABA-based interventions and practical examples of working with the children with ASD. After that, the leading teacher requested that one child would come to the front and show the other parents first-hand how to work with the child. This modelling technique gave parents a direct example of dealing with their children’s issues. For example, some children were lying on the floor to avoid the task and the teacher was able to show parents how to deal with this kind of avoidance behaviour. It also gave the parents a chance to raise questions. At the end of this session, teacher requested one parent-child dyad to come to the front to
practice on their own, which gave the parents an opportunity to observe directly the effect of the training. In addition, the teacher then asked the other parents to comment on the practice of parent-child dyad, before giving teacher’s feedback.

The 3rd session was snack time, in which children learned to wait and sit quietly before the snack was served. It also allowed parents some time to relax.

The 4th session was the first session in which parents practised with their child on their own. As parents were assigned homework after school, this section allowed the parents to practise their homework in front of the class and receive the teacher’s feedback. After morning courses were finished, parents and children went home for lunch break.

In the afternoon, classes began at 14.30 and finished at 16.30. There were two sessions including a 30-minute physical exercise session and work with musical instruments and outdoor activities (Figure 4.5). It gave children the opportunity to interact with parents and peers, which was helpful to develop their social communication and language skills.

Figure 4.5: Outdoor activities
(Permission was granted for the use of this photo)

The afternoon session included exercises that were modelled on Chinese mainstream school. In the outdoor exercise (Figure 4.6), a leading teacher stood in front of the students to guide parents and children. If a child was not able to follow the teacher’s
instructions, their mother/father physically would prompt their child to help them achieve the target response. The final session offered opportunities to continue the unfinished parents’ practice session.

![Image](image_url)

**Figure 4.6: Afternoon exercise**

(Permission was granted for the use of this photo)

It is worth highlighting that at times the children did not sit still very long. In order to bridge these periods of restlessness, parents brought toys or crafts for children to play with or make. For example, some children drew pictures while others did crafts, e.g., stringing beads.

**Homework**

In addition to the learning taking place at school, parents were also required to complete homework (Figure 4.7). The homework was based on children’s early stage IEP. Teachers at AC School required parents to practise their learning at home and take a video of the process to bring in to their leading teacher for a feedback the next day. Teachers assessed the homework and gave feedback. On Friday afternoons, an examination/test took place when teachers assessed parental learning of techniques and skills while working with their child and parents received a treatment integrity score. Parents had to prepare well in order to achieve a good score.
Figure 4.7: Homework

(Permission was granted for the use of this photo)

**Other schools’/organisations’ sample sites**

In addition to Beijing AC School, the researcher paid a visit to three other organisations at Beijing and one school at C city of Hebei Province (located in Northern China and adjoining Beijing) during the data collection in China.

Beijing BC Centre was founded by Jing in 2011, whose daughter was diagnosed with ASD at two and half years of age. Beijing EC School was founded by Dong, a Canadian Chinese, in 2004. Beijing FC Centre was founded by Juan, a Board Certified Behaviour Analyst (BCBA), in 2010. Hebei GC School was founded by Mrs Zhou in 2002.

Because of the far distance of Qingdao FC School (located in the Shandong Province of Northern China) from Beijing, the researcher did not visit there but utilised online surveys with the professional participants and had an telephone interview with the founder (See Study 2- Research Procedures)

**4.3 Pilot study**

A scoping study for the present research was completed in part-fulfilment of the author’s Masters by Research degree in Social Work, University of York (Liao, 2013). This study compared personal views of applications of ABA-based in
England and China. In this study, 15 participants were interviewed, of which 7 were from England (5 professionals and 2 parents) and 8 were from China (4 professionals and 4 parents), about their experiences with ABA-based interventions for children diagnosed with ASD. Findings showed the different modes of service delivery between England and China (also see Liao, Dillenburger, & Buchanan, 2016). In addition, one of the findings showed that in England, not every element of EIBI was implemented and participants stated that they would call their work ABA-based interventions rather than EIBI. It was found that Chinese participants did not know what EIBI programmes were and did not utilise this programme. Therefore, the broader term ‘ABA-based interventions’, which encompasses EIBI and many other interventions, was adopted for the study. Furthermore, this scoping study provided background knowledge to test and fine-tune the proposed methodology, and in the process a good relationship was developed with two participating organisations in each country, which facilitated the present study.
4.4 Study 1: Surveys

4.4.1 Rationales for the surveys

A deductive process, where the research design aims to test a hypothesis, can be applied to a quantitative study (Stake, 1995) and the non-experimental survey is one such type of these quantitative research methods (Neuman, 2013). It portrays the statistical information of a sample taken from a large population to describe variables and to test or to predict the correlation among variables (Creswell, 2002; Polit & Beck, 2004).

At the present research, a survey was used to collect quantitative data about parents of children with autism and professionals who work with these families. The survey aimed to investigate parents’ and professionals’ opinions, attitudes, and feelings about living/working with children with ASD, and to explore characteristics and trends of ABA-based interventions in the UK and China. The survey was based on an earlier study that was conducted in Victoria, Australia (Horiguchi, 2014) which allowed for some comparative analysis. However, there were some adaptations in the present survey to account for the target participants in the UK and Chinese (Lijphart, 1971; Verba, 1973; Ragin, 1987).

4.4.2 Participants

Participants in the survey were parents of children with ASD and professionals working with these children who lived either in the UK or in China.

The selection of parents/guardians met the following criteria: (a) they had one or more children with ASD and (b) at least one child had to be involved in ABA programmes. If there was more than one child diagnosed with ASD, parents were asked to respond in relation to the child who was doing the most intensive ABA-based intervention programmes, unless parents preferred to do otherwise.

The selection of professionals met the following criteria: (a) they worked with one or more children diagnosed with ASD and (b) if he/she was a supervisor, he/she managed and/or supervised ABA programmes. Or (c) if he/she was a therapist/tutor/teacher, he/she ran ABA-based interventions programmes that were managed/supervised by others.
4.4.2.1 Demographic information of parents/carers

A total of 120 parents participated in the parent survey questionnaire, 20 of whom were UK parents/carers and 100 were Chinese parents/carers. Some of the responding parents/carers did not meet the inclusion criteria of having at least one child with ASD in the family who is currently engaged in or had previously been engaged in ABA-based intervention programmes. Thus a total of 97 responses from parents and carers who met these criteria were screened as valid for this study, consisting of 12 UK parents/carers and 85 Chinese parents/carers.

The response rate of the UK survey was low, although two rounds of participation call were made during the research field work. The reasons for this low response rate are elaborated in the Research Procedure section.

Of the UK participants, 8 of participants (66.7%) lived in England and 4 participants (33.3%) lived in Northern Ireland (Figure 4.8). There were no responses from Scotland or Wales. In terms of national identity, 5 parents (41.7%) identified themselves as English, 2 parents (16.7%) identified as Northern Irish, 2 parents (16.7%) identified as Irish and 2 parents (16.7%) identified as other nationalities (specified as Pakistani) and the remaining one (8.3%) identified as British (Figure 4.9).

![Figure 4.8: UK participants’ country of residence](image)
The majority of Chinese parents who responded to the survey were from Hebei province (22.4%, n=19) and Beijing (16%, n=16) respectively, with the remainder from many other districts and provinces across China (Figure 4.10).

Figure 4.10: Chinese participants’ place of residence

Figure 4.11 sums up the geographical distribution of these participants. The proportion of participants who came from East China (22.73%) was comparable to that from South Central China (27.27%), and the proportion of participants who were from North China (18.18%) is similar to that from Northwest China (18.18%).
There is a difference in the economic development level between Chinese urban areas and rural areas. Figure 4.12 shows that the majority of the participants lived in urban areas (81.2%, n=69) while the remaining participants (18.8%, n=16) were from rural areas.

Figure 4.11: Participants’ distribution by regional geography

Figure 4.12: Urban and rural residence of participants

Table 4.2 reports parental relationship to the target child, parental gender, age, and marital status. Results from both the Chinese and UK surveys were included. Of the UK respondents, 10 participants (83.3%) were mothers and 2 participants (16.7%)
were fathers. Of the Chinese respondents, 71 participants (83.5%) were mothers, 13 were fathers (15.3%) and 1 identified himself/herself as other (1.2%), not specified. Of the UK participants, 10 participants (83.3%) were female and 2 participants (16.7%) were male, while 71 Chinese participants (83.5%) were female and 14 participants (16.5%) were male. The average age of UK parent participants was 40 years old (Min. =30; Max. =55; SD=8.892) and the average age of Chinese parent participants was 33.95 years old (Min. =21; Max. =42; SD=4.12). Of the UK participants, 11 participants (91.7%) were married and living with their husband/wife and 1 person (8.3%) was cohabiting with their partner; Of the Chinese participants, 79 parents (92.9%) were married and living with their husband/wife, and 3 parents (3.5%) were married and separated from their husband/wife.

Table 4.2: Demographic information of survey participants

<table>
<thead>
<tr>
<th>Relationship to the child</th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>10 (83.3%)</td>
<td>71 (83.5%)</td>
</tr>
<tr>
<td>Father</td>
<td>2 (16.7%)</td>
<td>13 (15.3%)</td>
</tr>
<tr>
<td>others</td>
<td>-</td>
<td>1 (1.2%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>10 (83.3%)</td>
<td>71 (83.5%)</td>
</tr>
<tr>
<td>Male</td>
<td>2 (16.7%)</td>
<td>14 (16.5%)</td>
</tr>
</tbody>
</table>

| Average age               | 40 (SD= 8.924) | 33.95 (SD= 4.12) |

<table>
<thead>
<tr>
<th>Marital status</th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married and living with</td>
<td></td>
<td></td>
</tr>
<tr>
<td>husband/wife</td>
<td>11 (91.7%)</td>
<td>79 (92.9%)</td>
</tr>
<tr>
<td>A civil partner in a legally-recognised Civil Partnership</td>
<td>-</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Married and separated from husband/wife</td>
<td>-</td>
<td>3 (3.5%)</td>
</tr>
<tr>
<td>Cohabitating with partner</td>
<td>1 (8.3%)</td>
<td>2 (2.4%)</td>
</tr>
</tbody>
</table>

| Total                     | 12 (100%) | 85 (100%)   |
Parents’ working/employment status
The working/employment status of the respondents was similar across the UK and China. A large proportion of respondents were in a status of looking after home or family full-time, with 5 UK parents (41.7%) and 33 Chinese parents (38.8%) respectively (Table 4.3). Of the two Chinese parents (2.4%) indicated going to school full-time means attending the parents’ training at autism organisations full-time. The two cases indicated as others, one specified as ‘unemployment for a long time’ and the other one did not specify.

Table 4.3: Parents’ working/employment status

<table>
<thead>
<tr>
<th>Status</th>
<th>UK</th>
<th>China</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looking after home or family full-time</td>
<td>5 (41.7%)</td>
<td>33 (38.8%)</td>
</tr>
<tr>
<td>Going to college full-time</td>
<td>1 (8.3%)</td>
<td>9 (10.6%)</td>
</tr>
<tr>
<td>Going to school full-time</td>
<td>-</td>
<td>2 (2.4%)</td>
</tr>
<tr>
<td>In paid employment or self-employed full-time</td>
<td>3 (25.0%)</td>
<td>24 (28.2%)</td>
</tr>
<tr>
<td>In paid employment or self-employed part-time</td>
<td>1 (8.3%)</td>
<td>4 (4.7%)</td>
</tr>
<tr>
<td>Permanently unable to work because of child’s disability</td>
<td>2 (16.7%)</td>
<td>11 (12.9%)</td>
</tr>
<tr>
<td>Others</td>
<td>-</td>
<td>2 (2.4%)</td>
</tr>
<tr>
<td>Total</td>
<td>12 (100%)</td>
<td>85 (100%)</td>
</tr>
</tbody>
</table>

Educational background
In the UK, an equal number of participants indicated that their highest educational background was a Master’s degree or an undergraduate degree. The Chinese respondents showed a similar trend where the largest proportion of participants held an undergraduate degree (Table 4.4).
Table 4.4: Participants’ highest education qualifications

<table>
<thead>
<tr>
<th>UK</th>
<th>China</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower secondary school qualification</td>
<td>Lower secondary school qualification</td>
</tr>
<tr>
<td>2 (16.7%)</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Primary</td>
<td>Junior high school</td>
</tr>
<tr>
<td>1 (8.3%)</td>
<td>10 (11.8%)</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>Vocational training</td>
</tr>
<tr>
<td>1 (8.3%)</td>
<td>5 (5.9%)</td>
</tr>
<tr>
<td>Senior high school</td>
<td>Senior high school</td>
</tr>
<tr>
<td>6 (7.1%)</td>
<td>6 (7.1%)</td>
</tr>
<tr>
<td>undergraduate</td>
<td>Technical college</td>
</tr>
<tr>
<td>4 (33.3%)</td>
<td>19 (22.4%)</td>
</tr>
<tr>
<td>Undergraduate</td>
<td>Undergraduate</td>
</tr>
<tr>
<td>32 (37.6%)</td>
<td>32 (37.6%)</td>
</tr>
<tr>
<td>Master’s</td>
<td>Master’s</td>
</tr>
<tr>
<td>4 (33.3%)</td>
<td>9 (10.6%)</td>
</tr>
<tr>
<td>PhD</td>
<td>PhD</td>
</tr>
<tr>
<td>1 (1.2%)</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Overseas qualification</td>
<td>Overseas qualification</td>
</tr>
<tr>
<td>1 (8.3%)</td>
<td>2 (2.4%)</td>
</tr>
<tr>
<td>Total</td>
<td>Total</td>
</tr>
<tr>
<td>12 (100%)</td>
<td>85 (100%)</td>
</tr>
</tbody>
</table>

Family income

The family income situation was different between the UK and Chinese respondents. Most of the UK participants were in the highest income bracket (>£25,000), while most respondents in China were in the lowest income bracket (<¥50,000 = approx. £5,400) (Table 4.5).

---

19 In Chinese: 中专 (Zhong Zhuan)

20 In Chinese: 大专 (Da Zhuan)
### 4.4.2.2 Demographic information of professional participants

There was a difference in the roles of professional participants between the UK and China in this study. In the UK, professional participants were therapists and their supervisors. As defined earlier by Love, Carr, Almason and Petursdottir (2009), supervisor was someone whose main role was supervising the therapist, and he/she was responsible for managing the ABA program; a therapist was someone who worked directly with the children and his/her main role was applying direct interventions aimed at specific curricula with children.
In China, professional participants were teachers, founders/principals of autism organisations and international trainers. In this study, a teacher was someone who worked directly with the children and his/her main role was applying direct interventions aimed at specific curricula with the children, often also responsible for undertaking individual ABA programmes (Liao, 2013). Teachers were often trained by experienced teachers or international trainers (Liao et al., 2016), so they were defined as someone who was responsible for designing and managing the ABA curricula. Based on the evidence from the pilot study and the observations in China, an international trainer/supervisor was someone who came from abroad and was invited to deliver workshops or train teachers. In addition, it was most probable that a small number of Chinese parents whose children were diagnosed with ASD also founded an autism organisation.

**UK professionals**

In the UK, 40 supervisors responded to the supervisor’s questionnaire; 23 of these questionnaires were not fully completed, which means there were 17 valid completed questionnaires. In addition, 7 questionnaires were excluded from the study because the participants were based outside the UK (1 Spain, 1 Greece, 1 France, 1 Republic of Ireland, 1 UAE and 2 USA). Hence, the remaining 10 questionnaires were included in the final analysis. All of the supervisors were female (100%, n=10) and the majority of the supervisors’ age were ranged from 25-44 years old (88.9%, n= 8). An equal number of supervisors identified themselves as English (40.0%, n=4) and British (40.0%, n=4). The remaining supervisors identified as Northern Irish (10.0%, n=1) and 1 ‘other’ (10.0%, n=1) who specified as White European; 2 of the 10 supervisors were bi-national, i.e., in addition to identifying themselves as English and British they also identified themselves as Canadian and Turkish, respectively. Half of the supervisors worked in England (50.0%, n=5) and the remainder worked in Northern Ireland or in more than one of the nations (Table 4.6).

The therapist’s questionnaire was completed by 21 participants, 6 participants were excluded because their questionnaires were uncompleted, 1 participant was excluded because she was based outside the UK (Republic of Ireland), and the remaining 14 therapist participants were included in the final analysis. All of the therapist participants were female (100%, n=14). The majority of the respondents were aged between 25-44 years old (57.1%, n=8) and nearly one third of them were 18-24 years.
old (28.6%, n=4). Most of the therapist participants identified themselves as English (42.9%, n=6). There were 3 therapist participants (21.4%) who identified themselves with other national identities, i.e., Portuguese, Greek and French respectively, but worked in the UK (Table 4.6). The majority of respondents worked in England (n=10, 71.4%).

Table 4.6: National identify and country of work

<table>
<thead>
<tr>
<th>National Identify</th>
<th>Supervisors</th>
<th>Therapists</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>4 (40.0%)</td>
<td>6 (42.9%)</td>
</tr>
<tr>
<td>Scottish</td>
<td>0 (0.0%)</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>Northern Irish</td>
<td>1 (10.0%)</td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>British</td>
<td>4 (40.0%)</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>Irish</td>
<td>0 (0.0%)</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>other</td>
<td>1 (10.0%)</td>
<td>3 (21.4%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Country work currently</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
</tr>
<tr>
<td>Northern Ireland</td>
</tr>
<tr>
<td>UK, Britain (more than one nation)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 (100%)</td>
</tr>
</tbody>
</table>

Chinese professionals

In China, 68 professionals filled in the questionnaires, 2 uncompleted questionnaires were excluded. A total number of 66 questionnaires were included in the final analysis, of which 45 were paper questionnaires and 21 were online questionnaires (see further under Research Instruments). Of the 66 participants, 60 were female (90.9%) and 6 were male (9.1%). The average age of Chinese professional participants was 31.42 (Min. =22, Max. =46, SD=5.97). The majority of the professionals (33.8%) were from Shandong province, 8 professionals (12.3%) were from Hebei province, and 6 professionals (9.2%) were from Beijing (Figure 4.13). Most of the professionals worked at Beijing and Shandong Province, with a number of 25 professionals (37.9%) and 20 professionals (30.3%) respectively (Figure 4.14).
Educational background

In the UK, more than half of the participants reported that their highest educational backgrounds were Master’s and above. Of the Chinese professionals around a quarter went to Technical College and half of them held an undergraduate degree and above (Table 4.7). 

![Figure 4.13: Chinese professional participants’ place of residence](image1)

![Figure 4.14: Chinese professional participants’ current work location](image2)
Table 4.7: Professional participants’ highest education qualifications

<table>
<thead>
<tr>
<th></th>
<th>UK Supervisors</th>
<th>UK Therapists</th>
<th>China Supervisors</th>
<th>China Therapists</th>
</tr>
</thead>
<tbody>
<tr>
<td>University or college qualification below a degree</td>
<td>1 (10.0%)</td>
<td>-</td>
<td>Vocational training</td>
<td>4 (6.1%)</td>
</tr>
<tr>
<td>Undergraduate</td>
<td>2 (20.0%)</td>
<td>6 (42.9%)</td>
<td>Technical college</td>
<td>32 (48.5%)</td>
</tr>
<tr>
<td>Master’s</td>
<td>6 (60.0%)</td>
<td>8 (57.1%)</td>
<td>Undergraduate</td>
<td>29 (43.9%)</td>
</tr>
<tr>
<td>PhD</td>
<td>1 (10.0%)</td>
<td>-</td>
<td>Master’s</td>
<td>1 (1.5%)</td>
</tr>
<tr>
<td>Total</td>
<td>10 (100%)</td>
<td>14 (77.8%)</td>
<td>66 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

Professionals’ work status

With regard to the ABA-related work (Table 4.8), half of the UK supervisor respondents were a sole trader, i.e., directly employed by the family (50.0%, n=5), and half of the therapists were employed by a service provider (50.0%, n=7). The three supervisor participants who specified as ‘others’ were as ‘self-employed’, ‘full-time therapy delivery to her/his child’, and ‘the owner of an ABA company’ respectively.

Most of Chinese teacher respondents identified themselves as being employed by a service provider. The five participants, who specified as ‘others’, were founders of an autism organisation.

Table 4.8: Professional participants’ employment

<table>
<thead>
<tr>
<th></th>
<th>UK Supervisors</th>
<th>UK Therapists</th>
<th>China Supervisors</th>
<th>China Therapists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed by a service provider</td>
<td>1 (10.0%)</td>
<td>6 (42.9%)</td>
<td>53 (80.3%)</td>
<td></td>
</tr>
<tr>
<td>A sole trader*</td>
<td>5 (50.0%)</td>
<td>7 (50.0%)</td>
<td>2 (3.0%)</td>
<td></td>
</tr>
<tr>
<td>Employed by a school</td>
<td>1 (10.0%)</td>
<td>1 (7.1%)</td>
<td>6 (9.1%)</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>3 (30.0%)</td>
<td>-</td>
<td>5 (7.6%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>10 (100%)</td>
<td>14 (100%)</td>
<td>66 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

* Directly employed by the family
Most of the UK respondents had more than one current role at work. Therefore, the total number of responses exceeded the number of respondents (Figure 4.15). Nearly half of the supervisor participants were programme supervisors (46.7%, n=7), and the proportion of site directors (20.0%, n=3) was equal to ABA therapists (20.0%, n=3).

Figure 4.15: Role of UK supervisor participants

In the UK, more than half of therapist participants identified themselves as ABA therapist (62.5%, n=10) and a third of them were ABA lead therapist (31.2%, n=5) (Figure 4.16).

Figure 4.16: Role of UK therapist participants
Of the Chinese professional participants, half identified as ABA teachers (55.1%, n=43), while fewer identified as managers (9.0%, n=7) and ABA supervisors (7.7%, n=6). The one participant who chose ‘others’ indicated that s/he was a ‘TEACCH teacher’ (Figure 4.17).

![Figure 4.17: Role of Chinese professional participants](image)

### 4.4.3 Instruments

The survey design was mainly based on an earlier study in Australia (Autism Behavioural Intervention Association, 2013; Horiguchi, 2014) called “Early behavioural intervention practice for children with autism in Victoria”. Although China and the UK were compared in the present study, the survey census from Australia allowed for cross-national comparison. Permission was granted from the researcher from Australia (Horiguchi, 2014) to replicate their survey.

Nevertheless, the questionnaires of the present study were adapted to the local environment taking into consideration the structural and cultural differences (Lijphart, 1971). In order to compare the similarities and differences of ABA-based interventions in the UK and China, Lijphart (1971) and Verba (1973) suggested that it was necessary to identify and define variables that are comparable (See Chapter 1-Theoretical Framework). Hence, most questions of UK questionnaires were
equivalent to those in the Chinese questionnaire. Some questions were revised to accommodate the cultural, economical and societal differences (Verba, 1973).

Three types of questionnaires were administered online (e.g., survey monkey) or on paper (more details under Research Procedures), including

1. Parents’ questionnaire
2. Therapists’ questionnaire, and
3. ABA programme supervisors’ questionnaire.

Questionnaires were created in English first and reviewed by the researcher’s supervisor and a post-doctoral researcher at Centre for Behaviour Analysis (CBA), Queen’s University Belfast. Subsequently, 2 parents and 2 professionals participated in a pilot trial of the survey. Minor revisions were applied as a result of this pilot. For example, the length of time allowed in filling in the questionnaire was added in front of the questionnaire to advise people approximately how long it would take to complete it and a ‘do not know’ response was considered for each question and included where it was needed. Question formats amendments were made where necessary and skip logic questions were also checked.

The final version of the questionnaires had a brief introduction at the beginning of the survey stating the research aims, inclusion criteria, and approximate length of completing the questionnaire. Data storage and ethical implications were also outlined. Participants were asked to read the consent information and choose whether or not they agreed to take part. For the online surveys, consent was assumed when the ‘yes’ box was ticked and the link to the survey was opened. The survey was immediately terminated if the ‘no’ box was ticked.

In terms of definitions, an explanation was added to clarify that ABA-based intervention programmes were those that included ABA-based interventions or the use of ABA strategies or principles. It was also made clear in the survey that the programme to which respondents referred could be comprehensive (covering many targeted areas) or target-specific (e.g. social skills training using ABA), intensive or non-intensive and in home-, clinic- or school-based settings. The programme could be undergone previously or currently. In addition, questions related to Early Intensive Behavioural Intervention (EIBI) were described as ‘early, intensive,
individualised and comprehensive [targeting a range of skill areas] programme using Applied Behaviour Analysis strategies or principles’.

All of the materials were translated into Chinese by the researcher. The questionnaires were then backward translated (i.e., back into English) by a bilingual Chinese-English translator (an independent researcher). Backward translation is a procedure frequently used in cross-cultural studies to ensure accuracy and validity of translations (Green, Bradby, Chan, & Lee, 2006; Bishop, Lim, Leydon, & Lewith, 2009). The two sets of English materials, i.e., the original English version and the backward translated English version, were compared and the final Chinese translation was revised accordingly to ensure accuracy. The final Chinese questionnaires were distributed to the Chinese sample.

Participants were told that the survey would take approximately 20-25 minutes.

4.4.3.1 Parents’ questionnaire

The UK parents’ questionnaire (Appendix 7) aimed to explore parents’ and children’s experiences in ABA-based interventions.

There were five sections in the survey questionnaire. The first part requested participants’ demographic information, such as age, marital status, and national identity. The second part focussed on information about interventions. For example, where the parent found out about the programme; who recommended the programme; the number of child/children doing or having completed the programme to date in their family; how much they spent on the ABA programme and any financial support for doing the programme. Section 3 focused on parents’ knowledge and understanding of autism, such as their understanding of the causes of autism, treatment to autism, and children’s socialisation. The fourth part of the survey was about child’s profile, such as their gender and the age of being identified or diagnosed with ASD and when they commenced the ABA-based programmes. Section 5 addressed the detail of child’s ABA-based intervention, such as ability/skills gains, generalisation before, during or after the programmes, how the intervention programmes were co-operated/incorporated with mainstream schools. Parent participants were also asked whether they were trained as a parent therapist, and if so, reasons for being a parent therapist, how they assessed their ABA delivery
level and how they attained the relevant knowledge/practical skills. There were some open ended questions in this section, such as whether parents had any comments about the barriers/experiences/survey, to give parents an opportunity to express their concern or opinions freely.

The Chinese parents’ questionnaire ( Appendix 8 ) was similar to the UK parents’ questionnaire, with minor adaptations to make it culturally and locally relevant. The original meaning and concepts in the questionnaire were maintained, but culturally sensitive Chinese expressions were used in the translation. Questions such as asking parents' educational background, family income and cost on ABA-based programmes were changed due to the difference in educational and economic processes. To be specific, in the first section of the Chinese parents’ questionnaire, a question was added regarding a participant’s living in a rural or urban area. This question was not added in the UK questionnaire because a very large UK population lived in urban areas ( National Statistics, 2011 ). Section 2, Section 3 and Section 4 were the same as the UK parents’ questionnaire. The final section was slightly altered. For example, one question was added to ask whether the child was undertaking or used to undertake the programme at hometown or elsewhere. This question was added due to specifics of service provision for autism in China, where most parents temporarily moved to Beijing to access interventions ( Liao et al., 2016 ).

4.4.3.2 Professionals’ questionnaires

Two different questionnaires were designed for supervisors and therapists, respectively. In China, professionals working in ABA-based schools are called teachers and therefore the term ‘teacher’ was used ( as defined earlier ). A modified and translated version of the UK therapists’ questionnaire was used for Chinese teachers.

The therapists’ questionnaire ( Appendix 9 ) focussed on the use of ABA-based techniques and principles, career development, research experiences, and qualifications.

The professionals’ questionnaires were shorter than the parents’ questionnaire. There were four sections in this questionnaire. Section 1 addressed demographic information. Section 2 required information about the current job, such as role in the
current job, number of boys/girls worked with, and quantity of children on a wait-list. Section 3 focused on early ABA-based interventions (specifically, EIBI). For example, enquiring about the type of current ABA-based programme offered, to what extent this programme involved family, was tailored to individuals’ needs, and was incorporated in inclusive mainstream settings. In addition, there was a question regarding whether or not the professional respondents provided EIBI for children, and if so, sub-questions were added to ask about the child’s starting age, and duration and intensity of the EIBI programme. If not, a ‘skip to the next question’ function was added. The final section of the questionnaire explored therapists’ experience in terms of number of years working in the field, how they rated their level of skills, professional activities development, qualification relating to ABA, supervisor’s support, theoretical knowledge, and practical practice in the area of ABA.

The supervisors’ questionnaire (Appendix 10) was similar to the therapists’ questionnaire, but with some changes due to occupational differences. This questionnaire also had 4 sections, starting with supervisors’ demographic information in Section 1 and their current job information in Section 2. Section 3 was about the supervisor’s treatment plan, monitoring of assessments, and mode of service delivery as well as their career development, research experiences and qualifications. The final section remained the same as the therapists’ questionnaire.

The Chinese professionals’ questionnaire (Appendix 11) was similar to the UK therapist’s questionnaire. It was translated and back translated (see earlier description of this process), and included some adaptations to Chinese systemic and cultural differences. For example, questions on teachers’ educational background and qualifications were changed due to differences in the education systems. The pilot study showed that most Chinese autism organisations provided other therapies in addition to ABA-based interventions. A question was added regarding type of services provided in participants’ working organisation, in which 13 options were given, such as ABA, Play Therapy, Occupational Therapy, Sensory Integration, and Auditory Integration.

At the end of the questionnaire, participants were asked whether they were happy to take part in a telephone interview. If so, they were asked to leave their telephone
number or email address in a blank box provided and follow-up telephone interviews were arranged (see Research procedures of Study 2).

4.4.4 Research procedures

4.4.4.1 Research procedures for the UK survey

The surveys in the UK were conducted online and the participants’ call was made nationally across all 4 countries (i.e., England, Scotland, Northern Ireland and Wales).

In order to reach as large a sample size as possible, the survey was administered online in the UK. A website of the project was created (Liao, 2014), which included introductions of the project and researchers, criteria of selecting participants, the ethical approval letter and the informed consent form, links to questionnaires, contact information for the researchers and some introductory information about EIBI, ABA and ASD. A translated Chinese web page was linked to this website. The link to the website and survey was widely distributed via email and social media, such as Facebook.

A package of documents was created as an introduction of the study, including a formal Participant Call poster (Appendix 12), a signed letter from the researcher’s supervisor, introductory letters to organisations, professionals and parents. After the preparation work, a formal email was written and sent to 17 major autism organisations in the UK.

In the end, 5 organisations agreed to circulate the participants’ call, 3 organisations refused to participate, and the remaining 9 organisations did not reply. In addition, 8 groups agreed to post the Participant Call poster on their Facebook homepage and the poster was ‘snowballed’ through social media sharing of the poster. Ethics approval letter, links to the website and survey and relevant introductory letters were sent to participants of those organisations who agreed to participate for pre-reading. A thank-you letter was sent to those organisations that rejected the call.

The first round of the UK online data collection took place from January to March 2015. Due to a low initial response rate, a second call was sent out and online data collection took place from May to June 2015.
The particularly low UK returns of the online questionnaire were disappointing, however, given that the questionnaire was based on the 36 empirical on ABA-based interventions in the UK (See Chapter 3 about rapid reviews of ABA-based intervention in the UK); ultimately a large enough sample was available for comparison of the UK. The present UK survey therefore is best regarded as an update for the existing UK data. In contrast, the Chinese survey on ABA-based interventions had never been done before and therefore (See Chapter 3 on Rapid reviews of ABA-based intervention in China), which yielded sufficient responses to provide a broad view of ABA-based practices in China.

4.4.4.2 Research procedures for the Chinese survey

A package containing hardcopy ethics approval, informed consent forms and basic information of the study were sent to AC school. The school agreed to take part in the research.

The researcher was invited to deliver workshops about ABA and EIBI for teachers at AC School (Figure 4.18). The researcher was permitted to introduce the project and requested the teachers to help identify potential participants. Delivering the workshop for teachers established a good rapport with participants and gave them information about the research. Strict ethical procedures were followed to ensure participation was entirely voluntary and unrelated to participation in the workshop.
The first round of data collection in China took place from March to April 2015. Data collection first started at AC School in Beijing, where parents and parents were from different regions to undertake parent training. At AC school, the Participant Call poster was put up in the classroom and on a board in the common area, in which a brief introduction of the study and the researcher’s contact details were provided. Consent was sought from parents and teachers before sending out questionnaires. The researcher also contacted staffs of autism organisations, Beijing BC Centre, Beijing DC School, Beijing EC Centre, and Hebei GC School (See Section 4.2: Other schools’/organisations’ sample sites). Permission was granted to circulate the participants call and send out questionnaires. The researcher was also invited to deliver a workshop about EIBI at Beijing BC Centre and Hebei GC School. The Chinese survey was mainly conducted on paper copies distributed throughout sample sites in Beijing, where the researcher was carrying out the field work of China. Standing in the emic perspective- an insider as a Chinese, paper copies are most likely to be accepted by participants. When the researcher returned to the UK, online questionnaires were made to further maximise the sample size, between May and June 2015. These online questionnaires were disseminated through a Chinese QQ group (online communication software), where parents and professionals
gathered online to share experiences and knowledge. The data collection of Qingdao FC School (See Section 4.2: Other schools’/organisations’ sample sites) was through online questionnaires.

4.4.5 Data analysis

IBM SPSS Statistics 23.0 was used to analyse the survey data and 5 datasets were created, i.e., UK parents’ data, UK therapists’ data, UK supervisors’ data, China parents’ data and China professionals’ data.

Data clearance was conducted before starting the analysis on SPSS. Uncompleted questionnaires were cleared. Those questionnaires which did not adhere to the participants’ selection criteria were also excluded, e.g., participants who were based outside the target countries were excluded.

Descriptive analysis was used in describing demographic information and results sections. Tables and graphs were also used to present data.

Content analysis was used to analyse the open-ended questions from SPSS (Miller, 1998). Texts were coded into units systematically and quantified objectively (Downe-Wamboldt, 1992; Babbie, 2012). In this study, all of the respondents’ answers were moved from SPSS to Excel because Excel allowed a more feasible edit and descriptive calculation. The content analysis for questionnaires’ open-ended questions included the following steps:

1) Selecting the unit of analysis. Table 4.9 showed an example of asking parents to leave comments about barriers they experienced. The unit of analysis is ‘barriers parents experienced’. The 2nd column is the responses of each participant.

2) Creating and defining the themes. The 3rd column shows common themes based on the key information extracted and the number of times they appeared.

3) Counting themes. Themes were given a code and counted. Excel was used to sum up the total number. The 4th column shows the code given and the total of the codes was counted.
4) Reliability and validity. In addition to the author, a second researcher
independently categorised responses into themes to assess the reliability. The
two independent categorisations were compared and discussed.

Table 4.9: Example of content analysis for open-ended questions

<table>
<thead>
<tr>
<th>No.</th>
<th>Responses</th>
<th>Themes</th>
<th>Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>We need money to support</td>
<td>Financial</td>
<td>a</td>
</tr>
<tr>
<td>2</td>
<td>I need more professional support</td>
<td>Lack of professionals</td>
<td>b</td>
</tr>
<tr>
<td>3</td>
<td>Ask for more public policy to support children</td>
<td>Public policy</td>
<td>c</td>
</tr>
<tr>
<td>4</td>
<td>Call for more financial investment</td>
<td>Financial</td>
<td>a</td>
</tr>
</tbody>
</table>

In order to ensure the credibility of codes, the researcher discussed the common
themes with a bilingual independent assessor. After this, the two assessors read all of
the participants’ responses and allocated each response to the themes independently.

The IOA is calculated on the basis of this formula: agreements/ (agreements +
disagreements)*100%, which yields the percentage of items that both assessors
agreed upon.

The inter-observer agreement (IOA) of “child’s quality of life changes after the
programmes” between assessor 1 and assessor 2 is 91.59%. Specifically, the IOA
rate of the UK responses is 88.89% and the IOA rate of Chinese responses is 94.29%.

The inter-observer agreement (IOA) of ‘barrier experienced by parents’ between
assessor 1 and assessor 2 is 93.65%. To be specific, the IOA rate of the UK
responses is 92.31% and the IOA rate of Chinese responses is 95.00%.

The two assessors met to discuss the conflicted themes. After this discussion, a
consensus was reached on the usage of themes.
4.5 Study 2: Semi-structured interviews

4.5.1 Rationales for semi-structured interviews

Qualitative research aims to discover and understand topics and relationships in the context of existing literature or lived experiences (Stake, 1995). Qualitative semi-structured interviews are directed by an interview schedule, which is developed from a framework of pre-determined themes (Yates, 2003; Bryman, 2015). The interview enables the researcher to learn about and understand a person’s life experiences in detail and to discover unexpected findings in the social world (Silverman, 2016), especially as people’s life changes, such as during maternity, marriage, child birth, starting a new job (Yates, 2003). Semi-structured interview method allows researchers to freely probe the areas of interest or of significance (Yates, 2003), prompting follow-up questions (Bryman, 2015) and pursuing a dialogue with the interviewee (Edwards & Holland, 2013).

Semi-structured interviews were conducted in the UK and in China in Study 2 to allow for a qualitative understanding of the culture and use of ABA in each of these countries. It provided supplementary information on issues that were not completely addressed in Study 1. The inside and outside perspective were used to guide the research design and research procedures in the field work of each country (Brislin, 1976). Thematic analysis (Braun & Clarke, 2006; Miles, Huberman, & Saldana, 2014) was used in analysing data collected from each country (more details in Data Analysis section).

4.5.2 Participants

A total number of 36 participated in the semi-structured interview. Specifically, 18 UK participants and 18 Chinese participants were interviewed.

4.5.2.1 UK participants

Of the 18 UK interviewees, there were 11 professionals and 7 parents. Anonymised names were used throughout this section. Table 4.10 presents the demographic information of each UK parent interviewee. Further details of each participant were as follows:
Four parent interviewees (No. 1-No.4) received the BCBA supervision from NIU charity. Lucy (No. 1), married, was employed full-time, and had two afternoons permitted off from work every week to accompany her daughter for the ABA-based home programme. She had three children. The youngest daughter started the programme right after diagnosis at 4 years of age, receiving 4 hours per week training and 2 hours supervision per month. Lucy’s other two children were typical ones, i.e., a 15 years old son and a 11 years old daughter.

Mary (No. 2), married, was not employed. She had two children. The older son was diagnosed with ASD at the age of 3 years and 9 months, receiving 4 hours per week with an ABA therapist and two hours supervision per month with a BCBA. The youngest child is a daughter who was 3 years old. Lucy and Mary hired an ABA therapist to work with the family, and Mary herself also worked extra hours for her son.

Daisy (No. 3), divorced, was part-time employed and lived in Northern Ireland for more than 10 years. Her son was diagnosed at the age of 2 years and 10 months and started a home-based ABA programme 2 months prior to the study.

Rose (No. 4), married, was full-time employed. Her son was diagnosed at 3 years of age. Daisy and Rose both worked as a parent therapist with their child every day. Both Daisy and Rose had only one child in the family.

Linda (No. 5), married, was not employed and moved to England 5 years ago. She had two sons. The older son started a home ABA programme at 5 years of age, receiving 15 hours per week training and 12 hours’ supervision per month. The younger one, who was 2 and half years old, was not diagnosed with ASD.

Jessica (No. 6), married, was a full-time college student and not employed. She had three children. The youngest son was diagnosed with ASD at 3 years and one month of age, receiving 25 hours per week therapies. The other two children were typical children, 19 years and 14 years of age respectively.

Carol (No. 7), married (combined family), was unemployed. She had four children. Her youngest son was diagnosed with severe autism. The older sister was 14 years old. There are two step daughters from her husband side, one a high-functioning child with autism and one a typical child studying at a University. The youngest son
was chosen by Carol to talk about the experience for this study. He was diagnosed at 2.75 years old and started the ABA-based intervention at 3 and half years old.

Table 4.10: A summary of UK parent interviewees

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Parents</th>
<th>Age</th>
<th>National identity</th>
<th>Education</th>
<th>Location</th>
<th>Child’s age (Year and Month)</th>
<th>Child’s gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lucy</td>
<td>Mother</td>
<td>39</td>
<td>British</td>
<td>BSc</td>
<td>NI</td>
<td>4y</td>
<td>F</td>
</tr>
<tr>
<td>2</td>
<td>Mary*</td>
<td>Mother</td>
<td>44</td>
<td>Northern Irish</td>
<td>BSc &amp; Undergoing MSc ASD</td>
<td>NI</td>
<td>4y5m</td>
<td>M</td>
</tr>
<tr>
<td>3</td>
<td>Daisy*</td>
<td>Mother</td>
<td>30</td>
<td>Russian</td>
<td>N/A</td>
<td>NI</td>
<td>3y6m</td>
<td>M</td>
</tr>
<tr>
<td>4</td>
<td>Rose</td>
<td>Mother</td>
<td>38</td>
<td>British</td>
<td>GCSE</td>
<td>NI</td>
<td>6y</td>
<td>M</td>
</tr>
<tr>
<td>5</td>
<td>Linda</td>
<td>Mother</td>
<td>39</td>
<td>Pakistani</td>
<td>Master Medicine</td>
<td>England</td>
<td>6y</td>
<td>M</td>
</tr>
<tr>
<td>6</td>
<td>Jessica</td>
<td>Mother</td>
<td>38</td>
<td>British</td>
<td>BSc &amp; Undergoing MSc ABA</td>
<td>England</td>
<td>4y</td>
<td>M</td>
</tr>
<tr>
<td>7</td>
<td>Carol</td>
<td>Mother</td>
<td>51</td>
<td>British</td>
<td>Masters in Classics</td>
<td>England</td>
<td>12y</td>
<td>M</td>
</tr>
</tbody>
</table>

*Participated in both interviews and direct observations

Table 4.11 presents the demographic information for the UK professional interviewees. Further details of each participant were as follows:

Three interviewees (No. 1-No. 3) came from the NIU charity. Jenifer (No. 1) had been working with children with ASD for 12 years. Laura (No. 2) had the experience of working at a residential unit (duration unknown) before working for NIU charity. Jennifer and Laura had been working at NIU charity full-time, for 5 and half years and 3 years respectively at the time of the interview. Both of them provided consultation for the children’s ABA home programme and delivered training and supervision for both behaviour analysts and parents. Jane (No. 3), a full-time ABA therapist, worked with NIU charity for 6 months. She completed a supervised 12-month internship at a large ABA-based autism school in the USA. Jane was under the supervision of Jenifer to become eligible for the BCBA exam. She was working with four families.
Nancy (No. 4) and Betty (No. 5) were both full-time, self-employed ABA tutors, who worked under the supervision of BCBA. They provided ABA home programme. Nancy was working with four children, who were 2 years old, 3 years old, 4 years old and 6 years old respectively. Betty was undergoing an MSc degree in ABA. She had been working as an ABA tutor for 6 years. She was working with 5 children, of whom 3 were in a mainstream school and 2 were in a special needs school. She was mainly working with children at 4 years of age.

Karen (No. 6) and Sharon (No. 7) were part-time ABA tutors who both worked with the family of a child with ASD and under the supervision of an experienced ABA consultant. Karen was also full-time employed by a local school and she had been working with this family for 5 months. Sharon had been working with this family for 2 months and she was undertaking a child care course at the time of being interviewed. Sharon had the experience of working with children but not with children with learning difficulties.

Stephanie (No. 8) was a full-time, self-employed ABA tutor and her experience came from her own son’s ABA-based programme of around 12 years long. Her son was 22 years old and resided in a college unit, with ABA integrated into his everyday life. He worked with 4 children who were diagnosed with ASD when interviewed.

Anna (No. 9) was self-employed since Jan 2015. She used to work for the NHS of her residence for nearly 20 years. She had a rich experience of working at both mainstream and special needs schools. Anna also worked for families, supervised therapists/tutors who want to go for BCBA status, and supervised overseas Master’s students. She had set up a clinical excellence network for speech and language therapists who were interested in ABA, similar to an official organisation.

John (No. 10), a full-time director, worked for Behaviour Analyst Certification Board (BACB). He is also a consultant behaviour analyst providing consultancy, training and related software solutions within the field of behaviour analysis. John also supervised PhD students, involved in research projects, co-authored peer review journal papers and engaged in editorial activities of journals.
Adam (No. 11), a full-time teacher, worked in the area of ABA for 30 years. He is the founder of NIU Charity and a professor of behaviour analysis at a university. Due to his efforts in the area of ABA, he has received many awards internationally. John and Adam were both invited to visit China to deliver workshops about ABA and they visited some of the autism organisations in China.

Table 4.11: A summary of UK professional interviewees

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>National identity</th>
<th>Education</th>
<th>Location</th>
<th>Positions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Jennifer</td>
<td>F</td>
<td>34</td>
<td>Irish</td>
<td>MSc ABA</td>
<td>NI</td>
<td>BCBA &amp; supervisor</td>
</tr>
<tr>
<td>2</td>
<td>Laura</td>
<td>F</td>
<td>31</td>
<td>British</td>
<td>MSc ABA</td>
<td>NI</td>
<td>BCBA &amp; supervisor</td>
</tr>
<tr>
<td>3</td>
<td>Jane*</td>
<td>F</td>
<td>26</td>
<td>British</td>
<td>MSc ABA</td>
<td>NI</td>
<td>Therapist</td>
</tr>
<tr>
<td>4</td>
<td>Nancy</td>
<td>F</td>
<td>23</td>
<td>British</td>
<td>MSc ABA</td>
<td>England</td>
<td>Therapist</td>
</tr>
<tr>
<td>5</td>
<td>Betty</td>
<td>F</td>
<td>28</td>
<td>British</td>
<td>BSc Psychology</td>
<td>England</td>
<td>Tutor</td>
</tr>
<tr>
<td>6</td>
<td>Karen</td>
<td>F</td>
<td>30</td>
<td>Polish</td>
<td>MSc Psychology</td>
<td>England</td>
<td>Therapist</td>
</tr>
<tr>
<td>7</td>
<td>Sharon</td>
<td>F</td>
<td>35</td>
<td>Chinese</td>
<td>BSc English Language</td>
<td>England</td>
<td>Tutor</td>
</tr>
<tr>
<td>8</td>
<td>Stephanie</td>
<td>F</td>
<td>42</td>
<td>British</td>
<td>Diploma in Computing/Business</td>
<td>England</td>
<td>Tutor &amp; Mother of an adult with ASD</td>
</tr>
<tr>
<td>9</td>
<td>Anna</td>
<td>F</td>
<td>49</td>
<td>Welsh</td>
<td>MSc ABA, PG Speech and Therapy</td>
<td>Wales</td>
<td>BCBA &amp; Speech Language Therapist</td>
</tr>
<tr>
<td>10</td>
<td>John</td>
<td>M</td>
<td>53</td>
<td>British</td>
<td>PhD in Behaviour Psychology</td>
<td>England</td>
<td>BCBA-D &amp; Director of International Development of BACB</td>
</tr>
<tr>
<td>11</td>
<td>Adam</td>
<td>M</td>
<td>62</td>
<td>Dual Irish/British</td>
<td>PhD</td>
<td>NI</td>
<td>BCBA-D &amp; Charity Founder</td>
</tr>
</tbody>
</table>

*Participated in both interviews and direct observations
4.5.2.2 Chinese professional interviewees

Table 4.12 presents the demographic information on the Chinese parent interviewees. All of the interviewees were recruited via Beijing AC School, but lived in different places across China. All parent interviewees were married. The majority of them had only one child in the family, except Bing and Wuling, who had an older son and a younger daughter respectively.

Qian’s (No. 1) daughter was diagnosed with ASD at three years and two months of age. Xiang’s son (No. 2) was not formally diagnosed but suspected by a doctor to be a child with high-functioning ASD at 5 years of age. Before coming to AC school, her son was in a kindergarten and participated in training at the autism organisation part-time. Before coming to AC school, Qian’s daughter had accessed 3 organisations for training in Beijing, and Xiang’s son had accessed one organisation, all of which claimed to operate based on the principles of ABA or said ABA was an important part the programme’s package. Both Qian and Xiang asked for short term leave from work to access services at Beijing AC School.

Chang (No. 3) and Bing (No. 4) knew each other at the autism organisation at Guangzhou (Southern China) because their children were under training at a same autism organisation. They decided to leave for Beijing AC School to learn ABA. Chang’s son was diagnosed at four years and five months. Bing’s son was diagnosed at two and half years old. Both women were full-time housewives.

Ling (No. 5) and Wuling (No. 6) and were from Shanxi province. Ling’s son experienced two organisations of training before coming to AC school, one at her hometown province and the other at Beijing BC Centre. Her son was formally diagnosed at 2 and half years of age. Wuling’s son was diagnosed at two years and four months of age. Before AC school, Wuling travelled with her son to two organisations for training, one at her home province and the other in Hebei province.

Meimei (No. 7) was self-employed in her hometown. She and her husband stopped working to access services at Beijing AC School. Her son was diagnosed at 3 years and 5 months of age. Beijing AC School was their first training organisation.
Table 4.12: A summary of Chinese parent interviewees

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Parents</th>
<th>Age</th>
<th>Education</th>
<th>Hometown location</th>
<th>Child’s age (Year and Month)</th>
<th>Child’s gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Qian</td>
<td>Mother</td>
<td>37</td>
<td>Technical College in Finance</td>
<td>Beijing (North)</td>
<td>6y</td>
<td>F</td>
</tr>
<tr>
<td>2</td>
<td>Xiang</td>
<td>Mother</td>
<td>36</td>
<td>Bachelor in Public Relations</td>
<td>Hunan (South)</td>
<td>6y6m</td>
<td>M</td>
</tr>
<tr>
<td>3</td>
<td>Chang</td>
<td>Mother</td>
<td>33</td>
<td>Primary school</td>
<td>Heilongjiang (North)</td>
<td>5y</td>
<td>M</td>
</tr>
<tr>
<td>4</td>
<td>Bing</td>
<td>Mother</td>
<td>35</td>
<td>Junior high school</td>
<td>Guangzhou (South)</td>
<td>5y</td>
<td>M</td>
</tr>
<tr>
<td>5</td>
<td>Ling*</td>
<td>Mother</td>
<td>34</td>
<td>Bachelor in Computer</td>
<td>Shanxi (North)</td>
<td>3y4m</td>
<td>M</td>
</tr>
<tr>
<td>6</td>
<td>Wuling</td>
<td>Mother</td>
<td>29</td>
<td>Technical Secondary School in Industrial...</td>
<td>Shanxi (North)</td>
<td>5y8m</td>
<td>M</td>
</tr>
<tr>
<td>7</td>
<td>Meimei*</td>
<td>Mother</td>
<td>25</td>
<td>Senior High school</td>
<td>Hebei (North)</td>
<td>4y3m</td>
<td>M</td>
</tr>
</tbody>
</table>

*Participated in both interviews and direct observations

Table 4.13 presents the demographic information of each Chinese professional interviewee. Further details of each participant were as follows:

Four founders (No. 1-No. 4) were involved in the interview, i.e., Chun, Jing, Dong and Zheng; three of them had a child diagnosed with ASD. Chun’s (No. 1) son, 31 years old, was diagnosed with autism in 1989. She started Beijing AC School in 1993. In 1995, Beijing AC School began to provide ABA training for parents. Jing’s daughter (No. 2) was diagnosed with ASD at two and half years of age. Jing started Beijing BC Centre in 2011. Zheng (No. 3) founded Qingdao DC Centre in 2000. Her son was diagnosed with Asperger’s Syndrome when he was three years and three months of age. The child was at the university at the time of the interview. The last founder, Dong (No. 4), a Canadian Chinese, started Beijing EC School in 2004.

Four trainers (No. 5-No.8) were selected for the interview. Both Meiyin (No. 5) and Lihua (No. 6) came from Beijing AC School. Meiyin had been working there for 21 years and Lihua for 22 years. Their main responsibility was doing evaluation
assessments for children with ASD at the pre- and post- programme and providing training for teachers. Kate (No. 7) incorporated a non-profit organisation, HC NPO, in China in 2006, which provided training for parents and teachers in China. She was earlier a professor in a university for 10 years. Juan (No. 8) attained her BCBA status in 2009 and she started Beijing FC Centre, a centre-based ABA company, in 2010. The centre provides consultation, assessment, intervention and transition services.

Three teachers (No. 9-No.11) were interviewed, who all came from AC school. Teng (No. 9) and Chow (No. 10) were responsible for parents’ training. Both of them worked in classes composed of 10 parents and 10 children. Teng had worked at AC School for 10 years and Chow for 3 and half years. Cui (No. 11) worked at AC School for 13 years and was responsible for teachers’ training. He also delivered a home-based programme for children on a part-time basis.
Table 4.13: A summary of Chinese professional interviewees

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Originally from</th>
<th>Education</th>
<th>Positions</th>
<th>Org. &amp; Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Chun</td>
<td>F</td>
<td>58</td>
<td>Beijing</td>
<td>Bachelor German Language and Literature</td>
<td>Founder &amp; Mother</td>
<td>Beijing, AC school</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Bachelor English</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Jing</td>
<td>F</td>
<td>42</td>
<td>Beijing</td>
<td>Founder &amp; Mother</td>
<td></td>
<td>Beijing, BC Centre</td>
</tr>
<tr>
<td>3</td>
<td>Dong</td>
<td>F</td>
<td>55</td>
<td>Canada</td>
<td>Law (degree unknown)</td>
<td>Founder</td>
<td>Beijing, DC Centre</td>
</tr>
<tr>
<td>4</td>
<td>Zheng</td>
<td>F</td>
<td>53</td>
<td>Qingdao</td>
<td>Master in Educational Psychology</td>
<td>Founder &amp; Mother</td>
<td>Qingdao, EC School</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(child with Asperger)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Meiyin</td>
<td>F</td>
<td>41</td>
<td>Beijing</td>
<td>Bachelor in Psychology</td>
<td>Trainer</td>
<td>Beijing, AC school</td>
</tr>
<tr>
<td>6</td>
<td>Lihua</td>
<td>F</td>
<td>41</td>
<td>Beijing</td>
<td>Technical College in Early Childhood Education</td>
<td>Trainer</td>
<td>Beijing, AC school</td>
</tr>
<tr>
<td>7</td>
<td>Kate</td>
<td>F</td>
<td>44</td>
<td>USA</td>
<td>PhD in Special Education &amp; International and Comparative Policy</td>
<td>Trainer</td>
<td>USA, HC NPO</td>
</tr>
<tr>
<td>8</td>
<td>Juan</td>
<td>F</td>
<td>34</td>
<td>HK</td>
<td>Master in Health Science (psychiatry)</td>
<td>Founder &amp; BCBA</td>
<td>Beijing, Centre FC</td>
</tr>
<tr>
<td>9</td>
<td>Teng</td>
<td>F</td>
<td>32</td>
<td>Beijing</td>
<td>Technical College in Social Work</td>
<td>Teacher</td>
<td>Beijing, AC school</td>
</tr>
<tr>
<td>10</td>
<td>Chow</td>
<td>F</td>
<td>26</td>
<td>Xi’an</td>
<td>Technical College in Social Work in SNE</td>
<td>Teacher</td>
<td>Beijing, AC school</td>
</tr>
<tr>
<td>11</td>
<td>Cui</td>
<td>M</td>
<td>34</td>
<td>Beijing</td>
<td>Bachelor in Behaviour Management</td>
<td>Teacher</td>
<td>Beijing, AC school</td>
</tr>
</tbody>
</table>

4.5.3 Instruments

A number of in-depth interview schedules were developed for parents, professionals and service providers in the UK and China to establish personal experiences in practices related to early ABA-based interventions. Topics used in the interview schedules originated from the review of the literature, the pilot study, and questionnaires of the surveys.
Similar to the survey design, the design of interview schedules also considered the comparable variables across nations (Ragin, 1987; MacInnes, 2006), which means most questions were similar in the UK and Chinese interviews, with some changes to suit the local environment.

Two types of interview schedules were developed: one for parent interviewees and one for professional interviewees. A subsection was added for families who had more than one child diagnosed with ASD, in other words, separate responses were documented for their experiences with each child.

The parents’ interview schedule contained five sections (see Appendix 13). Section 1 gathered the parents’ demographic information such as marital status, age, national identity, work status and education. Section 2 probed the familiar situation, for example, hours of care for the child with ASD and other siblings, number of children undertaking the ABA programmes, and the financial cost of the programme borne by the family. Section 3 established the child’s profile, including child’s age, gender, age when the symptoms were apparent and of diagnosis, perceptions of the diagnosis and treatment service, decisions made post-diagnosis and child’s enrolment in mainstream school or special needs school. Section 4 investigated early ABA-based behaviour interventions. Specifically, the reason of undertaking an intensive or non-intensive ABA programme, behaviour changes before and after the intervention, school’s inclusion and co-operation with ABA professionals, whether the parent worked as a parent therapist or not, and if so, the reasons for this decision. Section 5 explored the parent’s feeling and opinion towards the social policy, support or services received, challenges faced and their expectation for their child’s future. Parent interviewees were also asked to add comments they wanted to bring up at the end of the interview.

The professionals’ interview outline contained six sections (see Appendix 14). Section 1 contained questions relating to demographic information such as age, national identity, and education. Section 2 queried information on present job, for example, their role, work location and years of work. Section 3 examined the EIBI delivered, for example, number of hours and duration delivery, assessment and treatment plan, skill generalisation and maintenance. Section 4 probed the application of early ABA-based behaviour interventions. If interviewees did not
know or implement EIBI, they were asked about early ABA-based interventions, for example, parental involvement, the reason of undertaking a non-intensive ABA programme, the service delivery, barriers in delivering their ideal ABA-based programme, changes considered to be made and training requirements for people working in this area. Section 5 explored the professionals’ opinions regarding autism and ABA in the context of policy and culture. For example, interviewees were asked about their views on current special needs education, mainstream inclusion and social policy regarding children with ASD. The last question was an open-ended, where the interviewee was encouraged to contribute to additional comments.

All of the interview outlines were developed in English first and translated into Chinese (See Appendix 15 on Chinese parents’ interview schedule and Appendix 16 on Chinese professionals’ interview schedule). In order to ensure the accuracy of the translation and adaptability to its cultural norms, the same translation and back-translation approach was used as for questionnaires of the survey (see Methodology of Study 1-Survey).

4.5.4 Research procedures

The research procedure was guided by the inside and outside perspectives (Brislin, 1976). The inside perspective enabled the researcher to take a native point of view and the outside perspective enabled a culturally neutral perspective (Pike, 1954). The researcher was considered an insider and outsider simultaneously in both communities. This duality arises as she was trained (ABA intervention) and certified (RBT) in the UK so she was an insider. On the other hand, some social and cultural norms were foreign to her and in that sense, she was an outsider. This duality was also apparent in China, where the researcher was raised. However, in the field of behavioural intervention in China, she was an outsider. Both perspectives should not be viewed separately but in combination to interpret the social phenomenon (Pike, 1954).

4.5.4.1 Recruitment of UK interviewees

The selection criteria of UK parents and professional interviewees were identical to those of Study 1. The recruitment of UK interviewees were conducted through two
channels, i.e., through the questionnaire of the survey and through email circulation from NIU charity (see Sample Sites for details).

At the end of the survey questionnaire, participants were asked whether they were happy to take part in a telephone interview. Those who agreed to take part were asked to provide their contact details. The informed consent form and interview outline were sent to these interviewees by email. In addition to this, a formal email regarding study aims, digital record agreement, data storage regulations and ethical issues were also sent. The contact details of the researcher, including telephone number, email address and working address were all provided to interviewees, in case the interviewee had any issues they wanted to raise regarding the project or the researcher before, during or after the interview. The email address of the researcher’s supervisor was also provided. All of their names were given substitutes and all private information was anonymised.

With the help of the NIU charity, several participants agreed to take part in face-to-face interviews. The location of the interview depended on the interviewee’s preference. Two of the eleven professional interviewees, who were working in England, were interviewed by telephone call. Four of them, based in England, and one of them based in Wales, were interviewed through Skype teleconferencing due to distance. Two interviews were conducted face-to-face at the university’s offices, while another interview was conducted at the NIU charity. The last professional interviewee was interviewed through word document due to time constraint and further requests for supplemental information. Three of the eight parents were interviewed at their home and one at the university’s offices. Two of the parents were interviewed by telephone and the remaining two parents were interviewed over Skype.

4.5.4.2 Recruitment of Chinese interviewees

Similarly to Study 1 and Study 3, most of the interviewees were recruited during the researcher’s visit to China (March to April 2015). The selection criteria of Chinese participants were the same as those of the survey. Three methods were employed in the recruitment of Chinese interviewees: Through the questionnaire of the survey, where survey participants left their contact details at the end of the paper questionnaires; through Beijing AC School; and through other selected autism
organisations including Beijing BC School and Hebei GC School. (NB: in return for delivering a workshop for staff and parents at these schools, the researcher obtained permission to send out the questionnaires).

The place of interview was chosen by the interviewees, either at the school or at their home. Nine professional interviewees, based in Beijing, were interviewed face-to-face at their work-place, one was interviewed at home as requested, and the remaining one interviewee (Zheng, from Qingdao) was interviewed by telephone as the researcher had already returned to the UK.

All of the seven parent interviews were conducted at their accommodation in Beijing. Given that the majority of the parents were from different regions of China and had temporarily moved to Beijing AC School to undergo training in ABA programmes, they had rented their apartments. Before coming to AC school, some of them had also experienced ABA-based training at other autism organisations.

4.5.4.3 Interview procedure in both countries

Only participants who had signed the consent form were interviewed. Each interview was scheduled for approximately one hour. All of the interviews were recorded on a digital device, with the permission of the interviewee. During the interview, all of the participants were informed that they could refuse to answer any of the questions and withdraw from the study at any time. Any private addresses and telephone numbers were obtained with organisations’ and participants’ permission. All personal information was kept confidential. If the participant withdrew from the interview before completion, the material was not used unless the participant gave explicit permission.

It is worth mentioning that interview schedules were used as guides and not every interviewee was asked every question exactly in the same way, because each interview was different and the interview contents were adjusted on a case by case basis. However, all topic areas were addressed in all interviews, and asking the same/very similar questions across different interviewees provided a comparative perspective of seeing one topic under the same context (Edwards & Holland, 2013). For example, the interviewer asked every participant what kind of support had been received from the local authority and what they felt needed to be changed for the
future. In addition, Lijphart (1971) indicated that it is probable that people would talk too much about the negative side when being asking opinions of two sides. Therefore, interviewees were reminded to answer fully and put forward their opinions based on their own experiences in their own country, for example, a sub-question, like ‘can you only talk about this situation in China?’ was added, when participants were asking to describe their experiences.

Finally, all of the interviews were transcribed by the researcher. The name of the organisation and home location remained confidential through the use of substitute names. The researcher supplied the transcript to the interviewee at the participant’s request.

**4.5.5 Data analysis**

In this study, thematic analysis was used in the data analysis. The anthropologist Opler (1945) indicated that a theme means ‘a technical sense to denote a postulate or position, declared or implied, and usually controlling behaviour or stimulating activity, which is tacitly approved or openly promoted in a society’. In this sense, a theme could be considered as identifying a vital step in every culture (Ryan & Bernard, 2003). Boyatzis (1998) emphasized that thematic analysis is one tool in the qualitative analytic methods, but Braun and Clarke (2006) argued that thematic analysis should be considered to be an independent method. Thematic analysis is used to organise and to interpret data, either explicit or implicit, by different coding techniques (Guest, MacQueen, & Namey, 2012). In this study, four steps were applied in the data analysis.

*Step 1: Immersion in the data*

First of all, the researcher immersed herself in the data and got familiarised with the data. Braun and Clarke (2006) suggested that it is necessary for the researcher to immerse themselves in reading the data so as to get a full range of the contexts, and the whole data should be read more than once before moving towards the next step. In order to compile all the information into a readily accessible package, transcription of the interview was necessary. Transcribing data is time-consuming (Bryman, 2015). In order to improve the overall quality of the data analysis, Miles, Huberman and Saldana (2014) and Bryman (2015) indicated that data analysis
should be performed soon after data collection to allow the context and sentiment of the interview to be captured. When transcribing the data, the researcher took notes along the way. Just as Strauss (1987) put it, codes and memos generated during data collection give the researcher insights into the initial codes and themes and this information can feed into the questions to put forward to the subsequent interviewees.

In order to ensure the accuracy of the transcribed data, it is necessary to back-listen to the original raw data (Braun & Clarke, 2006). As the researcher is not a native English speaker, a second independent native English language speaker helped to cross-check for accuracy, after all of the private information had been anonymised. The Chinese audio interviews were transcribed into Chinese directly because the researcher is a native speaker. Considering the large amount of Chinese transcripts (17 Chinese audios), it was not feasible to translate the entire interviews into English. Selected excerpts of the transcripts were translated into English for use in the presentation of the data, as necessary (Appendix 17).

Step 2: Initiating codes

Many codes were generated when reading the data. Codes are the labels derived from the raw data to describe or infer the information or phenomenon (Boyatzis, 1998; Denzin & Lincoln, 2005; Braun & Clarke, 2006; Miles et al., 2014). Miles, Huberman and Saldana (2014, p97) indicated that ‘coding is analysis’, because it reflected meanings extracted from data chunks. During the process of coding, the researcher highlighted texts with different colours, bold, or italics, so that the relevant text was easily identified (Braun & Clarke, 2006). Braun and Clarke (2006) advised that it is better to make as many codes as possible (time permitting). At a later stage, similar data chunks can then be merged into the same code (Miles et al., 2014). A table was created to categorise the codes and texts. Table 4.14 outlines examples of how the texts were coded.
Table 4.14: Sample of codes

<table>
<thead>
<tr>
<th>Service delivery</th>
<th>We offer home-visits, maybe fortnightly, or monthly visits, depends on parents’ need, for two hours per session. We work closely with the parents to get there.</th>
</tr>
</thead>
<tbody>
<tr>
<td>EIBI</td>
<td>We do not have the capacity to really do EIBI, because we know the guidelines are not enough and many of our parents do not have that support or access services. <strong>Very few parents</strong> actually do EIBI. So that’s <strong>not very common</strong> with people.</td>
</tr>
<tr>
<td>Experience</td>
<td>I [have] work[ed] with children with ASD for 12 years now. I was in a university doing my undergraduate [study]. Then, I did my Master’s. Over the years, I’ve attended lots of trainings. Now, I am working towards my PhD. I had a lot of experience and [did] research on parent home training and programmes.</td>
</tr>
</tbody>
</table>

In addition, it is very important for the transcripts to follow a similar pattern (Strauss, 1987). Hence, all transcripts were transferred into a table format like Table 4.14, and irrelevant materials were placed at the end of the table (Appendix 18).

**Step 3: Developing and reviewing themes**

Themes are the nonconcrete or unambiguous expressions that are extracted or identified in the data collection (Ryan & Bernard, 2003). Ryan and Bernard (2003) emphasised that it is necessary to combine themes and expressions when describing the basic elements of the data. Themes are broader than codes and the procedure requires the researcher to merge the codes into sub-themes, and then, sub-themes into candidate themes (Braun & Clarke, 2006). Therefore, similar codes were merged into candidate themes, and candidate themes were reviewed into final themes.

Subsequently, two sides of candidate themes were developed between UK and China. For example, when illustrating types of service delivery in the UK, the candidate themes that emerged were home-based programmes, centre-based programmes, and children-centred ABA school; when demonstrating the types of service delivery in China, the candidate themes that emerged were parents-focused training programmes, children-focused ABA school and centre-based ABA programme. Braun and Clarke
(2006) suggested candidate themes need to be read and refine to see whether they were needed as a whole. The candidate theme: ‘ABA’ mixed with other methods, was included into the service delivery in China, considering a majority of participants experienced such programmes (see Chapter 7- Results of Study 2).

Step 4: Write-up the report

After coding and categorising the themes, direct quotations from the interviewees were extracted for the final results section. Braun and Clarke (2006) suggested that it is necessary to keep the words concise, consistent in a logical way, and telling the story in an interesting narration. As the survey’s report was completed, the results of semi-structured interviews were triangulated with survey results. For example, the theme ‘ABA and School’ emerged from interviews, which was unexpected out of the survey.
4.6 Study 3: Direct observations

4.6.1 Rationales for direct observations

The term ‘observation’ implies ‘watching and listening, and ‘participation’ refers to the researcher’s ‘involvement’ under a real life circumstance (Corbetta, 2003, p236). The direct data obtained from observations allow the researcher to have more social interactions with participants and to explore the issues in a more detailed and articulate way (Simpson & Tuson, 1995). The data-collection tool of questionnaire and interviews can only provide one aspect of the social reality, while direct participant observation helps to enrich and consolidate the data gathered. Though participant observation was established in the context of anthropological and ethnographical study (Corbetta, 2003), it is very suitable to explore unrecognised phenomena or little-known issues in other ranges of human studies’ areas (Jorgensen, 2015).

Most importantly, direct observation is the main data collection method used in behaviour analysis because it allows for verifiable first-hand data collection on behaviours and behaviour dimensions. In behaviour analysis, explanations of behaviour are based on the analysis of contingencies of which the behaviour is a function, rather than using mentalistic concepts (Keenan & Dillenburger, 2014). The dimensions of behaviour, which can be quantified, include duration, frequency and inter-response time (Cooper et al., 2007). Using any of these dimensional measures, direct observations serve to record behavioural data quantitatively and verifiably (i.e., allowing for Inter-observer Agreement measures), rendering the introduction of non-verifiable mental constructs unnecessary.

Study 3 was regarded as a case study (Yin, 1981), which played an important part in portraying a picture of autism organisations and reflecting how the application of ABA-based intervention, specifically DTT, was used across cultural settings. To be precise, it sequentially recorded how parents and professionals worked with children with ASD using DTTs. A format for data gathering and a metric table of data analysis were developed in this section (described in more detail later).
4.6.2 Participants

4.6.2.1 Sample parents in the UK and China

In total, 5 parents took part in Study 3, i.e., 3 parents from China and 2 from the UK. In the UK, all of the cases were from NIU charity. In China, all of the cases were from AC School. The detailed information of each interviewee is described below.

**Daisy**

Daisy (anonymised name) was a 30 years old (age roughly provided) mother originally from Russia, but had been living in Northern Ireland for more than 10 years. She was a single mother and her current working status was unemployed. She was doing some part-time job previously, but resigned 2 months prior to the Study to look after her son David (anonymised name). David was the only child of Daisy. David was 3 years and 6 months old. He was first suspected to be on the autism spectrum at 1 year old and 3 months. David was formally diagnosed when he was 2 years old and 10 months. A speech therapist from NHS came for visit for 30 minutes every week. David commenced a home-based ABA programme 2 months prior to the study. Daisy sent him to nursery school for 2 and half hours every day. After that, Daisy herself carried out the ABA-based intervention with David every day. A child support programme manager (MSc ABA) from NIU charity came to consult for two hours every week.

**Mary**

Mary (anonymised name) was a 44 years old mother from Northern Ireland. Her national identity was Northern Irish. Her husband was working full-time. Her current working status was unemployed, but looking after two children at home full-time. The older child was a son named Mark (anonymised name) who was diagnosed with ASD and the other child was a daughter who was 3 years old and she was a typically developing child. Mary held a Bachelor degree and she was currently pursuing a part-time Master’s degree in ASD at a local university. Mark was 5 years and 1 month old. He was first suspected to be on the autism spectrum when he was 12 months old. Mark was formally diagnosed at 3 years old and 9 months. After being placed on a waiting list for 3 months, Mark commenced a home-based ABA programme at 4 years old and 2 months. The family hired an ABA therapist to work
with Mark for 4 hours per week. In addition, Mary herself carried out an extra 20-hour per week ABA-based interventions with Mark. A Board Certified Behaviour Analyst (BCBA) from NIU charity came to visit to supervise progress every month.

**Ling**

Ling (anonymised name) was a 29 years old mother from a city of China’s Northern Province of Shanxi (around 505 kilometres from Beijing). Her national identity was Chinese. Her husband was working full-time in their hometown. Ling held a Bachelor degree in computer science. She took a leave from her regular job to move to Beijing to undertake courses at AC school. Ling rented a house which was around 5 minutes’ walk from AC school. The Grandfather accompanied Ling and Yun (anonymised name) to Beijing and carried out the domestic duties for Yun. Yun was 3 years and 4 months old. Yun was first suspected to be on the autism spectrum at 20 months of age. He was formally diagnosed at 2 and half years old. Once he got diagnosed, his doctor referred him to a local autism agency for intervention programmes, which were based on an eclectic approach with different kinds of methods, including DTT, sensory integration and floor time etc. Before coming to AC school, he had been placed on AC school’s waiting list for around 1 year.

**Meimei**

Meimei (anonymised name) was a 26 years old mother from a city of China’s Northern Province of Hebei (around 283 kilometres from Beijing). Her national identity was Chinese. She and her husband were self-employed at their hometown. Their highest educational background was high school education. The couple moved to Beijing to undertake courses at AC School and they rented an apartment which was about 5 minutes’ walk from AC school. The 4 year and 3 months old boy, Cheng (anonymised name) was first suspected to be on the autism spectrum when he was 3 years and 5 months old and formally diagnosed quickly, at almost the same time. Four months later, Cheng was sent to the local autism agency for intervention, which was based on an eclectic approach and included DTT, sensory integration and floor time etc. Before coming to AC school, he had been placed on school’s waiting list for around 1 year.
**Wangjun**

Wangjun (anonymised name) was a 26 years old father from a rural town of China’s Northern Province of Hebei (around 283 kilometres from Beijing). His national identity was Chinese. He and his wife made their living with farming. Their highest educational background was high school education. The couple moved to Beijing to undertake courses at AC School and they rented an apartment which was about 5 minutes’ walk from AC school. Wangjun was the main person who undertook the courses and his wife carried out domestic duties. The boy, Xiaobao (anonymised name) was around 4 years old. Other information was not provided.

**4.6.2.2 Sample professionals in the UK and China**

There were 3 professionals involved in this Study 3, i.e., one from the UK and two from China. The aim of including professionals in the direct participant observation was to understand how the DTT was applied by the therapist from the UK and teachers from China.

**Jane**

Jane (anonymised name), female, single, was a 26 year-old ABA therapist working at NIU charity, Northern Ireland. Her national identity was British. She held an MSc degree in ABA and had completed a supervised 12-months internship at a large ABA-based autism school in USA. Jane was engaged in further supervised practice to become eligible to take the BCBA exam. At the time of the study, she was working with four families. She had been working with NIU charity full-time for 6 months. Jane mostly offered home-based ABA programmes, but also offered school-based programmes if requested by parents. Jan was mainly conducting EIBI programmes for families. In this study, direct observation was carried out with a family for whom she provided 4 hours’ ABA-based interventions per day, two days per week for a 4 years old girl (anonymised to Lily). Jane was supervised by a supervisor (BCBA) every month.

**Xiaohong**

Xiaohong (anonymised name), female, married, was about 30 year-old teacher working at AC school. Her national identity was Chinese. Xiaohong held a junior college education in social work. Xiaohong had been working at AC School full-time for 11 years. She mostly offered school-based parents training in ABA-based
interventions, but also offered home-based programmes part-time, if families requested this. In this study, a direct participant observation was carried out with a class she was working with. Xiaohong was the head teacher of this class of a total of 10 children and 10 parents. She was working with the class for 5 hours per day. Xiaohong was trained by the experienced teachers at the school. In addition to regular internal teachers’ training at the school, she also went to USA for short-term intensive courses. She did not have any Behaviour Analyst Certification Board (BACB) qualifications and there were no BCBA to supervise teachers in this school.

**Liumei**

Liumei (anonymised name), female, single, about 25 years old, was a teacher working at Hebei GC School. Her national identity was Chinese. She offered school-based training for children. The information regarding Liumei’s educational background and working length was unknown. As introduced by the principal of GC School, the programmes in this programme include music therapist, arts, sensory integration and individualised training. The individualised training was between one teacher and one student which lasted for 30 minutes in a closed room. Liumei did not have any Behaviour Analyst Certification Board (BACB) qualifications and there were no BCBA to supervise teachers in this school.

**4.6.3 Instruments**

Discrete Trial Training (DTT) sessions were observed in each country. DTT is a frequently used procedure during the early stages of ABA-based interventions with children on the autism spectrum, especially if they lack basic academic or imitation skills. DTT was first made popular by Ivar Lovaas in the UCLA YAP model (Lovaas, 1987). In DTT, skills are broken down into small teachable learning units or ABCs (Tristram Smith, 2001) including the following steps:

1. **Antecedent stimulus (A)** is presented to set, cue, or trigger the target behaviour. An antecedent is the presentation of cues or triggers to promote desirable behaviour. This involves creating the right environment to get child involved and to minimise any barriers to the correct response (Cooper et al., 2007). According to the DTT curriculum guide by Devlin and Harber (2004), antecedents presented by the trainer provide a discriminate stimulus. This study included giving instructions for attending skills (e.g., sit quietly, eye
contact, responses to name), imitation skills (e.g., follow an instruction of ‘do this’), receptive language (e.g., identify/point to body parts, shapes, pictures and people), expressive language (e.g., label subjects, verbally request and answer questions), pre-academic skills (e.g., cards matches, distinguish colours, items, counting and simple independent activities) and self-help skills (e.g., use toilet, close the door and drink water).

2. Behaviour (B) denotes the target response that is triggered by the Antecedent stimulus. Oftentimes, in early DTTs the behaviour requires careful shaping, i.e., from partially correct responses to fully correct, unprompted response. A physical, verbal, gestural, or pictorial prompt (P) is used if behaviour does not occur unprompted. Especially during early DTT frequent prompts may be needed to ensure the child engages in the targeted response (Cooper et al., 2007). The prompt is faded as soon as the child initiates the target response on their own.

3. Consequence (C) denotes the reinforcer, i.e., the event/stimulus presentation that occurs after target response/behaviour (Cooper et al., 2007). A reinforcer and/or a preference assessment precede the use of DTTs to establish functioning reinforcers. To be specific, a positive reinforcer is a stimulus that, when it follows behaviour, strengthens the behaviour along a certain dimension, e.g., the likelihood of the behaviour recurring is increased. Frequently but not necessarily, a reinforcer is a stimulus that a child prefers, i.e., such as edible items or tangible items. In contrast, negative reinforcers are stimuli that when removed from the environment strengthen the behaviour along a certain dimension, e.g., the likelihood of the behaviour recurring is increased. Usually but not necessarily, these are stimuli a child dislikes, such as homework or bed time. A preference assessment is used to identify stimuli that the child prefers, while a reinforcer assessment is used to assess if the stimulus functions as a reinforcer. Consequently, if the C functions appropriately as reinforcer the behaviour will increase, i.e., it will be repeated in subsequent trials (Cooper et al., 2007).
The sequence of A (Antecedents)-B (Behaviour)-C (Consequence) is called a ‘learn unit’ (Tristram Smith, 2001). Observations of learning units were carried out to establish treatment fidelity of DTT in each of the sample settings (see more details under research procedure).

In order to record treatment fidelity in terms of DTT, the *Metrics for assessing the application of DTT* was developed for this study (Table 4.15). The 1st column represents the sequential classification of treatment fidelity, where 10 stands for 100% accurately implemented learn unit and 1 stands for 100% incorrectly implemented learn unit. In order to be able to graph the data collected in these observations, treatment fidelity classed as 10-7 (inclusive) was considered correctly implemented DTT, while treatment fidelity classed as 6-1 (inclusive) was considered incorrect application of DTT. The intervening numbers depict increasing levels of treatment fidelity.

The 2nd column gives details of the adherence to the A-B-C sequence in each of the observations. A stands for the delivery of an antecedent, B stands for the emission of the behaviour, C stands for the delivery of a consequence and P stands for the use of a prompt. For example, A-B-C means the full procedure of antecedent-behaviour-consequence was observed, while A-P-B-C means that a prompt was used.

The 3rd column depicts the brief explanations of manipulations. The final column denotes the recording on the observation sheet (Appendix 19) of the delivery of 3 components of each learning unit during the session. An accurate delivery of A was recorded as a horizontal line (‘—’). Accurate engagement of child in B was depicted as diagonal line (from top left to bottom right, ‘\diagdown’) and accurate delivery of C was depicted as diagonal line (from bottom left to top right, ‘\diagup’). If prompts were delivered accurately, this was depicted by P+.
Table 4.15: Metrics for assessing the application of DTT

<table>
<thead>
<tr>
<th>Definition</th>
<th>Manipulation</th>
<th>Explanation</th>
<th>symbol</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>A-B-C</td>
<td>Correct application of the learning unit using the A (Antecedents)-B (Behaviour)-C (Consequence) sequence in the learning unit</td>
<td>√</td>
</tr>
<tr>
<td>9</td>
<td>A-P-B-C</td>
<td>Correct application of the learning unit, but a prompt was added</td>
<td>P+</td>
</tr>
<tr>
<td>8</td>
<td>A</td>
<td>Application of the learn unit not complete and only A (Antecedents) used</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>A+P</td>
<td>Application of the learn unit not complete and A (Antecedents) and P (Prompt) used</td>
<td>P+</td>
</tr>
<tr>
<td>6</td>
<td>A-C-B</td>
<td>Incorrect application of the learn unit without prompt because Consequence (C) was delivered before Behaviour (B)</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>A-P-C-B</td>
<td>Incorrect application of the learn unit with prompt because Consequence (C) was delivered before Behaviour (B)</td>
<td>P+</td>
</tr>
<tr>
<td>4</td>
<td>C-A-B</td>
<td>Incorrect application of the learn unit because Consequence (C) was given before Antecedent (A) and Behaviour (B)</td>
<td>X</td>
</tr>
<tr>
<td>3</td>
<td>A-B, no C</td>
<td>Incorrect application of the learn unit without prompt, because no Consequence (C) was delivered</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>A-P-B, no C</td>
<td>Incorrect application of the learn unit with prompt, because no Consequence (C) was delivered</td>
<td>P+</td>
</tr>
<tr>
<td>1</td>
<td>C</td>
<td>Consequence (C) was delivered without presenting other components of learn units</td>
<td></td>
</tr>
</tbody>
</table>

The DTTs were delivered either by the parent or the therapist. The researcher was an observer only; she did not take part in the delivery of DTT. Each student-parent/professional dyads provided their own tasks’ instruments and reinforcers, for example, visual cards and toys (see more in the Results of Study 3).
4.6.4 Research procedures

Direct observation was conducted after permission was received from the organisations’ directors. Parents and therapists signed consent sheets prior to the commencement of direct observations. Given the very young age of the children and the level of their disability, gaining explicit child assent was not possible; however, this was not considered of serious ethical concern, given that the focus of the observation was on treatment fidelity, i.e., the adult therapist and parent, and not the child. Any adults or children mentioned in notes or transcripts were given substitute names. The focus of the observation was on the practitioner (professionals or parent therapist) and the child was indirectly included via their response to the DTT implementation, i.e., whether the target behaviour was displayed. The researcher was the only person with an access to these data.

4.6.4.1 Research procedures of UK direct observations

The researcher worked as a volunteer for NIU charity for 3 months prior to the study. The main component of this voluntary work was as a playday supervisor. In order not to result in conflict of interest and putting pressures on parents, the researcher was not the person who contacted participants directly to ask them to participate in the study, but staff who worked in the charity circulated the participant call.

First, permission was sought from NIU charity to do the study. After permission was granted, the Participants Call poster was sent to the staff by email. In this poster, the aim of this study, selection criteria for participants and contact methods for the researcher were outlined (See Study 1-Research Procedure).

Secondly, parents/professionals who were interested in taking part in the research provided their contact details to the staff of NIU charity, to be forwarded to the researcher.

Finally, the researcher contacted participants by email/telephone, sent them the informed consent form by email, and arranged for a convenient time and place to carry out the direct observations. The data collection procedure of each family was as follows:
**Daisy - David**

The direct observation of Daisy (mother) and David was conducted at home. A total of 4 observation sessions took place. The interval between each visit was one or two weeks; it took 2 and half months to complete the observation study. The final visit was cancelled because of Christmas. Because David was not able to sit for a long duration, Daisy usually did each session for 20-30 minutes. A 20-minute observation period was randomly recorded in the data sheet.

**Mary – Mark**

The direct observation of Mary (mother) and Mark was conducted at home. Mary had two children to look after, so she tried to get both of them on board because Mark’s training would be disturbed if her daughter was left alone (the daughter would try to get mother’s attention). The researcher had visited Mary’s home for 5 times. The first visit aimed to build rapport, which allowed the researcher and the participant to get familiar with each other. Data collection for the DTT between Mary and Mark was conducted for 4 sessions. Mary usually completed each session in one hour; a random section of 20 minutes of the training was selected and recorded into the data sheet.

**Jane – Lily**

The direct observation was completed with Jane (therapist) and Lily, at Lily’s home during 7 visits over a 2 and a half month period (separated by Christmas break). This dyad was used to develop and fine tune the Metrics for assessing the application of DTT (Table 4.15). Lily’s mother Lucy agreed these visits at her home and Lucy also participated in the interview (See Study 2 Participants).

During the first visit, the home environment was observed and described. This visit aimed to build relationship with participants and fine-tune the self-administered data collection sheets. The second and third visit functioned as pilot study. To collect data, a randomly selected 20 minute interval was chosen from the one hour DTT session.

All of the above visits were discussed with researcher’s supervisor and data sheets were developed and adjusted. The adjusted data sheet and data collection method were used at the fourth visit.
After that, a formal data collection regime for the DTT between Jane and Lily was conducted for 3 sessions. Jane carried out a one-hour long training session with Lily during each of the observation sessions and a 20-minute observation period was randomly selected for data collection in each session. The interval between each visit was one or two weeks.

4.6.4.2 Research procedures of Chinese direct observations

After receiving the permission to conduct the study at AC School (Appendix 20), the direct observations took place 5 days per week for 2 months. The researcher sat in one class for observation purposes. In the first week of the field work, the researcher observed the training provided to parents by the school. Specifically, a direct observation was made of how teachers worked with parents and children. It was evident that there were gaps in the knowledge and that some of the teaching did not conform to the current accepted best practices in ABA.

The teacher’s work with children was observed in the classroom. The parents’ work with their children was observed at different locations within the building or their home. The details were as follows:

**Ling – Yun**

Ling (mother) was observed at AC school, within Class X while each parent was required to do the parent-led practice session during Session 1 and Session 2 according to the school’s time-table (see Table 4.1). It took around one and half months to finish 4 observations and the interval between each observation was approximately 1-2 weeks. A small table and a chair were placed in front of the class, which enabled the parent-child dyad to do the work. It took around 30 minutes for Ling and Yun to finish the practice. A random 20-minute segment of each session was used to record the data.

**Meimei – Cheng**

Meimei (mother) was observed at her home delivering DTT with her son Cheng. There were 3 observations. The observations took place during homework hours after school (see Figure 4.7) at a mutually agreed, convenient time. It took around one month to complete the 3 sessions. The interval between each session was approximately 1-2 weeks. On average, it took Meimei one hour to finish the
homework, i.e., working with Cheng, and a randomly selected segment of 20 minutes was recorded.

**Wangjun - Xiaobao**

Wangjun (father) was observed at the AC school, but the DTT between him and Xiaobao was coded via the recorded video of his homework. In order to keep the consistency of procedures, videos were chosen based on one week intervals. However, not all of Wangjun’s work was completed in 20 minutes. Thus, a series of 10 minute long DTT videos were used for recording.

**Xiaohong- Yun and Cheng (students of Class X)**

On the first day with Class X, the researcher sat at the side of the classroom and spent a whole day in this class to observe, which provided an initial impression of the interactions among Xiaohong (teacher), parents and students. Consistent with the research protocol, DTT was the focus of the data collection. However, additional activities, such as outdoor activities, musical play and outdoor exercise, were also observed.

Two observations of DTT were selected to compare with the UK data. As Xiaohong’s DTT teaching demonstration was conducted with one of the students from Class X, observations were concerned with a number of different students (ref Table 4.15, 3rd column). The first session was between Xiaohong and the student Yun for 15 minutes and the second observation was between Xiaohong and student Cheng for 20 minutes. The reason for the 15-minute session was because the session finished in 15 minutes, but in the second observation, Xiaohong ensured that the teaching demonstration lasted beyond 20 minutes, so the researcher recorded a randomly selected 20-minute segment.

**Liumei- Hua**

Liumei (teacher) and Hua were observed at Hebei GC School, not the main sample site. The opportunity to conduct this observation occurred when the researcher visited Hebei GC School to send out survey questionnaires and delivered a workshop about EIBI for teachers at the School. The principal of Hebei GC School, Mrs Zhou (anonymised name), introduced the researcher to this school and the teacher Liumei
gave permission to be observed during individualised training with the student, Hua. A randomly selected segment of 20 minutes’ training was recorded into data sheets.

4.6.5 Data analysis

The data collected in these observations were collated into a graphical form for visual analysis. Figure 4.19 is a sample showing the accuracy of training delivery as time progressed.

Figure 4.19: Sample data output

Figure 4.19 is a sample data set for two observations across two stages. The performance of the delivery of DTT was ranked according to the metric as outlined in Table 4.15.

The vertical axis showed the level of accuracy which was defined from 1-10 as described in Table 4.15, which indicates correctly implemented DTT will be classed as 10-7 (inclusive), while incorrect application of DTT will be classed as 6-1 (inclusive). A horizontal dashed line (Score=6) was added to the graphs to show the boundary between accurate application of DTT (a score of 7 or above in vertical axis) and the inaccurate application (a score of 6 or below in vertical axis) for each observation. The intervening numbers depict increasing levels of treatment fidelity.

The horizontal axis showed the number of trials delivered by parents. Each observation was approximately 20 or 10 minutes. A vertical dashed line was added to separate each stage.
4.7 Chapter summary

This chapter outlined the research methodology. It described the question of ‘how to compare’. Specifically, three studies were detailed, described in this cross-national research project, outlining samples, instruments, procedures and data analysis. The next three chapters present findings of the three studies.
Chapter 5. Results of surveys

5.1 Overview
In this chapter, the results of Study 1 are reported. A total of 97 parents and 90 professionals took part. There were 12 parent participants and 24 professional participants (14 therapist and 10 supervisors) from the UK as well as 85 parent participants and 66 professional participants from China. The results of the surveys aim to answer the following four research questions:

1. What is the current situation and mode of delivery of ABA-based intervention programmes for children diagnosed with ASD in the UK and China?
2. To what extent is EIBI used for children with ASD in the UK and China?
3. How do professionals and parents work as ABA therapists?
4. What kind of changes do parents and children have after the ABA-based intervention programmes and what are the barriers experienced?

5.2 Children’s diagnosis, length of wait and hours of care

5.2.1 Children’s diagnosis
The majority of children were diagnosed, according to the DSM-IV (APA, 2000) or the ICD-10 (WHO, 1992), as having Asperger’s Syndrome or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), which included various subcategories of the autism spectrum. In addition, some Chinese children were assessed by doctors as having suspected ASD (yisi zibizheng). This category was unique to the Chinese situation as there was no such diagnosis in the UK. The following information about children was reported by parent participants.

In the UK sample (n=12), 9 parents (75.0%) had one child diagnosed with ASD in the family and 3 parents (25.0%) had two children diagnosed with ASD in the family. There were 10 (83.3%) boys and 2 (16.7%) girls and all of the children were reported to have been formally diagnosed at the time parents participated in the survey. Of the 12 UK children, 7 children (58.3%) had various co-occurring conditions described below. Table 2.1 showed that 11 children (91.7%) had the ASD

---

21 In Chinese 疑似自闭症
diagnosis, 7 children (58.3%) had the PDD-NOS diagnosis, 2 children (16.7%) had an Autistic Disorder diagnosis, 2 children (16.7%) had the Asperger’s Syndrome diagnosis and 2 children (16.7%) had other diagnoses, 2 children (16.7%) were specified as ‘other’: one case was diagnosed with Social Communication Disorder (SCD) as well as an ASD diagnosis, the other child was diagnosed with Type 1 diabetes as well as an ASD diagnosis.

In the Chinese sample (n=85), all of the parent participants each had one child diagnosed with ASD, including 71 boys (83.5%) and 14 girls (16.5%). Of the 85 children, 60 children (70.6%) had a single diagnosis, while 25 children (29.4%) had dual diagnoses. The details of the diagnoses are shown in Table 5.1: 55 children (64.70%) had the ASD diagnosis, 23 children (27.06%) had the autistic disorder diagnosis, 12 children (14.10%) had the PDD-NOS diagnosis, 11 children (12.9%) had the learning disability diagnosis, 8 children (9.4%) had the Attention Deficit Hyperactivity Disorder (ADHD) diagnosis, 5 children (5.90%) had the Asperger’s Syndrome diagnosis, 4 children (4.7%) had the epilepsy diagnosis, 4 children (4.7%) had other diagnoses, and 3 children (3.5%) had the cerebral palsy diagnosis. The other four cases (4.70%) were specified as suspected diagnoses.

Table 5.1: Children’s diagnoses for survey sample

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>11 (91.67%)</td>
<td>55 (64.70%)</td>
</tr>
<tr>
<td>Autistic Disorder</td>
<td>2 (16.67%)</td>
<td>23 (27.10%)</td>
</tr>
<tr>
<td>Asperger's Syndrome</td>
<td>2 (16.67%)</td>
<td>5 (5.90%)</td>
</tr>
<tr>
<td>PDD – NOS</td>
<td>7 (58.33%)</td>
<td>12 (14.10%)</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>-</td>
<td>3 (3.5%)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>-</td>
<td>4 (4.7%)</td>
</tr>
<tr>
<td>ADHD</td>
<td>-</td>
<td>8 (9.4%)</td>
</tr>
<tr>
<td>Learning disability</td>
<td>-</td>
<td>11 (12.9%)</td>
</tr>
<tr>
<td>Others</td>
<td>2 (16.67%)</td>
<td>4 (4.70%)</td>
</tr>
<tr>
<td>Total</td>
<td>24*</td>
<td>125*</td>
</tr>
</tbody>
</table>

*Total count is more than real sample due to child’s co-occurring conditions.
Table 5.2 shows diagnosticians of children with ASD. Of the 11 UK respondents (1 did not respond) and the 82 Chinese respondents (3 did not respond), 5 UK children (45.5%) and 48 Chinese children (58.5%) were diagnosed/assessed by paediatrician.

In the four cases of multidisciplinary team diagnosis of the UK sample (multiple team), team members were specified as ‘ASD paediatrician, speech and language therapist (SALT) and occupational therapist (OT) professionals’, ‘SALT and paediatrician’, ‘multi-disciplinary team at children’s hospital’ and ‘early intervention team and psychologist’. The Chinese sample reported single disciplinary diagnosis, ‘others’ was not specified.

Table 5.2: Diagnosticians of the children with ASD

<table>
<thead>
<tr>
<th></th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Paediatrician</strong></td>
<td>5 (45.5%)</td>
<td>48 (58.5%)</td>
</tr>
<tr>
<td><strong>Psychologist</strong></td>
<td>1 (9.1%)</td>
<td>5 (6.1%)</td>
</tr>
<tr>
<td><strong>Multiple team</strong></td>
<td>4 (36.4%)</td>
<td>23 (28.0%)</td>
</tr>
<tr>
<td><strong>Neurologist</strong></td>
<td>1 (9.1%)</td>
<td>5 (6.1%)</td>
</tr>
<tr>
<td><strong>Others</strong></td>
<td>-</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>11* (100%)</td>
<td>82** (100%)</td>
</tr>
</tbody>
</table>

* Data missing (n=1); **Data missing (n=3)

Table 5.3 presents the detail of the diagnosis age of children. Children’s average age in the UK (8.02 years-of-age) was higher than that of Chinese children (4.84 years-of-age) at the time of the survey. In the Chinese sample, 63 children (74.1%) had a formal diagnosis and 22 children (25.9%) were not diagnosed formally. Some parents did not think of the suspected diagnosis as a formal diagnosis, but some believed so because it was performed by a specialist. UK children were initially suspected as having ASD at 2.19 years of age and Chinese children were initially suspected at 2.74 years of age. Yet, both UK and Chinese children were formally diagnosed late, i.e., children in the UK received their formal diagnosis at 4.20 years of age and children in China received it at 3.22 years of age.
Table 5.3: Children’s age of diagnosis (in year)

<table>
<thead>
<tr>
<th></th>
<th>Child’s age</th>
<th>Suspected age</th>
<th>Formally diagnosed age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Min.</td>
<td>Max.</td>
</tr>
<tr>
<td>UK (n=12)</td>
<td>8.02</td>
<td>4.00</td>
<td>16.00</td>
</tr>
<tr>
<td></td>
<td>2.19</td>
<td>1.00</td>
<td>4.00</td>
</tr>
<tr>
<td></td>
<td>4.20</td>
<td>3.00</td>
<td>10.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>China (n=85)</td>
<td>Mean</td>
<td>4.86</td>
<td>2.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.74</td>
<td>1.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3.22</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Data missing (n=1); ** Data missing (n=1); *** Data missing (n=1); ****Data missing (n=15)

5.2.2 Children on the wait-list for ABA programme

Table 5.4 shows children’s age of starting the ABA-based programmes reported by parent participants. The UK children commenced ABA programmes at 4.16 years of age on average and the Chinese children were at 3.52 years of age on average. UK parents reported their child had to wait for 0.90 months on average and Chinese parents reported an average of 7.83 months.
Table 5.4: Children’s age of starting ABA-based programmes

<table>
<thead>
<tr>
<th></th>
<th>Starting age (year)</th>
<th>Length on a wait-list of (month)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>UK</strong></td>
<td>Mean</td>
<td>4.16</td>
</tr>
<tr>
<td>(n=12)</td>
<td>Min.</td>
<td>1.67</td>
</tr>
<tr>
<td></td>
<td>Max.</td>
<td>11.00</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>2.36</td>
</tr>
<tr>
<td></td>
<td>Sum</td>
<td>12</td>
</tr>
<tr>
<td>China</td>
<td>Mean</td>
<td>3.52</td>
</tr>
<tr>
<td>(n=85)</td>
<td>Min.</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>Max.</td>
<td>6.83</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>1.36</td>
</tr>
<tr>
<td></td>
<td>Sum</td>
<td>84**</td>
</tr>
</tbody>
</table>

* Data missing (n=2); **Data missing (n=1); ***Data missing (n=8)

The following information about the children’s wait list for the programme was reported by professional participants and was obtained from a sample of 10 UK supervisor participants and 14 UK therapist participants as well as a sample at 62 Chinese professional participants (4 did not respond).

In the UK sample area, there were fewer children placed on the wait-list for the ABA-based programmes. 5 supervisor respondents (55.6%) reported that there were no children placed on their wait-list of the ABA-based programmes. The other 4 participants (44.4%) indicated an average of 25 children participants (Mean=3.57, SD=4.00, Min=0, Max=11) on the waiting list. One participant did not respond to this question. Similarly, 11 UK therapist participants (78.6%) reported there were no children placed on their programme’s wait-list. The other 3 participants (21.4%) indicated an average of 27 children participants (Mean=3.38, SD=7.19, Min=0, Max=21) were on their waiting list.

In the Chinese sample area, of the 62 Chinese professional respondents, 53 professionals (85.5%) reported that there were children on their wait list. The median number of children placed on the wait-list was 35 (Mode=500, Mean =143.39,
SD=197.91, Min=0, Max=500). More than sixty percent of the participants were the main sample site- Beijing AC School (See Chapter 4 Methodology), which 500 children were reported on the school’s wait-list. Hence, this figure is not directly comparable with the number of children on the waiting list of UK professionals so a median number is better for description.

5.2.3 Length of time of parental care/support for the child

Table 5.5 shows the number of hours parents provided help/care for their child diagnosed with ASD per week. All of the 12 UK parent participants (100%) and 69 Chinese parent participants (83.1%) provided care over 20 hours per week.

Table 5.5: Number of hours per week providing help or care for the child

<table>
<thead>
<tr>
<th></th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 4 hrs</td>
<td>-</td>
<td>4 (4.8%)</td>
</tr>
<tr>
<td>10-14 hrs</td>
<td>-</td>
<td>5 (6.0%)</td>
</tr>
<tr>
<td>15-19 hrs</td>
<td>-</td>
<td>5 (6.0%)</td>
</tr>
<tr>
<td>20-34 hrs</td>
<td>2 (16.7%)</td>
<td>2 (2.4%)</td>
</tr>
<tr>
<td>35-49 hrs</td>
<td>2 (16.7%)</td>
<td>7 (8.4%)</td>
</tr>
<tr>
<td>50+ hrs</td>
<td>8 (66.7%)</td>
<td>60 (72.3%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>12 (100%)</td>
<td>83* (100%)</td>
</tr>
</tbody>
</table>

*Missing data (n=2)

5.3 ABA-based behaviour intervention programmes

5.3.1 Way to find about ABA-based interventions

Results reported here and some questions below were multiple responses, which means one respondent could choose more than one case for one question.

Parent participants from both the UK and China reported autism organisations were the main place to find out about ABA-based programmes, 8 parents (66.6%) in the UK sample and 48 parents (56.5 %) in Chinese sample.

Of the 12 UK respondents, 7 parents (58.3%) indicated finding out about ABA-based programmes through websites, 3 parents (25.0%) through family/friends, 3
parents (25.0%) from autism guidelines/handbooks, 1 parent (8.3%) through psychologist and 1 response (8.3%) through social media.

Of the 85 Chinese respondents, 25 parents (29.4%) found out about ABA-based interventions through autism guidelines/handbooks, 23 parents (27.1%) through website, 14 parents (16.5%) through paediatricians, 14 parents (16.5%) through occupational therapists, 9 parents (10.6%) through families/friends, 6 parents (7.1%) through social media, 6 parents (7.1%) through diagnosis/assessment teams, 5 parents (5.9%) through psychiatrists, 3 parents (3.5%) through psychologists, 2 parents (2.4%) through speech pathologist and 2 parents (2.4%) through other health professionals, such as audiologist.

5.3.2 Recommendation on ABA services

With regard to the question ‘who recommended the ABA-based intervention’, of the 12 UK parent respondents, 7 parents (58.3%) chose ‘not recommended’ (i.e. the decision to undergo ABA intervention was not prompted by external recommendation), 5 parents (41.6%) said recommended by autism organisations, 4 (33.3%) said recommended by family/friends, 2 parents (16.7%) said recommended by websites, 1 parent (8.3%) said recommendation by autism guidelines/handbooks and the remaining one parent (8.3%) said recommended by Autism Awareness.

Of the 85 Chinese parent respondents, 41 parents (48.3%) said recommended by autism organisations; 33 parents (38.9%) said recommended by professionals, with 16 by paediatricians, 7 by psychiatrists, 1 by psychologist, 1 by speech pathologist, 6 by occupational therapists, and 2 by other health professionals; 20 parents (23.5%) were recommended by autism guidelines/handbooks; 19 parents (22.4%) said recommended by families/friends; 13 parents (15.3%) said recommended by websites, 7 parents (8.2%) said recommended by diagnosis/assessment team and 4 parents (4.7%) said recommended by social media.

5.3.3 Number of supervision hours that parents received

The number of monthly supervision hours received by UK parent respondents per month (Mean =5.89, SD=5.44) was more than Chinese respondents (Mean =4.14, SD=7.95) (Table 5.6). The average amount of supervision was 5.89 hours per month in the UK sample area and 4.14 hours per month in the Chinese sample area. These
supervision hours included team meetings as well as phone and email communication between the parents and their supervisors.

Table 5.6: Amount of supervision received per month (in hours)

<table>
<thead>
<tr>
<th></th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>5.89</td>
<td>4.14</td>
</tr>
<tr>
<td>Min</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Max</td>
<td>12</td>
<td>40</td>
</tr>
<tr>
<td>SD</td>
<td>5.44</td>
<td>7.95</td>
</tr>
<tr>
<td>Total</td>
<td>9*</td>
<td>69**</td>
</tr>
</tbody>
</table>

*Data missing (n=3); **Data missing (n=16)

Table 5.7 shows the frequency of team meetings between parents and therapists/supervisors in the UK. Because of the difference in the service delivery mode of the ABA programmes (See Chapter 4: Pilot study of Methodology), this question was not asked to Chinese participants. Half of the UK parent respondents had team meetings with programme supervisor or therapists once a month (50.0%, n=6).

Table 5.7: Team meetings with therapists/supervisors in the UK

<table>
<thead>
<tr>
<th></th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once a year or less</td>
<td>1 (9.10%)</td>
</tr>
<tr>
<td>Every 2-6 months</td>
<td>2 (16.70%)</td>
</tr>
<tr>
<td>Every month</td>
<td>6 (50.00%)</td>
</tr>
<tr>
<td>Every two weeks</td>
<td>1 (8.30%)</td>
</tr>
<tr>
<td>Others (specified as every term)</td>
<td>1 (8.30%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><em><em>11</em> (100%)</em>*</td>
</tr>
</tbody>
</table>

* Data missing (n=1)

5.3.4 Parents’ cost and payment methods on the ABA-based programme

Due to the socioeconomic differences between the UK and China, the cost of ABA-based programmes is reported separately. Response categories are shown in Table 5.8. The cost also included parents’ spending money on materials. In the UK, 9
respondents (66.7%) indicated that they spent more than £3,000 on the ABA-based programme. Similarly, in China, 58 respondents (69%) reported they spent more than ¥25,000 (≈£2,553, as of exchange rates in early 2016) for their child’s programme.

Table 5.8: Cost reported on ABA-based programmes

<table>
<thead>
<tr>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-£500 2 (16.7%)</td>
<td>¥1000 or below (≈ £103 or below)* 6 (7.1%)</td>
</tr>
<tr>
<td>£500-£1,000 -</td>
<td>¥1001-¥5000 (≈ £103 – £510)* 3 (3.6%)</td>
</tr>
<tr>
<td>£1,001-£2,000 1 (8.3%)</td>
<td>¥10001-¥15000 (≈£1,021-£1,532)* 3 (3.6%)</td>
</tr>
<tr>
<td>£2,001-£3,000 1 (8.3%)</td>
<td>¥15,001-¥20,000 (≈£1,532-£2,042)* 5 (6.0%)</td>
</tr>
<tr>
<td>£3,001-£4,000 2 (16.7%)</td>
<td>¥20,001-¥25,000 (≈£2,042-£2,553)* 4 (4.8%)</td>
</tr>
<tr>
<td>£4,001-£5,000 -</td>
<td>¥25,001-¥30,000 (≈£2,553-£3,063)* 10 (11.9%)</td>
</tr>
<tr>
<td>£5,001-£10,000 2 (16.7%)</td>
<td>¥30,001 or above (≈£3,063 or above)* 48 (57.1%)</td>
</tr>
<tr>
<td>£10,000 or above 4 (33.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong> 12 (100%)</td>
<td>84** (100%)</td>
</tr>
</tbody>
</table>

* Currency conversion June 2016; **Missing data (n=1)

Figure 5.1 shows how parent participants paid for their child’s ABA-based programme. Of the 12 UK parent respondents and 83 Chinese parent respondents (2 did not respond), most parents of each sample site reported salary was the main method of payment, 9 parents (75.0%) in the UK and 75 parents (90.4%) in China.
Those who chose ‘others’ were three Chinese participants (2.4%, n=3), specified as receiving ‘direct financial support from child’s grandparents’.

*100% UK response rate; 97.6% Chinese response rate
**Zero percent represented by absence of bar

Figure 5.1: Payment methods for ABA-based programme

5.3.5 Mode of service delivery of the ABA-based programme

5.3.5.1 Mode of service delivery reported by parents

Table 5.9 shows mode of service delivery of the ABA-based programmes in the UK and China reported by parent respondents. Of the 12 UK respondents, 8 parents (66.7%) chose home-based programme; 4 parents (33.3%) chose school-based programme; 2 parents (16.7%) chose centre-based programme; 2 parents (16.7%) reported the kindergarten/school support from ABA therapists and 2 parents (16.7%) reported joining in ABA playgroup.
Of the 81 Chinese parent respondents (3 did not respond), 76 parents (93.9%) chose centre-based programme; 47 parents (58.0%) reported using home-based programme; 5 parents (6.1%) chose school-based programme; 4 parents (4.9%) chose the multidisciplinary programme (ABA + Speech +OT); 4 parents (4.9%) chose ABA playgroup; 3 parents (3.7%) chose ABA sports programme, 3 parents (3.7%) indicated ‘not sure’ and 1 parents (1.2%) chose kindergarten/school support from ABA therapists.

Table 5.9: Mode of service delivery reported by parents

<table>
<thead>
<tr>
<th>Mode of Service Delivery</th>
<th>UK (n=12)</th>
<th>China (n=81)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home-based 1:1 programme</td>
<td>8 (66.7%)</td>
<td>47 (58.0%)</td>
</tr>
<tr>
<td>Centre-based 1:1 programme</td>
<td>1 (8.3%)</td>
<td>42 (51.9%)</td>
</tr>
<tr>
<td>School-based 1:1 programme</td>
<td>4 (33.3%)</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Centre-based group programme</td>
<td>1 (8.3%)</td>
<td>34 (42.0%)</td>
</tr>
<tr>
<td>School-based group programme</td>
<td>-</td>
<td>4 (4.9%)</td>
</tr>
<tr>
<td>Multidisciplinary programme (ABA + Speech +OT)</td>
<td>-</td>
<td>4 (4.9%)</td>
</tr>
<tr>
<td>Kindergarten/school support from ABA therapists</td>
<td>2 (16.7%)</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>ABA playgroup</td>
<td>2 (16.7%)</td>
<td>4 (4.9%)</td>
</tr>
<tr>
<td>ABA sports programme</td>
<td>-</td>
<td>3 (3.7%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>-</td>
<td>3 (3.7%)</td>
</tr>
</tbody>
</table>

*Missing data (n=4)

Table 5.10 shows the mode of service delivery of the ABA-based programme reported by professionals. The top three modes of service delivery reported by UK supervisors were school-based programme (80.0%, n=8), home-based 1:1 programme (70.0%, n=7) and kindergarten/school support from ABA therapist (40.0%, n=4); Similarly, the top three reported by UK therapists were home-based 1:1 programme (84.6%, n=11), school-based 1:1 programme (53.8%, n=7) and multidisciplinary programme (30.8%, n=4). In the Chinese sample area, the popular modes of service delivery reported by Chinese professionals were centre-based 1:1 programme (72.7%,
n=48), centre-based group programme (60.6%, n=40) and multidisciplinary programme (47.0%, n=31).

Table 5.10: Mode of service delivery reported by professionals

<table>
<thead>
<tr>
<th></th>
<th>UK Supervisors (n=10)</th>
<th>UK Therapists (n=13)*</th>
<th>Chinese professionals (n=66)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home-based 1:1 programme</td>
<td>7 (70.0%)</td>
<td>11 (84.6%)</td>
<td>8 (12.1%)</td>
</tr>
<tr>
<td>Centre-based 1:1 programme</td>
<td>3 (30.0%)</td>
<td>3 (23.1%)</td>
<td>48 (72.7%)</td>
</tr>
<tr>
<td>School-based 1:1 programme</td>
<td>8 (80.0%)</td>
<td>7 (53.8%)</td>
<td>11 (16.7%)</td>
</tr>
<tr>
<td>Centre-based group programme</td>
<td>1 (10.0%)</td>
<td>-</td>
<td>40 (60.6%)</td>
</tr>
<tr>
<td>School-based group programme</td>
<td>2 (20.0%)</td>
<td>1 (7.7%)</td>
<td>10 (15.2%)</td>
</tr>
<tr>
<td>Multidisciplinary programme (ABA + Speech +OT)</td>
<td>3 (30.0%)</td>
<td>4 (30.8%)</td>
<td>31 (47.0%)</td>
</tr>
<tr>
<td>Kindergarten/school support from ABA consultation</td>
<td>4 (40.0%)</td>
<td>1 (7.7%)</td>
<td>12 (18.2%)</td>
</tr>
<tr>
<td>Kindergarten/school support from ABA therapists</td>
<td>3 (30.0%)</td>
<td>2 (15.4%)</td>
<td>5 (7.6%)</td>
</tr>
<tr>
<td>ABA playgroup</td>
<td>1 (10.0%)</td>
<td>-</td>
<td>6 (9.1%)</td>
</tr>
<tr>
<td>ABA sports programme</td>
<td>-</td>
<td>-</td>
<td>17 (25.8%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>-</td>
<td>-</td>
<td>8 (12.1%)</td>
</tr>
</tbody>
</table>

* Missing data (n=1)

Table 5.11 shows the characteristics of the ABA-based programmes. 10 UK parent participants (90.9%) and 44 Chinese parent participants (51.8%) indicated they were undertaking an intensive programme, though 2 UK respondents (18.2%) and 2 Chinese respondents (2.4%) indicated they were moving to a less intensive one. There was one Chinese participant choosing ‘others’ not specified.
Table 5.11: Characteristics of current ABA programmes

<table>
<thead>
<tr>
<th>Characteristics of Programme</th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intensive and comprehensive</td>
<td>7 (63.6%)</td>
<td>33 (38.8%)</td>
</tr>
<tr>
<td>Intensive programme targeting one specific skill</td>
<td>1 (9.1%)</td>
<td>9 (10.6%)</td>
</tr>
<tr>
<td>Intensive and comprehensive programme that moved to a less</td>
<td>2 (18.2%)</td>
<td>2 (2.4%)</td>
</tr>
<tr>
<td>intensive one</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comprehensive programme that started as non-intensive</td>
<td>-</td>
<td>26 (30.6%)</td>
</tr>
<tr>
<td>Non-intensive programme targeting one specific skill</td>
<td>1 (9.1%)</td>
<td>3 (3.5%)</td>
</tr>
<tr>
<td>Others</td>
<td>-</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Total</td>
<td>11* (100%)</td>
<td>74** (100%)</td>
</tr>
</tbody>
</table>

* Missing data (n=1); ** Missing data (n=11)

If participants indicated they were not undertaking an intensive programme, the question was skipped to the next questions. Figure 5.2 shows participants’ reasons for undertaking non-intensive ABA programmes, with 100% response rate. A similar number of UK parents reported the child does not need an intensive programme (30.0%, n=3), financial reasons (30.0%; n=3) and transition to school (30.0%; n=3). 2 parents (20.0%) indicated it is the nature of the programme. On the other side, time constraints (40.9%; n=18) and financial reason (36.4%; n=16) were the main reasons in the Chinese sample area. 12 Chinese respondents (27.3%) indicated there was no particular reason.
**5.3.5.2 UK: Specific aspects of ABA-based programmes**

**Specific approaches in the mode of service delivery**

The UK supervisors were asked about the specific methods used in service delivery (Figure 5.3). 8 respondents (80.00%) reported that they used the Verbal Behaviour approach (Sundberg & Partington, 1998), less than twenty percent of the respondents (18.2%, n=4); 4 supervisors (40.00%) used the UCLA model (Lovaas, 1987); 3 supervisors (30.00%) used utilised Autism Partnership model (Autism Partnership, 2011); 2 supervisors (20.00% ) used Early Start Denver Model (Rogers, 2013) and 2 supervisors (20.00% ) used Natural Language Paradigm (Koegal, O’Dell, & Koegel, 1987). One respondent reported their manuals were specifically made and one case said there was no use of any of these models or guidance. The case who selected ‘others’ specified using the Assessment of Basic Language and Learning Skills - Revised (ABLLS-R; Partington, 2006).
ABA services provided

Apart from ABA-based direct behavioural interventions, in the UK, ABA information sessions were the most common ‘other service’ provided (90.0%, n=9). It can be seen from Figure 5.4 that providing ‘ABA training’ and ‘initial consultation with families’ were equally common, with 8 responses each (80.0%). 6 supervisors (60.0%) provided ‘ongoing consultation with families’ and 6 supervisors (60.0%) provided ‘school ABA consultation’ for families. The number of supervisors who provided ‘school/kindergarten support’ and ‘family support programme’ was the same.
Figure 5.4: Other services provided by UK supervisor participants

Guidelines/training manuals followed

Figure 5.5 presents a summary of guidelines/training manuals that supervisors followed in the ABA-based programmes. The UK supervisor participants reported that VB-MAPP, BACB guidelines (BACB, 2016b), PECS (Frost & Bondy, 1996) and UCLA model (Lovaas, 1987) were the most popular guidelines/training manuals used in their ABA-based programmes, with a number of 7 supervisors (70.0%), 5 supervisors (50.0%), 3 supervisors (30.0%) and 2 supervisors (20.0%) respectively. There were two participants who stated ‘others’ (20.0%), one specified he/she used the Teaching Good Learner Repertoires (Ward, 2013), and the others did not specify any guideline or manual being used.
Number of hours delivered and supervised

The therapist participants indicated that they delivered an average of 26.79 hours of ABA-based therapy per week (SD=9.90, Min=8, Max=40). In addition, the average supervision hours that they received was 7.36 hours per week (SD=5.11, Min=1, Max=20).

The supervisor participants indicated that they provided an average of 8.70 supervision hours per week (SD=7.20, Min=3, Max=27) for one child.

The breakdown of the frequency of supervision delivery is as follows: of the 9 supervisor respondents (1 did not respond), 2 supervisor participants (22.2%) provided supervision weekly; 4 supervisors (44.4%) provided fortnightly and 3 supervisors (33.3%) provided monthly.
**Frequency of reviewing the IEP**
Of the 10 supervisor participants, 6 supervisor participants (60.0%) reviewed the IEP for a child/family every month; 3 supervisors (30%) reviewed every 5 months and the remaining one participant (10.0%) reviewed every 2 months.

**Duration of the ABA-based programmes**
The duration of ABA-based programme was typically more than 36 months, as reported by more than half of the UK supervisor participants (60%, n=6). 2 supervisor participants indicated the programme lengths were typically 24-36 months (10%, n=1) and 12-24 months (10%, n=1) respectively. The remaining one respondent (10%, n=1) indicated it was less than 3 months. One participant did not respond to this question.

5.3.5.3 **China: Specific aspects of ABA-based programme**
Table 5.12 shows services undertaken by Chinese participants.

The second column of this table shows parents’ reports about their child’s services or training received at autism organisation. Of the 80 Chinese parents, 65 parents (81.3%) reported their child received ABA programmes and 51 parents (63.7%) reported their child received sensory integration, 30 parents (37.5%) reported their child received play therapy. None of the children undertook the animal assisted therapy.

The third column of this table shows professionals’ reports about services that their organisations provided for children. Of the 62 Chinese professional respondents, 60 professionals (96.8%) reported providing ABA-based intervention services, 43 professionals (69.4%) reported providing TEACCH, 38 professionals (61.3%) reported providing sensory integration and 38 professionals (61.3%) reported providing play therapy. The one professional choosing ‘Others’ specified as providing fine motor skill service.
Table 5.12: Services undertaken by Chinese participants

<table>
<thead>
<tr>
<th>Services</th>
<th>Parents (n=80)*</th>
<th>Professionals (n=62)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABA</td>
<td>65 (81.3%)</td>
<td>60 (96.8%)</td>
</tr>
<tr>
<td>Sensory integration</td>
<td>51 (63.7%)</td>
<td>38 (61.3%)</td>
</tr>
<tr>
<td>Play therapy</td>
<td>30 (37.5%)</td>
<td>38 (61.3%)</td>
</tr>
<tr>
<td>TEACCH</td>
<td>17 (21.3%)</td>
<td>43 (69.4%)</td>
</tr>
<tr>
<td>Music therapy</td>
<td>15 (7.5%)</td>
<td>32 (51.6%)</td>
</tr>
<tr>
<td>Auditory integration</td>
<td>8 (10.0%)</td>
<td>6 (9.7%)</td>
</tr>
<tr>
<td>Acupuncture and massage</td>
<td>4 (5.0%)</td>
<td>2 (3.2%)</td>
</tr>
<tr>
<td>Biotherapy</td>
<td>3 (3.8%)</td>
<td>-</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>2 (2.5%)</td>
<td>7 (11.3%)</td>
</tr>
<tr>
<td>Hyperbaric oxygen therapy</td>
<td>2 (2.5%)</td>
<td>-</td>
</tr>
<tr>
<td>Arts learning</td>
<td>1 (1.3%)</td>
<td>21 (33.9%)</td>
</tr>
<tr>
<td>Mind reading</td>
<td>1 (1.3%)</td>
<td>9 (14.5%)</td>
</tr>
<tr>
<td>Animal assisted</td>
<td>-</td>
<td>1 (1.6%)</td>
</tr>
<tr>
<td>Others</td>
<td>-</td>
<td>1 (1.6%)</td>
</tr>
</tbody>
</table>

*Missing data (n=5); **Missing data (n=4)

5.3.5.4 Length of travel to the programme

In the UK sample, of the 11 parent responses (1 did not respond) about the length of time to access the child’s ABA-based programme, 7 parents (63.60%) indicated there was no travel required for their child’s current ABA programmes (n=7) because it was carried out at home; 2 parents (18.2%) reported less than 30 minutes travel and 2 parents (18.2%) reported 30-60 minutes’ travel.

Of the 11 UK parent respondents (1 did not respond) about length of time to receive supervision from the programme’s supervisor, 5 parents (45.50%) reported they received supervision hours from the programme’s supervisor at home while there was an even split between those parents who had to travel less than 30 minutes (18.2%, n=2) or 30-60 minutes (18.2%, n=2); there was an even split also between those parents who had to travel for 1-2 hours (9.1%, n=1) or 2-3 hours (9.1%, n=1).

As the service delivery of programme is different between the UK and China (See Methodology-pilot study), Chinese respondents were not asked questions of
accessing services and receiving supervision. In the Chinese sample, of the 84 parent respondents (1 did not respond), 43 parent respondents (51.2%) indicated they have to take their child out of their local place of residence about access the ABA-based programme.

### 5.3.6 Areas addressed in the ABA-based programme

Table 5.13 shows the areas addressed in the child’s ABA-based programmes. Communication skill was the most popular addressing area, with 10 UK parents (90.9%) and 68 Chinese parents (81.9%) responding. The other three popular areas reported by UK parents were social skills (81.8%, n=9), play skills (72.7%, n=8) and independent daily life skills (72.7%, n=8). The other three popular areas reported by Chinese parents were social skills (71.1%, n=59), independent daily life skills (48.2%, n=40) and academic skills (43.4%, n=36).

Table 5.13: Areas addressed in child’s ABA-based programmes

<table>
<thead>
<tr>
<th>Area</th>
<th>UK (n=11)*</th>
<th>China (n=83)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication skills</td>
<td>10 (90.9%)</td>
<td>68 (81.9%)</td>
</tr>
<tr>
<td>Social skills</td>
<td>9 (81.8%)</td>
<td>59 (71.1%)</td>
</tr>
<tr>
<td>Play skills</td>
<td>8 (72.7%)</td>
<td>28 (33.7%)</td>
</tr>
<tr>
<td>Independent daily life skills</td>
<td>8 (72.7%)</td>
<td>40 (48.2%)</td>
</tr>
<tr>
<td>Academic skills</td>
<td>7 (63.6%)</td>
<td>36 (43.4%)</td>
</tr>
<tr>
<td>Difficult/problematic behaviours</td>
<td>7 (63.6%)</td>
<td>22 (26.5%)</td>
</tr>
<tr>
<td>General knowledge and reasoning</td>
<td>6 (54.5%)</td>
<td>20 (24.1%)</td>
</tr>
<tr>
<td>Skills needed for group learning environment</td>
<td>6 (54.5%)</td>
<td>28 (33.7%)</td>
</tr>
<tr>
<td>Sensory issues</td>
<td>5 (45.5%)</td>
<td>12 (14.5%)</td>
</tr>
<tr>
<td>Obsessions and rituals</td>
<td>4 (36.4%)</td>
<td>7 (8.4%)</td>
</tr>
<tr>
<td>Dietary issues</td>
<td>4 (36.4%)</td>
<td>6 (7.2%)</td>
</tr>
<tr>
<td>Motor skills</td>
<td>3 (27.3%)</td>
<td>26 (31.3%)</td>
</tr>
<tr>
<td>Emotional issues</td>
<td>3 (27.3%)</td>
<td>5 (6.0%)</td>
</tr>
<tr>
<td>Sleeping issues</td>
<td>-</td>
<td>3 (3.6%)</td>
</tr>
</tbody>
</table>

* Missing data (n=1); ** Missing data (n=2)

### 5.3.7 Skills generalised to daily life

Figure 5.6 shows skills generalised to child's daily life. Both the UK and Chinese parents indicated that skills addressed in the session were well generalised into the
child’s daily life. 9 UK parents (100%) and 45 Chinese parents (54.9%) responded with “moderately” or above (Figure 5.6).

![Bar chart showing skills generalised to child's daily life](image)

*75.0% of response rate of the UK sample and 96.5% of response rate of the Chinese sample

**The bar did not appear means zero (0%)

Figure 5.6: Skills generalised to child's daily life

5.3.8 Programme inclusion

5.3.8.1 Co-operation with other professionals

Table 5.14 and Table 5.15 shows parent participants reporting on the incorporation of teachers from school/preschool, speech therapists, occupational therapists (OT) and psychologists into child’s ABA-based programmes.

When presented with the likert scale of ‘very little’, ‘somewhat’, ‘not sure’, ‘good’ and ‘very good’, most of the respondents chose the ‘very little’ and ‘somewhat’ options, while only a small number of participants selected ‘not sure’.

More than half the UK and Chinese participants shared a similar unfavourable perception regarding the extent of the child’s programme’s incorporation with school teachers, speech therapists, occupational therapists (OT) and psychologists. The detailed information is shown below:
Table 5.14: Professionals’ co-operation into the programme (1)

<table>
<thead>
<tr>
<th></th>
<th>Teachers/teachers’ assistant</th>
<th>Speech Therapists</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>UK</td>
<td>China</td>
</tr>
<tr>
<td>Very little</td>
<td>6 (60.0%)</td>
<td>45 (65.2%)</td>
</tr>
<tr>
<td>Somewhat</td>
<td>1 (10.0%)</td>
<td>5 (7.2%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>-</td>
<td>13 (18.8%)</td>
</tr>
<tr>
<td>Good</td>
<td>-</td>
<td>5 (7.2%)</td>
</tr>
<tr>
<td>Very good</td>
<td>3 (30.0%)</td>
<td>1 (1.4%)</td>
</tr>
<tr>
<td>Total</td>
<td>10 (100%)</td>
<td>69 (100%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
<td>16</td>
</tr>
</tbody>
</table>

Table 5.15: Professionals’ co-operation into the programme (2)

<table>
<thead>
<tr>
<th></th>
<th>OT</th>
<th>Psychologists</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>UK</td>
<td>China</td>
</tr>
<tr>
<td>Very little</td>
<td>5 (55.6%)</td>
<td>43 (68.3%)</td>
</tr>
<tr>
<td>Somewhat</td>
<td>-</td>
<td>5 (7.9%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>2 (16.7%)</td>
<td>10 (15.9%)</td>
</tr>
<tr>
<td>Good</td>
<td>-</td>
<td>5 (7.9%)</td>
</tr>
<tr>
<td>Very good</td>
<td>2 (16.7%)</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>9 (100%)</td>
<td>63 (100%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>3</td>
<td>22</td>
</tr>
</tbody>
</table>
5.3.8.2 Incorporation of Child’s special interests

Figure 5.7 shows the incorporation of the child’s special interests into the ABA-based programmes. Of the 9 UK parent respondents (3 did not respond) and 83 Chinese respondents (2 did not respond), 7 UK parents (77.7%) and 38 Chinese parents (58.3%) indicated their child’s special interests had moderate or better (specified as ‘very much’) incorporation into the programme. The remaining information is shown in the following figure.

*100% response rate of the UK sample and 97.6% response rate of the Chinese sample
**The bar did not appear means zero (0%)

Figure 5.7: Child’s special interests incorporated into the programme

5.3.8.3 Incorporation of family’s concern

Figure 5.8 shows parents’ perception of family concerns being incorporated into the ABA-based programme. Of the 9 UK parent respondents (3 did not respond) and 80 Chinese parent respondents (5 did not respond), 7 UK parents (77.7%) reported and 40 Chinese (50.1%), responding with moderately or better respectively.
Figure 5.8: Family’s concern incorporated into the programme

**5.3.9 Programme’s involvement of overseas organisations or professionals**

Table 5.16 shows the involvement of overseas organisations. The majority of the parent respondents from each country indicated that they used only local service providers, with 6 UK parents (66.7%) and 46 Chinese parents (59.0%). A small number of UK parent respondents indicated they used overseas providers (11.1%, n=1) or their ABA consultant was based overseas (22.2%, n=2). On the other hand, around one third of Chinese parents (29.5%, n=23) indicated they used overseas providers and a very small number of participants (3.8%, n=3) used ABA consultants who were based overseas. In addition, there were five Chinese participants did not know

Both the UK and Chinese professional participants reported some involvement of the overseas organisations in the ABA-based programmes. 2 UK supervisor participants (22.2%) indicated they only used local providers; 2 supervisors (22.2%) reported they used some overseas provision; 2 supervisors (22.2%) reported using overseas ABA consulates and 2 supervisors (22.2%) indicated their ABA providers were entirely based overseas. There was one participant (11.1%) reporting unknown. However, most UK therapist participants (64.3%, n=9) indicated they used only local providers, 3 therapists (21.4%) indicated the service is based overseas and 2
were unknowns (14.3%). Around half of the Chinese professional participants used some overseas providers (51.6%, n=32) and around a fifth of them (21.0%, n=13) reported their ABA consultant being based overseas.

Table 5.16: The involvement of overseas organisations

<table>
<thead>
<tr>
<th></th>
<th>UK</th>
<th>China</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parents (n=12)</td>
<td>Supervisors (n=10)</td>
</tr>
<tr>
<td>Only local providers</td>
<td>6 (66.7%)</td>
<td>2(22.2%)</td>
</tr>
<tr>
<td>Some overseas provision*</td>
<td>1 (11.1%)</td>
<td>2(22.2%)</td>
</tr>
<tr>
<td>ABA consultant is based overseas**</td>
<td>2 (22.2%)</td>
<td>2(22.2%)</td>
</tr>
<tr>
<td>ABA provider is entirely based overseas</td>
<td>-</td>
<td>2(22.2%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>-</td>
<td>1(11.1%)</td>
</tr>
<tr>
<td>Total</td>
<td>9 (100%)</td>
<td>9 (100%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>

* Specified as training and conference; **Specified as regular meetings with ABA provisions

5.3.10 Other types of services accessed by children

Though the study focused on exploring ABA-based programmes, the question of ‘other services currently accessed’ was also put to parents in the questionnaire (Table 5.17).

Both the UK and Chinese parent respondents reported that speech therapy was popular, with 5 UK parents (62.5%) and 37 Chinese parents (47.4%) respectively. Sports programme (50.00%; n=4) and music programme (37.50%; n=3) were popular services reported in the UK sample; In the Chinese sample, the non-behaviour early intervention programme (35.90%; n=28) and music programme (21.80%, n=17) were reported as the popular services.
Table 5.17: Other types of services accessed by children

<table>
<thead>
<tr>
<th>Service</th>
<th>UK (n=8)*</th>
<th>China (n=78)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech therapy</td>
<td>5 (62.50%)</td>
<td>37 (47.40%)</td>
</tr>
<tr>
<td>Early intervention programme</td>
<td>-</td>
<td>28 (35.90%)</td>
</tr>
<tr>
<td>(non-behavioural)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Music programme</td>
<td>-</td>
<td>17 (21.80%)</td>
</tr>
<tr>
<td>Sports programme</td>
<td>-</td>
<td>13 (16.70%)</td>
</tr>
<tr>
<td>OT</td>
<td>3 (37.50%)</td>
<td>7 (9.00%)</td>
</tr>
<tr>
<td>Medical treatment</td>
<td>1 (12.50%)</td>
<td>7 (9.00%)</td>
</tr>
<tr>
<td>None</td>
<td>-</td>
<td>14 (17.90%)</td>
</tr>
</tbody>
</table>

*Data missing (n=4); **Data missing (n=7)

5.4 EIBI programmes

In the UK, nearly three-quarters of the supervisor participants (70.0%, n=7) and half of the therapist respondents (50.0%, n=7) reported they offered EIBI programmes to families.

The EIBI section was not studied towards Chinese participants, though a question about ‘whether or not you undertake the EIBI programmes’ was still asked in the Chinese professional’s questionnaire, and around 90 percent of Chinese professional participants (90.5%, n=57) indicated they provided EIBI programmes for families. The reason for this exclusion was based on pilot study (Ref Methodology).

Those UK participants, who selected ‘yes-offer EIBI to families’, were asked to answer a series of questions about EIBI programmes in the UK. This question was set as a skip logic question, which means those who chose ‘no’ were guided to skip to the next section of ABA-based practice. Supervisor participants (100%, n=7) and therapist participants (100%, n=7) believed that EIBI was effective for children diagnosed with ASD. The detailed components of EIBI were reported as follows:
5.4.1 Age of beginning the intervention

The UK professional participants reported children’s average age of beginning the EIBI programmes was minimally 2 years old (Mean=2.34, SD=1.30, Min=1, Max=5) and maximally 8 years old (Mean =8.13, SD=3.91, Min=3, Max=15).

To be specific, the therapist participants reported that the onset age was minimally 3 years old (Mean =3.18, SD=1.23, Min=2, Max=5) and maximally 7 years old (Mean =6.90, SD=2.80, Min=3, Max=10). The supervisor participants reported the onset age was minimally 2 years old (Mean =1.54, SD=0.83, Min=1, Max=3) and maximally 10 years old (Mean =9.67, SD=4.97, Min=3.5, Max=15).

5.4.2 Intensity

The minimum average of intensity of the EIBI programme undertaken by the UK professional participants was 14 hours per week (Mean=14.00, SD=11.25, Min=2, Max=35); the maximum average of intensity was 23 hours per week (Mean=22.58, SD=10.06, Min=3, Max=35).

To be specific, the therapist participants undertook minimally 17 hours per week (Mean=16.59, SD=14.49, Min=2, Max=35) and maximally 21 hours per week (Mean= 21.14, SD=12.28, Min=3, Max=35). The supervisor participants undertook minimally 11 hours weekly (Mean= 11.43, SD=7, Min=3, Max=35) and maximally 25 hours weekly (Mean= 24.6, SD=6.58, Min=18, Max=35).

5.4.3 Duration

The minimum duration of the EIBI programme undertaken by the UK professional participants was 2.98 years (SD=3.24, Min=0.25, Max=10); the maximum average of duration was 4.78 years long (SD=4.05, Min=2.42, Max=12).

To be specific, the therapist participants were involved for an average duration of minimally 2.37 years (SD=2.22, Min=0.25, Max=6) and 5.23 years (SD=4.53, Min=2.42, Max=12). The supervisor participants were involved for an average duration of minimally 3.75 years (SD=4.48, Min=0.5, Max=10). The maximum duration of supervisor involvement could not be calculated due to incomplete answers by supervisors.
5.4.4 Cost of the EIBI programme

Supervisor participants reported a higher cost regarding families undertaking EIBI programmes. Table 5.18 shows the cost of undertaking EIBI programmes, which was reported by UK professional participants. At least half of the supervisor participants (57.2%, n=4) reported that a family had to spend more than £10,001 per year for the EIBI programme. However, half of the therapist participants (50.0%, n=3) reported it was below £1,000 annually, while the other half (50.0%, n=3) reported it was more than £5,001 annually.

Table 5.18: Cost of undertaking EIBI programme

<table>
<thead>
<tr>
<th></th>
<th>Supervisors (n=7)</th>
<th>Therapists (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>£0-£500</td>
<td>-</td>
<td>1 (16.7%)</td>
</tr>
<tr>
<td>£501-£1,000</td>
<td>-</td>
<td>2 (33.3%)</td>
</tr>
<tr>
<td>£1,001-£3,000</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>£3001-£5,000</td>
<td>2 (28.6%)</td>
<td>-</td>
</tr>
<tr>
<td>£5,001-£10,000</td>
<td>1 (14.3%)</td>
<td>2 (33.3%)</td>
</tr>
<tr>
<td>£10,001-£20,000</td>
<td>2 (28.6%)</td>
<td>-</td>
</tr>
<tr>
<td>£20,001+</td>
<td>2 (28.6%)</td>
<td>1 (16.7%)</td>
</tr>
<tr>
<td><strong>Sum</strong></td>
<td>7 (100%)</td>
<td>6 (100%)*</td>
</tr>
</tbody>
</table>

*Missing data (n=1)

ABA techniques utilised in EIBI Table 5.19 indicates ABA techniques used by UK professionals. The UK supervisor respondents indicated that DTT (Discrete Trial Training), differential reinforcement procedures, chaining procedures, and PECS were the most popular used techniques in children’s EIBI programme, with a same number of participants choosing (n=7, 100%). The UK therapist participants indicated DTT, Natural Environmental Training (NET), chaining procedures and specific shaping procedures, with a same number of participants (n=7, 100%).
Table 5.19: Techniques utilised in the EIBI programme

<table>
<thead>
<tr>
<th>Technique</th>
<th>Supervisors (n=7)</th>
<th>Therapists (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discrete Trial Teaching</td>
<td>7 (100.0%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Natural Environmental Training</td>
<td>5 (71.4%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Differential reinforcement procedures</td>
<td>7 (100.0%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Specific Prompting procedures</td>
<td>6 (85.7%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Functional analysis</td>
<td>6 (85.7%)</td>
<td>5 (71.4%)</td>
</tr>
<tr>
<td>Pivotal Response Training</td>
<td>4 (57.1%)</td>
<td>5 (71.4%)</td>
</tr>
<tr>
<td>Incidental teaching</td>
<td>5 (71.4%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Activity embedded trials</td>
<td>4 (57.1%)</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Task analysis</td>
<td>5 (71.4%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>PECS</td>
<td>7 (100.0%)</td>
<td>5 (71.4%)</td>
</tr>
<tr>
<td>Video Modelling</td>
<td>3 (42.9%)</td>
<td>6 (85.7%)</td>
</tr>
<tr>
<td>Social Stories</td>
<td>7 (100.0%)</td>
<td>5 (71.4%)</td>
</tr>
<tr>
<td>Chaining procedures</td>
<td>7 (100.0%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Specific shaping procedures</td>
<td>4 (57.1%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Reciprocal Imitation Training</td>
<td>3 (42.9%)</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Self-management training</td>
<td>2 (28.6%)</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Verbal Behaviour</td>
<td>5 (71.4%)</td>
<td>6 (85.7%)</td>
</tr>
</tbody>
</table>

Table 5.20 shows features of EIBI programmes reported by UK professional respondents. Of these, 7 UK supervisor respondents (100%) reported individualised intervention, focusing on increasing and decreasing behaviours, transition to mainstream school after gaining skills; 7 UK therapists (100%) reported focusing on increasing behaviours and building new repertoires.
Table 5.20: Features of the EIBI programme

<table>
<thead>
<tr>
<th>Feature</th>
<th>Supervisors (n=7)</th>
<th>Therapists (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehensive treatments</td>
<td>4 (57.1%)</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Targeted at all skill domains</td>
<td>6 (85.7%)</td>
<td>5 (71.4%)</td>
</tr>
<tr>
<td>Individualised intervention</td>
<td>7 (100.0%)</td>
<td>6 (85.7%)</td>
</tr>
<tr>
<td>Gradual transition from small to large group</td>
<td>3 (42.9%)</td>
<td>2 (3.1%)</td>
</tr>
<tr>
<td>Focused on increasing behaviours</td>
<td>7 (100.0%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Building new repertoires</td>
<td>6 (85.7%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Focused on decreasing behaviours</td>
<td>6 (85.7%)</td>
<td>6 (85.7%)</td>
</tr>
<tr>
<td>Parental involvement</td>
<td>7 (100.0%)</td>
<td>5 (71.4%)</td>
</tr>
<tr>
<td>Starting at home</td>
<td>6 (85.7%)</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Generalised to other settings</td>
<td>6 (85.7%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>Normal developmental sequences guided by long and short goals</td>
<td>6 (85.7%)</td>
<td>6 (85.7%)</td>
</tr>
<tr>
<td>Transition to mainstream school after gained skills</td>
<td>7 (100.0%)</td>
<td>5 (71.4%)</td>
</tr>
</tbody>
</table>

5.5 Data collection of the programme

Table 5.21 shows a distribution of data collection methodologies in the ABA-based programme between UK and China. Of the 10 UK parent respondents, 7 parents (70.0%) reported continuous data measurements (for example, frequency, duration, or intensity) were used, to record targeted behaviours, by professionals. Of the 80 Chinese respondents, 42 parents (52.5%) indicated professionals used evaluation
In addition, 4 Chinese participants (5.0%) left comments as part of the ‘others’ option. One participant specified that the programme’s data collection was through daily observations, and the other 3 cases indicated there was no data collection in the programme.

Table 5.21: Data collection in ABA-based programmes reported by parents

<table>
<thead>
<tr>
<th>Data Collection Method</th>
<th>UK (n=10)*</th>
<th>China (n=80)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuous frequency/duration/intensity of target behaviours</td>
<td>7 (70.0%)</td>
<td>13 (16.3%)</td>
</tr>
<tr>
<td>Evaluation assessments</td>
<td>4 (40.0%)</td>
<td>42 (52.5%)</td>
</tr>
<tr>
<td>Parent interviews/questionnaires</td>
<td>3 (30.0%)</td>
<td>25 (31.3%)</td>
</tr>
<tr>
<td>Casual chats with therapists</td>
<td>3 (30.0%)</td>
<td>10 (12.5%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (20.0%)</td>
<td>18 (22.5%)</td>
</tr>
<tr>
<td>Others</td>
<td>-</td>
<td>4 (5.0%)</td>
</tr>
</tbody>
</table>

*missing data (n=2); **missing data (n=5)

Table 5.22 shows data collection reported by professionals. The results reported here should be considered with caution because in the UK sample, a question was asked about data collection in the EIBI programme, while in the Chinese sample, a question was asked about data collection in the ABA-based programme.

Specifically, 7 UK supervisors (100.0%) and 7 UK therapists (100.0%) reported using frequency as the data collection. 27 Chinese professionals (42.2%) reported using duration as the data collection. Of the three Chinese parents who indicated ‘others’, one specified he/she was learning another data collection method, and the other two cases did not specify.

Table 5.22: Data collection in ABA-based programmes reported by professionals

22 Autism organisations designed their own evaluation assessments, which were used to examine the child’s ability, such as communication and language skills.
<table>
<thead>
<tr>
<th></th>
<th>UK</th>
<th>China</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Supervisors (n=7) *</td>
<td>Therapists (n=7) **</td>
</tr>
<tr>
<td>Frequency</td>
<td>7 (100.0%)</td>
<td>7 (100.0%)</td>
</tr>
<tr>
<td>duration</td>
<td>5 (71.4%)</td>
<td>5 (71.4%)</td>
</tr>
<tr>
<td>latency</td>
<td>3 (42.9%)</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Time sampling</td>
<td>3 (42.9%)</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>Interval recording</td>
<td>3 (42.9%)</td>
<td>3 (42.9%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Others</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

*missing data (n=3); **missing data (n=7); ***missing data (n=2)

5.6 Professionals’ working status and self-evaluation

5.6.1 Number of children worked with

In the UK, supervisor respondents were working with 120 children, including 97 boys (Mean=9.70, SD=9.73, Min=2, Max=30) and 23 girls (Mean=2.30, SD=2.63, Min=0, Max=9). On average, each supervisor worked with 9.70 boys and 2.30 girls.

Therapist respondents were working with 85 children, including 73 boys (Mean=5.21, SD=8.82, Min=0, Max=34) and 12 girls (Mean=0.92, SD=1.80, Min=0, Max=6). On average, each therapist worked with 5.21 boys and 0.92 girls.

In China, professional participants surveyed worked with a total of 1,133 children, including 945 boys (Mean=17.18, SD=20.67, Min=0, Max=100) and 188 girls (Mean=3.24, SD=7.12, Min=0, Max=50). On average, each professional worked with 17.18 boys and 3.24 girls.

In sum, the ratio of boy to girl was 4.63:1 in the UK and 5.30:1 in China; the average ratio of boy to girl was estimated to be 5:1.
5.6.2 Length of time working in the area of ABA

The UK professional participants reported that they had been basing their work on the area of ABA-based intervention programmes, on average, for approximately 7 years (Mean = 6.56, SD= 7.06, Min= 0.5, Max= 30). Specifically, the supervisor participants worked in the area longer than the therapist participants. The 13 therapist participants (1 did not respond) reported they had been basing their work on ABA for an average of 5 years (Mean = 4.70, SD= 8.51, Min= 0.5, Max= 30). The supervisor participants (n=10) indicated they had been working in the area for an average of 9 years (Mean = 8.61, SD= 4.62, Min= 2.25, Max= 14.5).

The Chinese professional participants reported they had been basing their work on the area of ABA-based intervention programmes for an average of around 6 years (Mean = 6.21, SD= 5.27, Min= 0.17, Max= 22.08).

5.6.3 Training undertaken

Table 5.23 shows training undertaken by both UK and Chinese professionals. The majority of UK professional respondents were undertaking qualification training by Behaviour Analyst Certification Board (BACB). Specifically, of the UK sample, 3 supervisors (60.0%) were undertaking the BCBA-D training, 2 supervisors (40.0%) were undertaking the BCBA training and 1 supervisor (20.0%) was undertaking BCaBA training; 8 therapists (88.9%) were undertaking the BCBA training and 1 (11.1%) was undertaking BCaBA training.

On the other hand, of the 60 Chinese professional participants, only 5 professionals (8.3%) were undertaking BCaBA training. 22 professionals (36.7%) did not undertake any training; 14 professionals (23.3%) were undertaking special educational teacher’s training and 7 professionals (11.7%) were undertaking teacher’s training for a typical school.
Table 5.23: Training undertaken by professionals

<table>
<thead>
<tr>
<th>UK Supervisors (n=5)*</th>
<th>UK Therapists (n=9)**</th>
<th>China Professionals (n=60)***</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generally registered psychologist</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Educational/developmental psychologist</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Clinical psychologist</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Speech Therapist</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Social worker</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>BCBA-D</td>
<td>3 (60.0%)</td>
<td>-</td>
</tr>
<tr>
<td>BCBA</td>
<td>2 (40.0%)</td>
<td>8 (88.9%)</td>
</tr>
<tr>
<td>BCaBA</td>
<td>1 (20.0%)</td>
<td>1 (11.1%)</td>
</tr>
<tr>
<td>Teacher of typical school</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Special education teacher</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Teacher’s aide</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>None</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Others</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

*Missing data (n=5); **Missing data (n=5); ***Missing data (n=6)

5.6.4 Self-evaluation of the skills and techniques

Table 5.24 shows professional participants’ self-evaluation of skills related to work with children on the autism spectrum disorder. More than half of the UK professional participants indicated that their skills related to children with ASD were somewhat high or above, with 10 supervisor participants (100%) and 11 therapist participants (78.5%) respectively. In contrast to the UK, two fifths of the Chinese professional participants (40%, n=26) reported their skills were low (36.9%, n=24) or very low (3.1%, n=2). At least half of the participants reported their skills were
fair (53.8%, n=35) and only a small number of them (6.2%, n=4) believed their skills were ‘somewhat high’.

Table 5.24: Participants’ self-evaluation of skills relating to children with ASD

<table>
<thead>
<tr>
<th></th>
<th>UK Supervisors (n=10)</th>
<th>UK Therapists (n=14)</th>
<th>Chinese Professionals (n=66)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Low</td>
<td>-</td>
<td>-</td>
<td>2 (3.1%)</td>
</tr>
<tr>
<td>Low</td>
<td>-</td>
<td>-</td>
<td>24 (36.9%)</td>
</tr>
<tr>
<td>Fair</td>
<td>-</td>
<td>3 (21.4%)</td>
<td>35 (53.8%)</td>
</tr>
<tr>
<td>Somewhat high</td>
<td>6 (60.0%)</td>
<td>8 (57.1%)</td>
<td>4 (6.2%)</td>
</tr>
<tr>
<td>Very high</td>
<td>4 (40.0%)</td>
<td>3 (21.4%)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>10 (100%)</td>
<td>14 (100%)</td>
<td>65 (100%)*</td>
</tr>
</tbody>
</table>

*Missing data (n=1)

Table 5.25 presents answers to a specific question of ‘How do you rate your level in applying ABA techniques as an individual practitioner’? Similarly, most of the UK professional respondents believed their skills were somewhat high or above, but more than half of the Chinese professional respondents believed that their skills were low or fair.

Table 5.25: Participants’ self-evaluation of applying ABA techniques

<table>
<thead>
<tr>
<th></th>
<th>UK Supervisors (n=10)</th>
<th>UK Therapists (n=14)</th>
<th>China Professionals (n=66)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Low</td>
<td>-</td>
<td>-</td>
<td>2 (3.0%)</td>
</tr>
<tr>
<td>Low</td>
<td>-</td>
<td>-</td>
<td>27 (40.9%)</td>
</tr>
<tr>
<td>Fair</td>
<td>-</td>
<td>5 (35.7%)</td>
<td>34 (51.5%)</td>
</tr>
<tr>
<td>Somewhat high</td>
<td>6 (60%)</td>
<td>6 (42.9%)</td>
<td>3 (4.5%)</td>
</tr>
<tr>
<td>Very high</td>
<td>4 (40%)</td>
<td>3 (21.4%)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>10 (100%)</td>
<td>14 (100%)</td>
<td>66 (100%)</td>
</tr>
</tbody>
</table>
5.6.5 Frequency of accessing research evidence on ABA

Table 5.26 shows the frequency that professionals accessed research evidence on ABA. Of the 10 UK supervisor respondents, 4 supervisors (40%) accessed a few times a year. 4 supervisors read the research evidence once a month (30%, n=3) or once a week/more (10%, n=1); Of the 14 UK therapist respondents, a majority accessed the research evidence once a month (28.6%, n=4) or several times a week (42.9%, n=6); Of the 80 Chinese professional participants, 25 Chinese professionals (38.5%) accessed a few times a year and 15 parents (23.1%) accessed once a year or less.

Table 5.26: Frequency in accessing ABA research evidence

<table>
<thead>
<tr>
<th></th>
<th>UK</th>
<th>China</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Supervisors</td>
<td>Therapists</td>
</tr>
<tr>
<td></td>
<td>(n=10)</td>
<td>(n=14)</td>
</tr>
<tr>
<td>Never</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Once a year or less</td>
<td>2 (20.0%)</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>A few times a year</td>
<td>4 (40.0%)</td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>Once a month</td>
<td>3 (30.0%)</td>
<td>4 (28.6%)</td>
</tr>
<tr>
<td>Once a week or more</td>
<td>1 (10.0%)</td>
<td>6 (42.9%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>10</strong></td>
<td><strong>14</strong></td>
</tr>
</tbody>
</table>

*Missing data (n=1)

5.6.6 Parents’ perception of professionals’ support

A large proportion of the UK and Chinese parent participants indicated that professionals were supportive (Table 5.27). To be specific, more than half of the UK parent respondents (88.9%, n=8) believed that ABA supervisors and therapists were moderately or very supportive. Similarly, a majority of the Chinese parent respondents believed ABA teachers were moderately or very supportive (n=65.0%, n=52), while a small number of them did not think that professionals they contacted were very supportive (17.6%, n=14).
Table 5.27: Parents’ perception of the extent of professionals’ supportiveness

<table>
<thead>
<tr>
<th></th>
<th>UK parents’ perception on (n=12)</th>
<th>Chinese parents’ perception on (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>supervisors</td>
<td>therapists</td>
</tr>
<tr>
<td>Not at all</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>A little</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Somewhat</td>
<td>1(11.1%)</td>
<td>1(11.1%)</td>
</tr>
<tr>
<td>Moderately</td>
<td>1(11.1%)</td>
<td>1(11.1%)</td>
</tr>
<tr>
<td>Very much</td>
<td>7(77.8%)</td>
<td>7(77.8%)</td>
</tr>
<tr>
<td>Total</td>
<td>9(100%)*</td>
<td>9(100%)**</td>
</tr>
</tbody>
</table>

*Missing data (n=3); ** Missing data (n=3); *** Missing data (n=5)

5.7 Parents who worked as ABA therapists

Most of the UK and Chinese parents ran ABA therapy sessions for their own child as a parent therapist, with 7 UK parents (77.8%) and 67 Chinese parents (78.8%).

5.7.1 Reasons for being an ABA therapist

Table 5.28 shows reasons that parents who worked as ABA therapists. This is a skip logic question. If answered yes, participants were led to indicate the reasons.

Familiarity with the child was chosen by most respondents, 5 UK parents (83.3%) and 50 Chinese parents (79.4%). A number of parents wanted to improve their skills and knowledge on ABA, amounting to 4 UK parents (66.7%) and 42 Chinese parents (66.7%). Financial reasons weighted with 4 UK parents (66.7%) and 25 Chinese parents (39.7%). A certain number of Chinese parents (n=27, 42.9%) reported the reasons to be the difficulty of recruiting therapists at their local residence.

Table 5.28: Reasons for working as an ABA therapist

<table>
<thead>
<tr>
<th>Reasons</th>
<th>UK (n=6)*</th>
<th>China (n=63)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Familiarity with the child</td>
<td>5 (83.3%)</td>
<td>50 (79.4%)</td>
</tr>
<tr>
<td>To improve skills and knowledge on ABA</td>
<td>4 (66.7%)</td>
<td>42 (66.7%)</td>
</tr>
<tr>
<td>Financial reasons</td>
<td>4 (66.7%)</td>
<td>25 (39.7%)</td>
</tr>
<tr>
<td>Difficulty in recruiting therapists</td>
<td>1 (16.7%)</td>
<td>27 (42.9%)</td>
</tr>
</tbody>
</table>

*Missing data (n=1); **Missing data (n=4)
5.7.2 Types of training received

Half of the UK parent respondents (50.0%, n=4) went for the individual training, while a majority of the Chinese parent respondents (72.8%, n=59) went for the group training (prior to or at the time of responding to the survey (Table 5.29). Individual training meant that individuals took a proactive role in taking, for example, distance learning or private study; group training meant classroom-based training and this usually lasted longer than self-teaching.

Table 5.29: Types of training received

<table>
<thead>
<tr>
<th></th>
<th>UK (n=12)</th>
<th>China (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group training</td>
<td>2 (25.0%)</td>
<td>59 (72.8%)</td>
</tr>
<tr>
<td>Individual training</td>
<td>4 (50.0%)</td>
<td>5 (6.2%)</td>
</tr>
<tr>
<td>Both group</td>
<td>1 (12.5%)</td>
<td>2 (2.5%)</td>
</tr>
<tr>
<td>No training</td>
<td>1 (12.5%)</td>
<td>8 (9.9%)</td>
</tr>
<tr>
<td>Total</td>
<td>8 (100%)</td>
<td>81 (100%)</td>
</tr>
</tbody>
</table>

*Missing data (n=4); **Missing data (n=4)

5.8 Changes after starting the programme

5.8.1 Changes of children’s quality of life

Both the UK and Chinese parent respondents reported that their child’s quality of life was higher than before starting the ABA-based programme (Figure 5.9), i.e., 9 UK parent respondents (100%) and 55 Chinese parent respondents (66.3%) reported being higher and above.
5.8.2 Reasons for changes of child’s quality of life

This is an open-ended question. Hence, it should be noted that not all parents left comments. The inter-observer agreement (IOA) between assessor 1 and assessor 2 is 91.59%. Specifically, the IOA rate of the UK responses is 88.89% and the IOA rate of Chinese responses is 94.29%. The two assessors had reached a consensus to the following themes.

A large number of parents reported their child’s quality of life improved because of the child’s changes. Respondents commented ‘He is [a] happy child now enjoying playing with [his] brothers, doing well at school, enjoying going out, enjoying doing things just like other kids do, e.g., watching TV, DVDs and playing video games’ or ‘He can use an appropriate way to express his thoughts and his needs’.

There were more reasons such as that “professionals’ support”, ‘parental skills improved’ and ‘positive attitudes of the family’ had changed a child’s life quality. For example, there were comments about professionals’ support such as ‘1:1 teaching’ or ‘the intervention helps’; comments about parental skills such as ‘parents no longer follow his (child’s) minds to do things but insisted principles’; ‘When met something he cannot make it, we can teach him how to do it based on our learning’.

Figure 5.9: Changes of child’s quality of life
There was comment about positive attitude such as ‘the attitudes of adults to the child have changed in some aspects’.

The details of responses are attached in Appendix 21.

5.9 Barriers experienced by parents

This is an open-ended question. The inter-observer agreement (IOA) between assessor 1 and assessor 2 is 93.65%. To be specific, the IOA rate of the UK responses is 92.31% and the IOA rate of Chinese responses is 95.00%. The two assessors had reached a consensus to the following themes.

The UK and Chinese parent participants reported some common barriers such as ‘financial constraints’, ‘lack of public recourse’ and ‘misunderstanding towards behaviour interventions’. In addition, Chinese parents reported the barriers they experienced were ‘lack of professional support’, ‘time constraints’, ‘effectiveness of the intervention’, ‘parents’ lack of guidance on ABA’, ‘parents’ psychological pressure’, ‘distance constraints’ and ‘family member conflicts’.

The details of responses are attached in Appendix 22.

5.10 Chapter summary

Findings show that parents report about their child’s diagnosis in the UK and China. Both UK and Chinese parents reported a wait-list for being diagnosed. Parents were self-funding their children’s programme, and government financial support made up only a very low proportion.

Autism organisations were the main source of information for parents about ABA-based programmes, rather than the health care system, especially in the UK. Home programmes were the main service delivery format of ABA-based intervention programmes in the UK. Centre-based or school-based programme were the main service delivery format in China. Over half the Chinese parents had to move away from their place of residence to access training programmes. Many Chinese parents did not know what data-collection method was applied to their child’s intervention.

Communication skill was the area most commonly addressed in children’s ABA-based programmes. Both parents indicated that the skills were well addressed in therapy sessions and improved child’s quality of life. There was a poor incorporation
of school teachers, speech therapists, occupational therapists and psychologists into a child’s ABA-based programmes.

Most UK and Chinese professionals indicated they provided EIBI programmes for families.

It was found that each UK supervisor worked with approximately 10 boys and 2 girls and each UK therapist worked with 5 boys and 1 girl. Each Chinese professional worked with 17 boys and 3 girls. More than half of the UK professional participants rated highly their working skills, but two-fifths of the Chinese professionals reported their skills as low. Around 70% of the UK and Chinese parent respondents ran ABA therapy sessions for their own child. Both sets of parent respondents reported their child’s quality of life had improved after the ABA-based programme.
Chapter 6. Results of qualitative interviews

6.1 Overview
The previous chapter provided an overview of the early ABA-based intervention in the UK and China. This chapter builds on Study 1, by providing an in-depth understanding of children with ASD and ABA under the context of policy, society and culture in family and school settings. A total number of 36 participated in the semi-structured interviews, with a number of 18 UK participants (7 parents and 11 professionals) and 18 Chinese participants (7 parents and 11 professionals). The following research questions were addressed in semi-structured interviews with parents and professionals:

1. What other popular therapies are also used in addition to ABA?
2. What is participants’ understanding towards the children diagnosed with ASD?
3. What categories of the ABA-based intervention programme are used in each country and how do culture, policy and society impact service delivery?
4. To what extent are EIBI services used in the UK and China and why?
5. What are the challenges faced by families?

The following themes emerged from interviewees’ experiences and opinions: (a) children’s diagnosis, (b) ABA-based intervention programmes, (c) ABA and the school setting, (d) ABA in the context of policy, (e) ASD, ABA and societal and cultural contexts.

6.2 Children’s diagnosis

6.2.1 Pre-diagnosis

Generally, parents in this study were the first to notice that their child showed behavioural differences when compared to typically developing children, e.g., in terms of developmental delays, language communication, social interaction, ritualised behaviour and sensory issues.

Table 6.1 presents the age of the child at which the parent interviewees noticed these differences in their child’s behaviour. The average age at which this occurred for UK
children was 15.86 months (SD=9.58), while the average for Chinese children was 24.57 months (SD=10.79).

Table 6.1: Age of child when parents identified developmental delay (in months)

<table>
<thead>
<tr>
<th></th>
<th>Lucy</th>
<th>Mary</th>
<th>Daisy</th>
<th>Rose</th>
<th>Linda</th>
<th>Jessica</th>
<th>Carol</th>
<th>Average age</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>15.86 (SD=9.58)</td>
</tr>
<tr>
<td>At birth</td>
<td>9</td>
<td>15</td>
<td>30</td>
<td>27</td>
<td>12</td>
<td>18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>China</td>
<td>Qian</td>
<td>Xiang</td>
<td>Chang</td>
<td>Bing</td>
<td>Ling</td>
<td>Wuling</td>
<td>Meimei</td>
<td>24.57 (SD=10.79)</td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>36</td>
<td>27</td>
<td>6</td>
<td>20</td>
<td>18</td>
<td>41</td>
<td></td>
</tr>
</tbody>
</table>

6.2.1.1 Comparison with siblings

Five out of the seven UK parent interviewees had more than one child in the family, while two out of the seven Chinese parents had multiple children. Of the 5 UK interviewees, 4 interviewees reported the child diagnosed with ASD being the younger one and they identified developmental delays and differences in behaviour by comparing the behaviour of their younger child with their typically developed siblings. In China, at the time of the interview, the one-child policy had not been relaxed. Both Chinese interviewees who had more than one child reported ASD in their older child.

[The Child] was different when she was born. She was just different to my other children because she cried all the time. She was very difficult to comfort. Because I had two other children I knew it wasn’t normal behaviour.  
(UK mother, Lucy)

Since he was born, [regarding symptoms] something was just not right. And it’s hard then if it’s your first child, you have nothing really to compare it to. It’s just like a feeling that something is just not right. (UK mother, Mary)

6.2.1.2 ‘Grow out of it’ and ‘Great minds mature slowly’

Many of the parents dismissed or underestimated their children’s symptoms. Both the UK and Chinese parent interviewees reported they did not know about ASD until their children had seen a doctor. Some of them mentioned they mistakenly thought that the child’s behaviour would adjust over time, i.e., grow out of ASD.
[When she was] 1 year and three months I found some problems but I did not take it seriously. (UK mother, Daisy)

I started to think about [whether] anything was wrong. We didn’t take him anywhere until he was about 18 months old, because you’re thinking things in your head, and you hope things are just going to correct itself (themselves). (UK mother, Jessica)

[The symptoms] became very obvious at two years of age, but I only suspected he might have some kind of language delay, just spoke at late age. (Chinese mother, Wuling)

When he was diagnosed at two and half years old, I was staying at home for almost one year because I could not believe it and I refused to accept the fact. I was thinking he would grow out of it. When he grew older, he would become better. (Chinese mother, Bing)

The UK parents reported their observations and concerns about their child to their GP and Health Visitor, but this was generally ignored. Both the UK and Chinese interviewees reported that a number of professionals from the health system also lacked knowledge of ASD.

There was no feedback at that time so we had gotten referred to a speech therapist. But he was discharged from that service, [it was] said that he was young and it was typical of his development. I did notice, at 2 years and 3 months say, most words were not particularly clear nor was it making much sense. I did notice at that time it was alarming….Before that I did notice the speech but thought it was alright. (UK mother, Linda)

When he was about 18 months we took him to our health visitor to talk about something that was wrong. I told them I thought he was autistic, [but] they still wouldn’t listen. (UK mother, Jessica)

It’s horrendous…I don’t think there’s a path; a direction of where to go…Nobody tells you what to do. It seems that even the professionals don’t know what to do. The health visitor didn’t really know where to send me. (UK mother, Mary)
In China, parents had similar experiences, but there was a different cultural phenomenon. There is a widely known quote from *the Analects of Confucius*: ‘Great minds mature slowly; Great vessels will be long in completion’. This mentality influenced Chinese parents, particularly children’s grandparents, who were the older generation, when faced with children’s delayed language development.

*I took him to H city for a check. The doctor said he did not look like a child with autism, but definitely had developmental delay, and he made me wait for a while. I waited for half a month. If he still did not speak, I would have taken him to check again. How I wish I could take him for a check earlier! As half a month passed, he started to call Mummy, very clearly. I thought he might be like other people, as said, great mind speak late, so I did not take him for a further check. ‘Let’s see and wait.’* (Chinese mother, Chang)

*Always, the elder people say boys speak late! People around us do have children who speak very late, but become smart later. I never thought such child like with autism would come to my family.* (Chinese mother, Xiang)

### 6.2.2 Diagnosis and the health service

#### 6.2.2.1 UK: Delays in diagnosis

In the UK, children waited for extended periods before getting the final diagnosis, particularly those children whose ability sat between the middle and high-functioning end of the spectrum. For example, Jessica’s son waited for one and a half years until he received diagnosis. It took at least two years for Lucy’s daughter to get diagnosed after she first raised concerns with the Health Service.

*I asked for [the child] to be referred around July 2012 and I got an appointment. She was first seen [in] April 2013. [They said] it definitely looked like autism. There were a lot of indicators and they would diagnose it. And they diagnosed her in November 2014.* (UK mother, Lucy)

Table 6.2 shows the average age of UK children was 38.43 months (SD=5.31) at diagnosis, while the average for Chinese children was 40 months (SD=11.45), which

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23 In Chinese: 贵人语迟，大器晚成
means the UK sample’s children with ASD were two months younger than the Chinese children of this study.

Table 6.2: Children’s age when diagnosed (in month)

<table>
<thead>
<tr>
<th></th>
<th>Lucy</th>
<th>Mary</th>
<th>Daisy</th>
<th>Rose</th>
<th>Linda</th>
<th>Jessica</th>
<th>Carol</th>
<th>Average age</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>48</td>
<td>45</td>
<td>34</td>
<td>36</td>
<td>36</td>
<td>37</td>
<td>33</td>
<td>38.43</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(SD=5.31)</td>
</tr>
<tr>
<td>China</td>
<td>Qian</td>
<td>Xiang</td>
<td>Chang</td>
<td>Bing</td>
<td>Ling</td>
<td>Wuling</td>
<td>Meimei</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>38</td>
<td>60</td>
<td>53</td>
<td>30</td>
<td>28</td>
<td>30</td>
<td>41</td>
<td>(SD=11.45)</td>
</tr>
</tbody>
</table>

With regard to the diagnosis procedure, UK parents reported it took a long time for the panel of health service staffs to discuss whether or not to give the child a diagnosis of ASD. The child would be referred to paediatricians and speech language therapists (e.g., Mary’s son), educational psychologists and nursery nurses (e.g., Jessica’s son) for a diagnosis.

*A lot of testing times and nobody [is] there to tell me, so I was feeling very down.* (UK mother, Linda)

*So they had us take him to lots of different groups, and then things still weren’t working. And they sent different professionals to observe him, like, educational psychologist, speech therapist, nursery nurses; and then what they do is they wait for everybody to have done their own report, and then they get everyone’s report and compare them. Different professionals do different reports. They send them all to this panel and the panel reads them all. And I feel like somebody who has never met him decides whether he is or he isn’t. That’s what the process is. It really shouldn’t take that long. That process should take 2 weeks. But, lots of different people [were] making different appointments… we got the workloads…* (UK mother, Jessica)

The report and long discussion of the final diagnosis delayed children’s opportunities for early intervention. During this long procedure, there was also a lack of guidance on how to deal with children.
The Health Trust doesn’t mention it. They didn’t tell us about that [ABA] but they didn’t tell us about any other interventions either, because [the child] was not completely diagnosed initially. They don’t give you any information about autism and things you can do to help because they say they don’t want to send you down the wrong path, if it doesn’t turn out to be autism. But I think they should give you the information anyway on what you can do to help. Not even a leaflet about autism- so you’re kind of left after the first appointment where they say ‘there is a problem but we can’t say today that it is autism but it looks like autism’. They don’t actually give you any information so you’re left for a long time just trying to find out for yourself.... They were so negative about her, telling me there was a problem but not giving me any guidance as to what to do. (UK mother, Lucy)

6.2.2.2 China: Exclusive tests to determine diagnosis

In contrast, the diagnosis in China was gone through with procedures of elimination in hospitals. Due to a lack of expertise in regional areas of China, children would often undergo a range of tests on the physical functions of the body, for example, Hearing Screening (HS)\textsuperscript{24} and Magnetic Resonance Imaging (NMRI)\textsuperscript{25} on the brain, with no clear diagnosis. Therefore, children were generally brought to a major city for diagnosis by experts. Lihua, an experienced Chinese professional from Beijing AC School, said that she had seen lots of children who came to AC School with different diagnosed names, such as ‘autistic features’ (zibizheng qingxiang), ‘suspected autism’ (yisi zibizheng) or ‘autism tendency ’ (zibizheng bianyuan)\textsuperscript{26}. The diagnosis by a doctor was very quick, about 10-15 minutes. In particular, high-functioning children were not given a definite diagnosis. For example, Xiang and Meimei’s children were diagnosed as ‘suspected ASD’, because their children’s language was good, but they displayed difficulty in social communication. The ability to maintain eye contact and to talk with people placed Xiang’s son on the higher functioning end of the spectrum.

\textsuperscript{24} In Chinese 听觉筛查
\textsuperscript{25} In Chinese 核磁共振

183
He is not as obvious as the others. He is able to hold eye contact, able to converse and has some social skills. If he is in a good mood, he can talk to you and knows what he is doing. When he is not, that is when we have issues and he would grunt or growl. He is not like lower functioning children who would avoid your gaze and be completely aloof. (Chinese mother, Xiang)

We did both (HS & NMRI), and (the child) was fine. We spent thousands money on a variety of checks, but they were fruitless, everything appeared to be normal. (Chinese mother, Bing)

What they were using [methods of diagnosis] was a process of elimination. Exclude other conditions, nothing else, then, only left one possibility [i.e., autism]. Then we took the child to Beijing S hospital, an authoritative hospital in China. The expert said it looks like autism. Until now, his Dad was thinking whether or not our boy was on the autism spectrum or just had a developmental delay. (Chinese mother, Meimei)

I was very worried, my child was diagnosed as autistic disorder at the Women and Children Hospital of D city, but the doctor drew a question mark beside it. I asked the doctor what does that mean? The doctor answered: he might be [autistic] or might be not, but he definitely had a delay in language, but [the doctor] could not give a definite diagnosis [of ASD]. (Chinese mother, Chang)

Because of the long process of looking for a doctor to get a diagnosis, most of the UK and Chinese parents said that they did not wait for the final diagnosis before sending their children for training or treatments. For example, UK mother Lucy said: ‘I already made all the decisions prior to the final diagnosis. The Chinese mother Xiang said,

The doctor told me he is either Asperger or high-functioning autism. I felt like it could be counted as a diagnosis and I did not need an exact name for it. I was not concerned about which one in these two it was. There is no meaning to me. He is already like this. I think what he needs is to get the training, to learn to adapt to the society, despite the diagnosis. (Chinese mother, Xiang)
6.2.3 Post-diagnosis

Both UK parents and Chinese parents tried many ‘treatments or therapies’ in the post-diagnosis period.

In UK, there was also a lack of health services for children with ASD. When comparing children with ASD to children with other disabilities, the health service system could not adequately handle the needs of children with ASD and was neither able to provide a timely diagnosis nor adequate treatment services. For example, Jessica compared her youngest son, who was diagnosed with ASD, to her oldest son who was diagnosed with diabetes.

\[\text{When [the older child] got diagnosed with diabetes, we came home with lots of information; we came home with after-hours numbers to call in case of emergencies, lots of support.}\]

\[\text{I think the NHS is terrible. When [the younger son] got diagnosed, he saw a paediatrician. She more or less said: ‘Just discharge him’. ... It is like: they are autistic; there is nothing anybody can do, go home and deal with it. (UK mother, Jessica)}\]

Jessica reasoned that the discharge recommendation was made due to the paediatrician’s having little knowledge of ASD. Most parents noted that after their child was diagnosed with ASD, few professionals from the health service were able to direct them regarding what to do next and where to go.

\[\text{Delays and lack of resources, so basically you will have to figure it out yourself. (UK mother, Lucy)}\]

Parents themselves spent much time finding any approaches that might work for their child, even those from the internet which was not evidence-based. UK parents reported trying a wide range of intervention approaches.

All of the UK parents of this study said their children received free speech and language therapy from the NHS.

\[\text{He had a speech therapist come once a month for 30 minutes. She is not helpful, completely, not helpful for him. (UK mother, Daisy)}\]
It was more like play therapy, and teach her [the child] to do something and then you can get her to do something else. Just to get her to comply. About 6 months of the speech therapy was getting her to sit in her seat and doing what they were asking her to do, because she was not interested in doing anything anyone wanted her to do. (UK mother, Lucy)

Hyperbaric therapy, oxygen therapy and diet were also used by some parents.

We tried Hyperbaric Therapy and Oxygen Therapy. He quite enjoyed that; he liked going in the oxygen chamber. He used to sit there for a full hour with the oxygen on his head and he quite liked it. I do not know whether it gave him any benefit, I am not sure. We did a trial of that. He also had a dairy and fruit diet, but we did not feel like that had given us any different results. (UK mother, Jessica)

Some parents took their children to Occupational Therapy (OT), Speech and Language Therapy (SALT) and Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH).

I tried SALT and OT, and TEACCH, all rubbish, that’s rubbish, did not even touch it, did not help at all, useless. OT, in particular, I found just, it’s very sweet; it’s like a PE lesson... But it’s nothing to do with making the autism better. It’s just a myth. And the speech [and] language therapist, we hired her privately for a year, and after around 6 months, she looked at me very sadly and said, your boy will never speak, I am afraid. [The speech language therapist suggested that] we had better go to sign language. The TEACCH School I sent him to be utterly useless, and it was just baby-sitting. (UK mother, Carol)

The use of art therapy and music therapy were also reported.

If there are other interventions, it’s usually been things like painting [art] therapy and music therapy, all the things that we know do not have any facts. It’s more like nice things you are going to do, but I don’t think it actually works. (UK ABA therapist, Nancy)
One instance of Rapid Prompt Method (RPM) and medication treatment was reported by a UK professional.

One of the families is starting to use RPM, if you have heard of that. It looks like assisted communication with keyboard. There was not much evidence behind it. It’s quite hard to explain to her [the mother]. Some of them had medication to control. (UK ABA tutor, Betty)

In China, children with disability were mostly cared for by their family. Also, professional interviewees said that children who had severe symptoms mostly stayed at home, and children who were between middle- and high-functioning were taken by parents for ‘treatment’ or training. Another difference is that, some of the families believed that there was a cure. ‘Parents regarded training as a cure,’ said Chun, the founder of Beijing AC School. Such a ‘cure’ included behaviour and non-behaviour therapies. Some of the Chinese doctors even suggested medical ‘treatment’. As a result, parents spent a large amount of money looking for a ‘cure’.

Just like my husband said, believe me, he would recover! They all said I was the one who was sick [rather than the child], [because of constantly] taking the child outside looking for a treatment. (Chinese mother, Chang)

Chinese parents mentioned that they tried sensory integration, auditory integration, ABA-based intervention, music therapy, arts, and medical therapy. Professional interviewees reported that many autism organisations put forward PCI (Play and Culture Intervention) and RDI (Relational Development Intervention) therapies. The Chinese founder, Dong mentioned that one of her students was taken by parents to try SCT (Stem Cell Transplantation), despite SCT being banned nationally. In her words,

The parents were told to try this and try that, try a lot of different things to find effective treatments. I think it’s not uncommon to spend two or three years to find out what’s wrong with the child, and then spend four or five years trying every method they hear about. As a result, they miss the best time for intervention and parents give up. What’s worse, they have tried methods already superseded, such as auditory integration. (Beijing DC School, Dong)
When I was in the Maternal and Child Health Care Hospital of D city, the doctors suggested to me to inject mouse Nerve Growth Factor (NGF), cerebral protein, to try sensory integration, something along the lines of brain wave or magnetoencephalographic (MEG)... He [the doctor] suggested I get on the wait-list. I still am [on the wait-list] right now. Then I went to the Children’s Behavioural Development Centre (province-level hospital). The doctor only prescribed some medication, some sort of syrup, said to be good for the brain... He later prescribed cerebral protein... If the treatment is effective and my son can be like other typical children, could go to school, I will do that... I feel it is a scam. (Chinese mother, Chang)

It was reported by parents that they tried every approach and got lost in the end. This long journey delayed the use of effective interventions.

6.2.4 Accessing ABA-based intervention

6.2.4.1 UK children accessing ABA

Parents and professionals reported that professional from NHS did not have sufficient knowledge about ABA-based intervention and it was also not recommended by NHS. Parents found ABA through the internet and ‘it is usually the last thing that comes across... there are a lot of parents that come to me [and] say they [are] completely lost what to do,’ said Jane, a UK professional.

One of the mothers, Lucy, said that she made her decision prior to the diagnosis by researching and finding that ABA might be effective for her daughter. Another mother, Mary, started an MSc ASD course at a local university, in which she learned that ABA is an evidence-based approach.

All parent interviewees said they applied the ABA-based intervention programme for their child because they found out other therapies did not really work.

The UK mother Rose reported that she took her son to different interventions when he first got diagnosed. At one organisation, he spent 12 weeks to be taught to sit.

* * * ABA seemed the only intervention that had some, like, scientific proof behind it. And it seems, for us, the only intervention that shows the best results. That’s why we went towards ABA. (UK mother, Rose)
Linda hired a speech therapist for around a year for her son.

*I thought earlier [that] when his speech was alright, his problems would be over, but it's not like that. The speech improved quite quickly, but his communication problems were still there, socialising problems were still there so the behaviour hasn’t changed. So we started ABA therapy. ABA is the only way we're using now. The school is also applying other things, with the non-behavioural things, but we do ABA.* (UK mother, Linda)

*[The speech language therapist] just did not appear to know how to motivate him to speak, she did not appear to have the tools, and I think actually she gave me the boost that I needed to try ABA.* (UK mother Carol)

Linda, Rose and Carol all noted that the speech and language therapy helped the child to learn language, but was not able to help with their social communication and social interaction skills. In the end, they all accessed ABA-based intervention programmes.

### 6.2.4.2 Chinese children accessing ABA

ABA-based interventions came to China later than the UK. The founder of Beijing AC School, Chun, is regarded as one of the first to bring ABA-based interventions to China from the USA. AC School sent many teachers to America to visit autism organisations and to undertake training in ABA.

In contrast to UK practices, diagnosticians in hospitals recommended ABA-based programmes to parents. The Chinese mother Ling said that the Daifu (doctor) urged her to take the child for training. Ling said, *'he presented me a list of organisations and recommended me to choose one of them.’* Meimei also added:

*No matter whether my son was diagnosed as ASD or other developmental Disorder, [I think] learning ABA is not wrong. ABA is not only for children diagnosed with ASD, but for everybody.* (Chinese mother, Meimei)

The majority of the parent interviewees knew about ABA through the internet, TV broadcasts and public lectures. The Chinese parents knew that ABA would help their

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27 Daifu (in Chinese: 大夫) is a general term for a medical practitioner regardless of whether they practised Chinese or Western medicine.
child. Just as Chinese mother Chang said, ‘after diagnosis, parents like me often had an attitude that the child was taken there for training. He would become better after this’. Three out of the four Chinese founders expressed the same opinions as Chang. The founder of Beijing BC School, Jing, claimed that parents expected their children to change totally in a very short period of time, but professionals could not guarantee a speedy progress.

*I believe that even [if] the top ABA experts come, the outcome will be the same, because in addition to techniques, he [the ABA expert] also needs the time [to work with the child].* (Beijing BC School, Jing)

Meiyin, the teacher of Beijing AC School, further pointed out that for children who were within the mid- or high-function spectrum of autism disorder or Aspergers Syndrome (AS), parents would try harder to make their children appear like typical children.

*The parents had another point of view: If my child’s IQ is not high and my family not rich enough, then why would I train him?! No matter how much he was trained, he would still be a ‘shazi’ (stupid person)28. Some parents thought that by putting effort into taking the child for training, the child would recover.* (Beijing AC School, Meiyin)

The founder of Beijing AC School, Chun, added her opinion that ‘they [parents] have to know that ABA is helpful for children to learn to adapt to the society in the future rather than curing their children’. Many Chinese professional interviewees expressed their pressure over the difference between the parents’ expectation and the reality.

Finally, the educational quality of ABA-based intervention services in China varies greatly. Many teachers of AC School said a number of parents had taken their children to different organisations before coming to the school, and some of them learnt lots of incorrect knowledge about ASD and ABA.

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28 Shazi in Chinese: 傻子, means stupid and foolish.
6.3 ABA-based behaviour intervention programmes

6.3.1 UK ABA-based programme

6.3.1.1 Home-based programmes of professionals-led

Home-based programmes constituted a large proportion of service delivered in the UK. Specifically, 6 out of the 7 parent interviewees said their child was undertaking a home-based ABA programme and 9 out of the 11 professional interviewees were providing home-based ABA programmes for families.

The role of supervisors and therapists was clearly differentiated for home-based ABA programmes in the UK. A supervisor, either a BCBA or an experienced consultant who was working towards BCBA accreditation, designed the curriculum of the programme (IEP), defined the targets, and assessed the child. The therapist/tutor worked on the IEP and delivered the ABA-based intervention programme for families. The short-term and long-term goals of the programme were well-defined. ABA therapists/tutors all stated that the supervision by an experienced supervisor was necessary and very useful.

The supervisor has a lot of experience working in the school, working with parents, working at different organisations. They have the real knowledge [on what needs to be done, so that] parents [who] want their child to go to mainstream schools [can do so]. I’ve learnt a lot from my supervisor in the past 6 months. (UK therapist, Jane)

The number of supervision hours received by therapists depended on the family’s arrangement with supervisors. Jane reported that she received 2 hours of BCBA supervision for a family she worked with and Nancy received 3 hours of BCBA supervision through working with one family. A therapist/tutor’s job was to work with the child directly and to record data on the child’s progress.

Based on individuals’ needs and motivations, professionals utilised different techniques within the science of ABA, such as non-verbal imitation, labels, receptive to instructions, matching, and self-control. Programme supervisors of UK interviewees also tried to make the programme more individualised and meet the family’s needs.
We would tailor our behaviour programmes for life to that which can be done instantly rather requiring than sitting at all day... if a family said to me I am in the middle of the force I cannot do all of that, I will give them some small target until I see them again because I want to give them something to keep them going and they need reinforcement that they can make change with their child’s behaviour too. (UK BCBA, Jennifer)

Generally, the ABA-based programme was play-based and structured. Parents wanted the child to become independent and allowed to function within society.

Social skills, turn taking, communicating with peers, imitation, saying hello, greeting people. [We] used a variety [of techniques], like differential reinforcement of different behaviour. (UK therapist, Karen)

[Programmes] mostly were communication things, increasing independent skills, dressing, toileting, mostly daily skills, DIT, incidental teaching, chaining and task analysis and reinforcing the contingencies. His [the child] communication skills [need improvement]. When he was angry, [and] he wanted something and cried, [I] just gave him a more functional way to communicate his needs. If the target behaviour is communication, we want him to functionally explain when he wants something. It’s more about reinforcing because he is getting the things he requested. He is quite good at explaining why he is upset. That helps if we see a tantrum. He can tell us now, instead of [the] negative behaviour we did not want to see beforehand. (UK therapist, Jane)

The number of hours delivered at home-based programme varied because majority of UK parents had to self-fund their child. Jane said she provided 4 hours per week for one of her families in Northern Ireland. Nancy worked in England and one of her students’ programmes was up to 20 hours per week. Karen and Sharon worked together for Jessica’s son for 25 hours per week as Jessica received funding support from the local authority.

Yet, parents were concerned with their child’s social communication, social interaction and generalisation problems because learning mostly occurred at home in the home-based ABA programme.
But the area I've expressed concern [about] is her social skills. And it’s hard to practise those in the environment. You need to be out with other children to practise that and it’s one of her biggest deficits ... You can’t do that in a false environment. She just needs to learn social skills at nursery and [in] her day to day life. I think a smaller one [group] where people are aiming [to work on social interaction] would help. (UK mother, Mary)

Mary raised an important issue of generalisation. The English tutor Karen said: ‘when the child [has] mastered the programme, we can then generalise’, which means generalisation across other people in addition to therapists and generalisation across other settings outside the home.

Home-based programmes usually took place after school, and sometimes combined with school settings. Parents preferred to combine mainstream school/special needs school with home-based programmes. For instance, Jessica indicated her child was having 15 hours per week at school and 25 hours per week of home ABA-based programme, ‘because the school provides a chance for social interaction and communication’. In home-based programmes, parents could also listen to and observe the on-going session between the professional and their child.

Some parents would ask the therapist to work with their child at school so as to generalise the learnt skills, especially social skills, to a school setting. However, due to the lack of understanding and knowledge of the science of ABA in schools, some schools did not allow behaviour therapists to enter. This phenomenon will be illustrated further in Section 6.4.

Data collection is a very important part of the home-based ABA programme. Professional interviewees took data before, during and after the intervention for a targeted behaviour.

For example, a swiping behaviour, swiping stuff on the table, I just keep a note in my diary to see the numbers during the session. If it’s been a problem across a few weeks, you know you need to do something trying to stop it. If she had this behaviour again, she has to pick it up and give a track of it, and to see if the number [data collected of swiping is] going down. (UK therapist, Jane)
6.3.1.2 Clinic-based programmes of professionals-led

Two different types of centre-based programmes will be described in this section, i.e., one was mainly providing supervision services in Northern Ireland and the other was providing on-site training programmes in England.

NIU charity, as introduced earlier (ref. Chapter 4-Sample Site), is a parent-led charity with 4 BCBAs which provides consultation and regular supervision services for families who run home-based ABA programmes, and hold ‘playday’ activities for families once a month. Similar to home-based ABA programme, the BCBA certified supervisors would go to a family’s home, child’s nursery and school to assess the individualised programme.

The skills across different settings were addressed in the programme to meet the child’s needs. An IEP was written which involved interviews with parents and observations of their child. Parents hired individual therapists to work on the IEP. BCBAs of the NIU charity provided supervision for both therapists and the child. For example, Jane (therapist) was hired by Lucy (mother) to work with her daughter under the supervision of Jenifer (BCBA). In addition, data collection was conducted along with the programme so that the supervisor was able to update the programme as the child progressed.

In NIU charity, ‘Parents are the main stakeholders’, said Jenifer (BCBA). Parents contacted the charity and were offered two-hours of home-visit sessions. These visits occurred fortnightly or monthly, depending on parents’ request. They worked closely with parents and organised workshops on the science of ABA for those parents who wanted knowledge or to train their own child.

However, NIU charity did not provide on-site programmes, as Jenifer said: ‘we did not have a specific structure or guidance/model, if we were a clinic or based in a school, we would follow that instruction, but we worked at home’. Limited by parents’ abilities to meet costs and professionals’ time, they were mostly able to provide supervision once a month.

[The service was] good. [They were] very strict on how many people they can employ and strict by time. I think they have got a hard job, [but] they are
doing a great job. If there is more funding, they will be able to do more. (UK therapist, Jane)

Unfortunately, once we leave, it’s up to the parent. The parent is paying for the services themselves as well. They have to deal with it. (UK BCBA, Jenifer)

Because of a lack of sufficient government funding in Northern Ireland, parents have to pay themselves.

We definitely [do] not overcharge parents. We are also under the pressure in terms of how much supervision we can offer because we have so many families. (UK BCBA, Laura)

Many centre-based programmes provided on-site services in the UK. For example, the English mother, Linda, mentioned that her family lived in Sheffield but the service provider was in Leeds. They had their own therapists in Sheffield and travelled on-site to the centre at Leeds every two weeks for supervision. In addition, Linda said the programme also involved a consultant who came from the USA, providing supervision twice a year.

6.3.1.3 School-based programmes of professionals-led

Carol’s son was enrolled in an ABA school in England. She reported that there were 8 schools that provided pure ABA or ABA-based educational training for children diagnosed with ASD in England. Carol’s son was on the severe side of ASD. Her son started ABA-based intervention at 3 and a half years of age at home for 3 hours a day which subsequently increased to 6 hours a day. Then he moved to mainstream school part-time, with an ABA trained shadow and had the rest of the day at home from 4 to 7 years of age. However, her son found it difficult to cope in mainstream school, so she had to fight for a place in a full-time ABA school. The council eventually agreed to pay for her son to go to a full-time ABA school for 35 hours per week. This school was like a Special Needs Education (SEN) school, but used the science of ABA and employed ABA professionals. The ABA school was play-based and Verbal Behaviour was used predominantly.
In Britain... you could not just rent. People move, it’s like ABA tourism. Although people move to get into the catchment area of these schools, you still have a legal battle to get into these schools, and largely speaking, you have to have evidence that ABA works if you privately do it. Essentially, it’s only the rich people who get ABA. (UK mother, Carol)

This school was like other typical schools but embraced the ABA methodology for teaching. The school had PE, arts, sports, lunch and regular breaks. The programme was self-motivated and play-based. This programme was less intensive than full ABA-based programmes and included OT and SALT.

In Britain, you would not get an ABA school approved if it’s all intensive, because you get monitored by of-state, and of-state have to see the kids get breaks, they get PE, they get play time, they do a national curriculum as well as ABA, so what the school has done is very cleverly brought ABA into the right normal educational system... It’s not like sitting at a table and doing ABA all day. No way! But they [the school] do have one-to-ones and they do have BCBAs in charge. Also, they do OT and SALT in that school too, just because over here, for some reason, they love OT and SALT, so that school thinks, oh, well, I just do it to shut them [government monitor] up. (UK mother, Carol)

This school provided educational services up to 19 years of age. After that, parents might send their child to an ABA College.

The Treehouse has started a college called Ambitious College. Those parents who started the school realised we need something till 25 as well, so I think gradually, more colleges will spring up using ABA as the tough parents like me are starting to get older kids. (UK mother, Carol)

6.3.2 Chinese ABA-based intervention programme

6.3.2.1 School-based programmes of parents-focused training

Beijing AC School is a parent-focused educational NGO, which was started by Chun (See Chapter 4 Methodology-Sample Sites). This school initially started with children-focused training in 1993, developing into parent-focused training in 1995. The preschool sector aims to provide training for parents whose children are
diagnosed with ASD (aged 3-6, up to age 7 on some occasions). It offers entry-level knowledge of ABA-based intervention for parents through an 11-week long ‘crash course’. The other sector of AC School, the teenage sector, was not included in this study.

Due to the shortage of quality ABA services in small cities and other provinces of China, the majority of parents studying at Beijing AC School were from across the country. In order to get study at AC School for around three months, parents would rent temporarily near the school. Parents were required to bring their child into the classroom. The 50 students were divided into 10 classes, based on their level of function.

*Though one teacher supervised ten students in a classroom, actually it was a one-to-one [mode] because parents supervised their child. We were training the parents, and used the power of parents [to supervise their child].* (Beijing AC School trainer, Meiyin)

In these 11 weeks, children would first be observed and assessed for two weeks and then the teacher would develop an IEP for them. Teachers discussed the IEP with families. Parents studied and practised ABA theories and techniques for 8 weeks. The final week was for further evaluation and to develop the Individual Family programme (IFP).

Beijing AC School was regarded as one of the best organisations in China. The interviewees of Beijing AC School said that it is impossible to have a one-to-one training like the Western countries.

*The model of service delivery at our AC School is unique, because there are no other countries in the world similar to China. When attention was raised about the needs of people with ASD, the social welfare policy, educational system, professional structure of the country [and] personnel training were all not ready.* (Beijing AC School founder, Chun)

In addition, Chun pointed out that the existence of AC School was influenced by China’s unique culture and social structure. Chun believed that the aim of the ABA-
Based intervention is an ‘acclimatisation training’\textsuperscript{29}, because parents expected their children to return to mainstream schools after these three-months. The preschool sector created a mainstream environment where students were trained to follow classroom disciplines and communication norms around peers. Similar to a mainstream classroom, for example, students needed to sit for a class (45-minutes), were required to keep quiet and to listen to the teacher.

The school teacher at AC School, Chow, realised the problem in what some parents called, ‘table training’\textsuperscript{30}.

\textit{Children diagnosed with ASD not only need to learn [parents’ demonstration], but also need to sit together with parents for 45 minutes. These 45 minutes [are hard enough] for typical children, let alone children with ASD.} (Beijing AC School, Chow)

Nevertheless, Chow reasoned that the public need to see Beijing AC School as a transition from small group to mainstream school. The idea of transition to mainstream school was embedded in the service delivery. AC School also incorporated music and group activities, which were claimed to be under the principle and guidance of ABA because children were taught to listen, to observe and to socialise with other children. In addition, Chun talked about why parents were emphasized in the programme.

\textit{[The Chinese culture] If one family member is sick, it is the family that takes care of him/her, to spend the money … and has nothing to do with the society. With people diagnosed with ASD, there is no one else, except their family …willing to take care of him/her.} (Beijing AC School founder, Chun)

This focus on transition may exclude those who have severe ASD who may be kept at home as they may not be able to keep up.

\textit{Neither the high function students nor low-function were easy to teach. The high-function class may focus on learning projects [learn new skills], while the low-function may focus on emotional management and problematic behaviour management. For them [low-function children], the learning

\textsuperscript{29} In Chinese: 适应性训练
\textsuperscript{30} Chinese parents called: 小板凳训练
In contrast to the Western ABA professionals, teachers at AC School seldom collected data. One important reason was that AC School provides parent-training, so teachers did not pay attention to data collection on the individual child. Instead, parents were required to submit recorded videos of them practising the learnt techniques with their children to serve as data collection. The parents were asked to keep a record of the percentage of correct responses when working with the child, the frequency of prompts used and other relevant data. The next day, a teacher would check the video against the parents’ records. Though they did not have a clear statistical description of children’s development in the IEP, they used the video to evaluate students’ changes in participatory ability, imitation and understanding ability, language and academic skills. The USA trainer, Kate, further explained that the length of the course, parents’ financial situations and the large number of children all impacted on data collection.

*Autism is a life-long disability ...but the problem in China [is that], there’s no government funding. The Beijing AC School has 3 months. A lot of them [schools] are short-term, you do not have the time to take the data and look [at] the long-term of the child’s progress. Coz you see them for three months, Goodbye, then you get new students, goodbye, then new students... there is not follow-up with the kids because it’s expensive. There is some reimbursement, but it’s not enough...There are so many children. The workload is so heavy... It is hard to imagine the way you do it in the UK or the way we do it in the US. (USA trainer, Kate)*

Teng also talked about the teaching load being a factor. The head teachers not only have to teach parents but also maintain order in class, which distracts them from data collection.

The majority of parents waited for around a year to enrol their child at Beijing AC School. For example, Xiang (from Hunan province) asked temporary leave from her job to take her son to this school.
The professionals of Beijing AC School reported the service delivery at the school as being very systematic and mature. Discrete Trial Training (DTT) is the main teaching approach. It was not until the 8th week of the course that teachers would teach the knowledge and technique of chaining, shaping and generalisation.

Parent interviewees also expressed their concerns about the school’s high expectation on parents. However, the extent to which desired results were achieved was questionable.

_I was most dissatisfied with the insufficient planning for the one-to-one [parent and child dyad practice] despite attending the parents-focused training every day. The child had already been sitting in the school for a whole day and he needed to relax at home, so I prefer using the natural environment, to prompt him to speak, to ask something by himself._ (Chinese mother, Qian)

Input of other ABA-based interventions, such as Natural Environmental Teaching (NET) and Verbal Behaviour (VB), were urgently needed. The mother, Xiang, held the same opinion and wanted to teach skills in a real environment rather than on the table. In addition, the classroom environment was sometimes perceived by parents as having a negative impact.

_He started to imitate others. For example, when some other children screamed, suddenly he heard it and would also scream. It [imitation] happens very quickly... I could not do anything to stop him._ (Chinese mother, Xiang)

The teachers of AC School also identified this issue but argued that the classroom setting is more beneficial.

_If the children are placed in a natural environment, other problems are going to arise. What the parents learnt here is how to deal with children’s problematic behaviours as they are arising. If the parent did not have a good knowledge of generalisation, he could not sort problems out when back home. For example, he might have forgotten prompt, reinforcement after finishing the three month period time of learning. That is a hard nut to crack._ (Beijing AC School, Teng)
Many professional interviewees, like Teng, commented on the multiple roles of parents of children with ASD at AC School. In China, parents had to take the role of ABA therapist in addition to being the main caretaker of the child in daily life, which overburdens them. Some of the parents lack formal education and found it difficult to understand the science of ABA. One of the students was accompanied by his grandmother who was illiterate.

6.3.2.2 Clinic-based programmes of professionals-led and parents-assisted

Jing, the founder of Beijing BC School, said that there were 60-70 children who came to the training programme over three and a half months. There were different classes including individualised ‘ABA’ training, sensory integration facilities, arts and PE. The individualised training is ‘ABA’-based table work between a teacher and a child where parents do not need to come. While in ‘parents and children class’, parents were required to come with their child. Beijing BC School provided training for parents on ABA on Friday afternoons.

*We are all based on the principles and techniques of ABA: using this, we can create different kinds of classes. In the individualised training, we use the methods and techniques of ABA-based intervention, while other group classes are also based on the principles of ABA. It doesn’t matter what you call it, the key is that we target the main characteristics of ASD and blend the techniques and principles of ABA.* (Beijing BC School, Jing)

It is worth mentioning that autism organisations, like the Beijing BC School, were not rare in China. The majority of the parent interviewees had taken their children to more than one autism organisation. Before they accessed the training programme at Beijing AC School, Chinese mother Qian’s daughter trained at three other autism organisations; Wuling’s son and Ling’s son had been to two other organisations; Xiang’s son, Chang’s son and Bing’s son had been to one organisation previously. Meimei’s son was the only child who came to Beijing AC School directly.

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31 The reason to give a quotation mark is that some autism organisation used the DTT (mainly), PECS and PRT, or part of these techniques in the programmes, but they considered they were undertaking the ABA-based intervention. Due to a certain number of such organisations in China, the terminology used by these organisations is retained in this study.

32 ‘parents and children class’ in Chinese 亲子班
Parents’ experiences in previous training programmes were similar (Wuling’s child and Ling’s child in Shanxi province, Qian’s child in Beijing and Xiang’s child in Hunan province), i.e., individualised ‘ABA’-based intervention was not only used in a stand-alone class but also integrated into other classes, such as using facilities of the sensory integration class, music class, arts class, fine motor skills class (to practise with fingers such as stringing beads). Parents were asked to act as an assistant, for example, to help with their child’s lunch or to take the child to the toilet and to assist the child’s interaction with peers. Each class was 30-35 minutes. Some parents (e.g., Wuling’s child’s and Ling’s child’s programme) reported they were allowed to watch the individualised ‘ABA’ training between the professional and child, but some parents (e.g., Xiang’s child’s programme) reported that they were not allowed to observe the session.

[I took my son] to an organisation in Shanxi province. It provided individualised [‘ABA’] training sensory integration, fine motor and play therapy. ‘ABA’ was done as individualised training twice a day. [I could] watch the session, but [they seldom] explained how and why something was done. [I felt they were] not professional. [Different therapies were] all mixed. Sensory integration is [playing with] facilities [e.g., balls, swings and slide]. It was said to influence the child’s mind. (Chinese mother, Wuling)

I feel what they were using was not ABA. I think the teaching methods were messy. It might have some elements of ABA, but also has TEACCH, structured stuff such as following the flow charts of images on the wall. But when you ask about specifics of [the programme], everything was messy. (Chinese mother, Bing)

Parents reported that teachers who worked in those autism organisations were not professional. Some mothers really wanted to learn ABA to help their children.

I did not know what to do. I was directionless. You stood outside [the classroom] and saw the teacher in class with the child for half an hour, but you were standing outside and not inside... I imitated everything and did the same as with my child when I got back home. However, as time went on, I did not know what to teach. There was no methodology, no theoretical basis, just blindly copying what they did. (Chinese mother, Bing)
After learning ABA systematically at Beijing AC School, parents such as Bing and Chang said that they would not send their son to such autism organisations, but perform intervention themselves.

Due to the lack of quality teachers at some autism organisations, parents did not see appreciable changes in the child after the ‘ABA’-based intervention and said it was a waste of their time and money. Lihua of Beijing AC School mentioned that teachers also found some children picked up problematic behaviours from previously attended organisations.

*You would find out during the entrance assessment [of Beijing AC School] that some of the children had attended [some low quality autism organisations] for one or two years, [but they] had not learnt how to sit, and displayed many problematic behaviours, such as no quiet hands [when working with teacher] and no eye contact. I cannot understand what the child had done in the past two years, and parents said they did not know either. ‘The child was in those organisations, doing individualised [ABA] intervention!’* (Beijing AC School, Lihua)

### 6.3.2.3 School-based programmes of professionals-led and parents-assisted

Qingdao EC School is a school-based organisation founded by Zheng in 2000, which mainly uses individualised one-to-one ABA training. Sensory Integration, music training, play training and situational training are used as supplemental techniques. A total of 150 professionals worked at EC School full-time, at whom 5 of them were BCaBAs.

Approximately 300 students were enrolled at the school for a duration of around three months. Zheng said that each student would have an IEP and the students were classified based on their age and ability. Students with a higher ability would be given more academic learning, such as maths and language.

*If one equates ABA with DTT, I think that is an affront to ABA. DTT is the most fundamental part in ABA that we have to learn. DTT emphasises, giving simple stimulus, performing errorless teaching, and most importantly breaking down tasks, Tasks need to be divided into teachable components if a child feels the task is too difficult. We need to be clear that if the child cannot*
perform the required task, you need to give a prompt, either physical or vocal, but you also need to later remove the prompt (when the child can complete the task). When the child completes a task very well, we need to reinforce him/her immediately. The reinforcement should change as the child progress, moving from primary reinforcement to secondary reinforcement. The child would take this in and completely accept this, which is encouraged by us. For those students just entering our EC School or those students who are on the low-function of the spectrum, we definitely use DTT. For those high-functioning students, we definitely generalise their learnt skills. Generalisation feeds into Natural Environmental Teaching (NET). If there is no generalisation, then the learning doesn’t extend to the natural environment. We can have incidental teaching anywhere and everywhere, especially for VB. (Qingdao EC School, Zheng)

Zheng noted that it is necessary to use ABA in a natural environment rather than restrict it to the table. She agreed that DTT, NET, VB and generalisation falls under the science of ABA.

What the child learns on the table needs to be generalised to the child’s life and make him/her be able to use it. Our goal is to decrease the child’s problematic behaviour and increase their joy of living. (Qingdao EC School, Zheng)

Zheng disagreed with those organisations like Beijing BC School which combine different approaches with ABA.

We would not believe in an eclectic approach. What I said was sensory integration is effective on a physical level, that’s why we use it. We would use sensory integration under the guiding principle and strategies of ABA, as a supplementary method. We would not tell the parents, if you use sensory integration, your child would become better. (Qingdao EC School, Zheng)

When talking about data collection of the ABA-based programme, Zheng held the same opinion as professionals from Beijing AC School.

It is hard to collect data for every child at EC School because we have so many. We definitely record some data. This data is mainly the initial
assessment and some after a period of training … There are other cases [where data records are thorough], especially those teachers who are studying the BACB course sequence which requires cases and relevant data records. (Qingdao EC School, Zheng)

The training programme at Qingdao EC School included individualised training and group training classes. The individualised training is the one-to-one ABA training between the professional and the student, while the group training would involve professionals, parents and students. Qingdao EC School required a parent to accompany his/her child at the school because parents took an important role in the group training, for example, to prompt the child’s social communication. Similar to Beijing AC School, parents at Qingdao EC School would have theory sessions every weekend. Parents and children who came to EC School were mostly from other provinces.

6.3.2.4 Clinic-based programmes of professionals-led

Beijing FC Centre is a centre-based ABA organisation founded by Jing, a BCBA. It provides one-to-one ABA training for children diagnosed with ASD ranging from 18 months to 6 years of age.

Beijing FC Centre is not like most other autism organisations in China. The child’s IEP is discussed between the responsible therapist and the family. Children with ASD undergo an hour and a half of one-to-one training per day. Those who displayed a high-function on the spectrum or at the transition to mainstream education would be put into the three-hour small group class. There were seven therapists working at Beijing FC Centre who had an Education or Psychology background. FC centre did not provide home-based ABA training like the UK or the USA, due to ‘safety reasons and insufficient quality therapists to provide home-based ABA training’. Furthermore, the IEP was a short-term teaching plan for three months rather than a longer term, such as one year, because:

The IEP in foreign countries may be designed by a team, but we do not have so many professionals. Chinese parents may not understand your long-term plan, they would prefer to know the present, so we try to make a short-term plan for the child, but adjust it to the child’s needs. (Beijing FC Centre, Jing)
The IEP of ABA-based programmes at Beijing FC Centre were also three months long. Jing reported that each child was assessed pre-intervention as a baseline. During the intervention, the evaluation of children’s progress was based on age and ability. For example, the evaluation of the younger children happened every 6 months, but older children would be evaluated once a year. Jing and her colleagues were working to bring in the Verbal Behaviour Milestones Assessment and Placement Programme (VBMAPP) for more children in China.

6.3.3 EIBI programmes

None of the parent interviewees said their child was undertaking an EIBI programme. Only 3 of the 8 UK professional interviewees said they were doing EIBI programmes for families, though one of them said she would prefer not to call it EIBI due to the non-intensive hours. The UK professional interviewees prefer to call it ABA-based intervention rather than EIBI.

> I do not really call it EIBI, but say, ABA or VB, [because] EIBI is not a market saying. People advertise ABA or ABA strategies... I think the ABA saying is broader and I think parents specifically want VB because that’s all that the internet parents want at the moment. Even though they call it ABA therapy, they call it VB therapy rather than anything else. (UK tutor, Nancy)

> I think what we are working is probably similar [to EIBI], but we don’t often call it that. I am not sure what they say that makes sense... Yeah, I’ve never called it that, though that happened. (UK tutor, Betty)

None of the Chinese professional interviewees said they were doing EIBI.

The reasons for the lower penetration of the EIBI programme in the UK and China are presented below.

6.3.3.1 Lack of understanding of EIBI

Respondents lacked sufficient understanding towards EIBI programmes. In this study, 3 out of the 7 UK parents (42.9%) and 1 out of the 7 Chinese parents (14.3%) had heard about EIBI. 6 out of the 8 UK professional interviewees (75%, 3 did not answer, n=11) and 5 out of the 8 Chinese professional interviewees (62.5%, 3 did not answer, n=11) reported they heard about EIBI.
As indicated earlier by UK mother Carol, whose son was in an ABA school, the local government did not support intensive programmes. UK professionals Jenifer and Betty talked about government staff and GPs of the health service lacking understanding of EIBI.

*In terms of behaviour analysis, such is not provided or recommended by statutory service provision here so parents do not have an access to that level of service.* (UK BCBA, Jenifer)

*I don’t think it [EIBI] is so well-known... in the places that you go to seek help, in the doctor’s. The parents that I work with don’t get talked [to] about it by their GP. When they have to ask about therapy, they get told there isn’t any. I think that is what people are being told.* (UK tutor, Betty)

On the other hand, the Chinese parents had seldom heard of ABA-based interventions before coming to autism organisations, let alone EIBI programmes.

*I may have never heard about the name EIBI, but I think I have heard about the intensive intervention by Lovaas. I want to follow his model, but I do not know how to do so. I do not think many Chinese know EIBI, and if there are, they are a minority.* (Beijing BC School founder, Jing)

### 6.3.3.2 Funding constraints

Parents generally lacked external funding to support their children through ABA programmes. Mary told the researcher that her son’s ABA-based programme was not supported by the local authority, so she had to self-fund. Though Mary had the therapist Jane come to deliver the programme 4 hours per week, she herself also worked with her son due to the financial burden of hiring a therapist to work for more hours.

*As you know there was no EIBI provided by the Government here. Both the Health and Education departments had never offered us anything other than autism awareness workshops, which were of no help to us. The only help we got was from NIU charity ... I do not know if you can call it EIBI, because it was just me doing it.* (UK mother, Mary)
UK professional interviewees pointed out that the number of hours of training delivered depended on parents’ financial situation.

*EIBI is... much depends on the parents. We can say the more you do this, the more the child will pick up skills. But a lot of them do not have the time and resources to implement it. I kind of find it hard to define how many hours they should be doing, because it comes to how much money they are going to spend. We would not call it early intensive, if you say intensive, parents go. They think money probably. It is time-intensive and cost-intensive.* (UK BCBA, Laura)

As a result, cost restricts both the intensity (hours per week) and duration of the programme.

### 6.3.3.3 Time, energy and distance constraints

The main elements of EIBI, intake at an early age and 20-40 hours of intervention per week, were not readily achieved in reality.

As mentioned in the diagnosis section (Section 7.2), some children received a late diagnosis and missed the optimal time of intervention at the child’s early ages. Nevertheless, professional interviewees reported they were taking in children at younger ages.

Both the UK and Chinese professional interviewees stated difficulty in achieving the recommended 20-40 hours per week in the EIBI model. That is why many UK professionals preferred to refer to what they were doing as ABA-based programmes rather than EIBI programmes.

*Very few of the families would be meeting those strict guidelines. So I would not stand up and say EIBI programmes, but we are getting kids at a young age and we are training the parents to do what they can do and if they need a therapist we can access that but we are not doing the 30-40 hours per week they recommended. We would call it ABA home programme; solely [because] it’s not as intense as it [is] recommended to be.* (UK BCBA, Jenifer)

Some of the UK parents could not access the service providers in their local area and, like Chinese parents, had to travel to cities to access services such as consultation.
(e.g., English mother Linda, living in Sheffield, travelled to Leeds to access supervision). It was found that without the effort of NIU charity providing ABA-based intervention, parents from the sample area would not be able to access such services for their children.

_We do not have the capacity to really do EIBI, because we know the guidelines are not enough and many of our parents do not have that support or access to services._  (UK BCBA, Jenifer)

**6.3.3.4 Resources constraints**

Autism organisations lacked sufficient resources to undertake EIBI. NIU charity had to self-finance, which means there is no government funding to support their operations. As a result, NIU charity were not able to hire more consultants to provide supervision, so they mostly supervised a family once a month. Moreover, there was a wait-list for other children to undertake the ABA-based intervention so the labour ratio of the supervisor to the child was not equal. This phenomenon was reported in both the UK and China.

_We have a waiting list [such] that we cannot actually bring someone on board on a casual basis. At the minute, we don’t have the resources to offer the EIBI programme, which we would love. They may have it in America that is not to say that things don’t change. But at the minute, we don’t have the capacity to offer._ (UK BCBA, Jenifer)

_When we were doing ABA-based intervention programmes, we knew that [EIBI] requires vigorous and intensive training, and for now these requirements cannot be met in China._ (Beijing AC School, Meiyin)

A lot of the professional interviewees indicated they were working towards the EIBI model and gave recommendations on promoting the use of EIBI in practice.

**6.3.3.5 Recommendations for EIBI in practice**

Since it is not possible for most to provide the standardised EIBI in practice, several professionals put forward suggestions for the use of ABA-based interventions in reality.
Age at intake and duration of intervention

The organisations of each country’s sample site were working hard to intake children at an early age. For example, Laura from NIU charity said that she was working with children as young as 18 months and young people as old as 21 years of age.

*The much younger kids come through, which is brilliant, and you can make such big progress if you get them in early.* (UK BCBA, Laura)

The duration of the programme depended on children’s ability.

*As for duration, I do not really say duration, I tend to say until the child is mainstreamed, and becoming successful until they do not need any support any more.* (UK tutor, Nancy)

Intensity of the intervention

Three UK professional interviewees suggested at least 20 hours per week of ABA-based interventions. For example, UK therapist Betty said that none of the families she supervised implemented 40 hours of training but most of them used between 20 and 25 hours per week.

*I usually say I recommend [to] parents at least 20 hour a week, but I always say the more the better.* (UK tutor, Nancy)

Welsh BCBA, Anna, said that researchers and professionals were exploring to utilise a low intensity behaviour intervention model in special schools at Wales.

*We understand that EIBI is not an economic model that can be followed within the NHS; very intensive, it requires a high level of training. We are looking at how we can use what we call low intensity behavioural intervention in special schools.* (UK Speech and Language therapist and BCBA, Anna)

Skills addressed

A child’s programme should be individualised in addressing their needs. UK ABA tutor Nancy studied ABA in the USA. She indicated that some of the elements of standardised EIBI, such as child’s age at intake and the individualised needs and motivations driving design of the curriculum, were similar with America. In her
opinion, an individualised programme was more important than the defined number of hours per week.

It depends on what skill the child really needs to have. Older students already have communication skill, so you are just focusing more on the independent skills, using the bath, dressing themselves. That is going to be more focused, but when it is 7 and 9, there are a lot of behaviour problems. (UK therapist, Jane)

6.3.4 Professionals’ skills and qualifications

All of the UK and Chinese interviewees longed for systematic and professional training in ABA. Particularly, professional interviewees expressed their willingness to be certified in the field of behaviour analysis. Both the BCaBA and BCBA certifications had a high recognition in both countries.

In the UK, some of the professionals and parents’ therapists said they would like to be certified but they were concerned about the cost along with eligibilities of taking BACB’s exam as most of them were self-employed and the families were paying. More than one UK therapist said their salary was not much.

I hate, I really do not like [to] ask families to charge money, ‘cos they are really [under finance pressure], but I have to make a living. (UK therapist, Jane)

By contrast, Chinese teachers were not self-employed but employed by schools or organisations. The young teacher Chow, from Beijing AC School, indicated that she could not see opportunities for career progression in this area.

There was a shortage of ABA professionals in both UK and China. In both countries, staffs were working towards more professional training.

If a person is trained to BCBA level, then they can deliver programmes in any country. The nature of the programmes depends on the issues being addressed. (UK BCBA-D, Adam)

Because it [certification from BACB] demonstrates that you met a minimum components of the list whatever else you do. You’ve been supervised, and you
have an appropriate degree to pass the exam. I think the craziest thing is that many people they think they do ABA and schools say we are doing TEACCH. And I think you should not say you are doing ABA ... in China or in UK, I swear, behaviour analysis is not yet established as a profession which is why it is a crazy situation. (BACB staff and UK BCBA, John)

Adam said that it was very important for those who delivered programmes to be certified. John indicated that the profession of ABA was not yet established in the UK and China.

In China, despite an increasing number of professionals beginning training in ABA, their educational and teaching levels were varied. The majority of the Chinese professional interviewees do not have a background in education or psychology. Those who had an ABA background were from abroad or Hong Kong. For example, Kate, the international trainer, was from the USA; Dong, the founder of Beijing DC School, was from Canada, and Juan, the founder of Beijing FC Centre, moved to Beijing from Hong Kong.

Chinese professionals were undertaking online BCBA/BCaBA training programmes offered abroad. Particularly, many teachers from Qingdao EC School were undertaking a distance BCaBA training from a university in the USA. The founder of Qingdao EC School, Zheng, reported that at least 30 teachers received systematic ABA training from BCBA supervisors, who were based in the USA, in the last five years. Meanwhile, they also invited five American-Chinese BCBAs to offer ABA training for school teachers in Qingdao. Kate also brought BCBAs from America to train Chinese parents and teachers. Nonetheless, there was a shortage of BCBA supervisors to provide supervision for ABA students in China.

Juan, a Chinese BCBA and the founder of Beijing FC Centre, said that, ‘Because of the difference (of educational systems between China and the US), we need to consider whether it [certification of BACB] fits our national conditions’. Many professional interviewees expressed concern over the difficulty in reading translated material and accessing the required supervised practice hours. Some of the professional interviewees expressed their willingness to take the BCaBA exam, but the training was expensive. Juan said China’s Disabled Persons’ Federation (CDPF) was assessing the number of professionals who worked with children with ASD in
China, and would propose a systematic training and certification programme for professionals to the local authority.

Language was considered to be the biggest barrier preventing Chinese professionals from learning and taking the BACB exam. John mentioned there were three approved course sequences in China and they were all taught in Chinese. The biggest problem was a lack of supervisors in China. However, this phenomenon was not unique to China.

_I guess every country has to start somewhere, so it could take 5 or maybe 10 years for China to get [to] the point of where it’s much more self-sustaining in that there are enough people there to teach and supervise, to sustain the growth [in] the number of people. I mean there are enough people in China, but it is such a huge country, so we need to have them really very based around the course sequence where they are... The biggest problem is man-power really; [they] have not reached that quickly, [and it is] not easy to grow quickly._ (BACB staff and UK BCBA, John)

John suggested that supervision could be offered remotely via Skype or similar.

**6.3.5 Parents who worked as ABA therapists**

Data showed that a significant number of the UK and Chinese parent interviewees mentioned they worked as a therapist for their child. This is mainly due to financial constraints. Some regions of the UK and China did not have enough service providers, especially for small cities in China, so parents would prefer to learn the science of ABA rather than travelling far from their home to access services. The following described the strengths and challenges brought by parents acting as therapists.

**6.3.5.1 Learning the function of behaviour**

Both the UK and parent interviewees said that they learnt the function of the behaviour of their child by learning about ABA, e.g., for behaviours such as escape or avoiding the task and getting tangibles.

The UK mother Mary said she learnt from the therapist by joining in the home-based ABA intervention.
The best thing I’ve ever learnt is to be able to do a functional assessment, to be able to functionally identify why he’s doing something. With the analysis, I am able to know what the reason for this behaviour is, by doing that, his [motivation]. Without that, I would be lost. (UK mother, Mary)

Before the parents’ training, some of the Chinese mothers reported they did not understand the function of behaviour, they mistakenly believed their child was not learning well or making a mistake on purpose. In some situations, they would scold and hit their child.

I did not smile to him previously because I hate him. He destroyed my life plan... I sometimes treated him like other typical children, to beat him, and believed that he might learn [a lesson] so he would not make [a mistake] again. As a result, I beat him up several times, but he did not learn [from the mistake] at all. I did not know the reason [for the problematic behaviour] until I learnt ABA. (Chinese mother, Wuling)

Wuling began to accept her son after learning about ABA.

I felt my heart has opened a little. I smiled at him sometimes. He was giving a very bright smile in return. (Chinese mother, Wuling)

Parents reported that they could implement ABA in children’s daily lives.

I probably do ABA almost naturally now... it just becomes second nature to use reinforcement, to use extinction. It is a part of your parenting anyway. (UK mother, Jessica)

6.3.5.2 Mother and father working together

Though mothers took the main responsibility for training the child, it was not uncommon to find that fathers were also engaging in the child’s programme. The UK mother Rose said her husband was starting to work with their son two weeks ago. Rose was also working full-time, so she was not able to work with her son constantly. Under the suggestion of their supervisor, Laura, her husband started to take turns with Rose to work on their child.
The motivation for me [as a parent therapist] is because I could see he starts to say words now. I just wanted him to speak and his behaviour was a lot better as well. He was sitting down for me, while before he was just [responding] no no no no... [He] would not do anything for me. The reason for my husband to do it was the same as with me, because he saw the difference, and he knew I also worked on my job like him, and some nights when I came home. I was just exhausted. He knew I could not do it every night, so he decided to take [on] home, [and] seemed to enjoy it when he did it; a sense of achievement to see the progress. (UK mother, Rose)

Rose raised an important point, which mother was not only taking the role of looking after children at home but also needed to work. Furthermore, the father was motivated by his child’s progress. UK mother Linda said: ‘2 days a week I act as the therapist. By that time my husband comes back from work and it’s easy for me to get involved.’

Similarly in China, it was observed that some fathers travelled to Beijing AC School to undertake the ABA-based programme with mothers. For example, Meimei and her husband were teaching their son together so he will listen to not only Meimei’s instruction but both of them.

In addition, there was an involvement of other family members. Sometimes, the child’s siblings were happy to join in the programme to increase the possibility of social interaction and skill generalisation.

[The older] children were very independent and helped with [the youngest child]. They understand [the child] had problems and we could tell them to do, not ABA, but certain techniques like, you could ask some things...When they came in they would make him say “hello”, greet them, and then when he wanted something they would make him say “help me”. They were quite good. (UK mother, Jessica)

This was not the case for Chinese children, as most of them were the only child in the family at the time of the interview. It was observed that child’s grandparents also travelled together with the parent and child to Beijing AC School, though their main job was taking care of the child afterschool. Results found that some grandpas would
join in the ‘Group Class’ of Beijing BC Centre because some of their parents needed to work during the day.

6.3.5.3 Time, energy, educational and emotional constraints

A large number of parents had quit their job to take care their child with ASD because they had insufficient time and energy to balance between work and family.

In the UK, mothers not only looked after the child with ASD, but also other children. For example, Mary said her younger daughter always wanted to get her attention when Mary herself was working with her son. Mary had to pay attention to both of her children and get them involved in a task.

_When I try to work with both of them my daughter [younger daughter] tends to take over and he [child with ASD] will escape from the tasks, though this is getting easier now as he is starting to get competitive._ (UK mother, Mary)

Daisy, a single mother, was working part-time previously but had quit two months ago.

_It’s not easy for me to find the time to do all day. But I am trying to learn something._ (UK mother, Daisy)

In China, Beijing AC School required parents to come together with children and the majority of them were not local, which means they had to leave their job. In other Chinese autism schools, parents were still required to engage in the group activities. Most importantly, many Chinese parent interviewees expressed difficulty learning ABA because their educational background was insufficient (Ref Participants of Methodology - Study 2).

_It was just me learning every day [rather than the child diagnosed with ASD] and he just followed with me to school. He sat beside me watching the teacher’s demonstration. I was wasting my time. I don’t think I learnt very well so I couldn’t apply it on him and haven’t been able to teach him any skills yet._ (Chinese mother, Ling)

Parents did not have experience working with children with ASD besides their own child. Based on the researcher’s observation at Beijing AC School, it was found that
parents had to manage multiple tasks simultaneously: listen to teacher’s theory, watch the practical demonstration, and sometimes, quiet their child because it was crying and not willing to sit.

In addition, some parents found it difficult to be professional due to emotional attachment. Jane mentioned that when faced with a crying child, the mother might find it difficult to insist on the assumed principles. Jessica gave more reasons why she did not want to work as a parent therapist.

\[ I \text{ would like to do ABA on a child that isn't mine. Because I think that would be easier. I felt it was difficult to do it on my own child because of the emotional attachment, where you have not got that with somebody else’s child. I think it is very difficult to do it on your own [child] because one minute you’re being a mum and one minute you’re being a teacher. And I think sometimes that confuses [child] as well. During the night time I’m being a mum and I’m cuddling him and kissing him and during the day I’m doing ABA and I’m being quite strict and ignoring behaviours. (UK Mother, Jessica) } \]

\[ It’s difficult for the child because of the emotional connection. The children cried and cried very hard, [the mother] sick with saying no, but it’s easier for me [to manage]. I think the child could understand why it’s not allowed. (UK therapist, Jane) \]

6.3.5.4 Working with other children

A small number of UK and Chinese parents not only worked with their own child, but also worked with other children when their child grew older or was placed in a residential unit.

In this study, UK therapist Stephanie’s experience working with children of ASD came from teaching her son because he had undertaken the ABA programme for around 12 years. She was also a member of an autism organisation and was trained by experienced professionals. At the time of the interview, Stephanie’s 22 years old son was in a residential college, funded by the local authority. She was working with 4 children on weekdays. She outlined her reasons for providing services for families.
Motivation of being a therapist is because I know ABA very well and I know how successful it is. And it’s become second nature to me. I know how it works. It’s easier for me because I have this experience [of living with my own child]. (UK therapist, Stephanie)

In China, the first generation of founders started autism organisations for their children. The founder of Beijing BC School, Jing, said that 80% of the founders were parents whose child was diagnosed with ASD. In addition, Beijing AC School had a long history of training parents since the 1990s. Mr Cui reported that at least half of the founders, who were from small cities or towns, were the school’s alumni (parents).

I started AC School because of my child who was diagnosed in ’89. At the time there were only three doctors able to diagnose. At that time, there were no post-diagnosis services for ASD. This was a blank area. I got to know behaviour intervention from Western literature. I did not know the specifics to intervene; it was translating and learning, and then, practice.’ (Beijing AC School founder, Chun)

The advantage of parent therapists who work for other families is that they can better understand the needs of the family and feeling of the parents. A majority of Chinese parent therapist, especially the founders, were really looking forward to more professional training in addition to the three-month ‘crush’ courses.

Previously, lots of autism organisations were started by mothers, but now, I feel the proportion is getting smaller. Parents in China took their child to visit a lot of organisations for treatment and I think they mastered some techniques. That’s why they were doing it. However, now, more professional teams are starting autism organisations. We [parent founders] lacked technical expertise. Compared with the international level, we had a long way to go. (Beijing BC Centre founder, Jing)

6.3.6 Co-operation among professionals and parents

The data suggested that parents and professionals should work together to achieve the best outcome for children. Professional interviewees indicated consistent training by professionals and by parents at home are beneficial because children would be
confused if the parents indulge behaviours that the professional is trying to suppress. Professionals encouraged parents to have some knowledge of ABA in order to apply the principles and techniques of ABA to children’s daily life.

In the UK, parents reported that home-based ABA professionals provided them opportunities to raise questions and to receive feedback, especially for those parents who worked as a parent therapist with their child. Many therapist interviewees expressed the views that some parents had a good knowledge of ABA and parents would record the data when working with the child at home.

*In everything I am doing, I think, like challenging behaviour, [I am] by sharing with them about the progress.* (UK therapist, Karen)

*Some of our parents are fantastic, they give you everything before the next visit and say, this is what is going on, I need more things to do. …we also do that in our [home] visits, for example, what behaviour caused you problems [when therapist was away]. We would suggest the parent take the data for me, and then I would come back and go for the intervention and I would demonstrate to them if the child was there. It is difficult for toilet training, but generally, I will talk them through it, try to demonstrate for them, look out for them, get them to practise while I am there, and then, they can carry on.* (UK BCBA, Laura)

In China, parents who were involved in the parent-focused training or group training said that they were relieved psychologically when discussing questions with professionals and sharing concerns with other parents at the autism organisations. As parents took one of the main roles in the mode of service delivery in China, the strong tie between the professional and the parents was obvious.

Both the UK and Chinese interviewees agreed on the importance of co-operation between parents and professionals. Parents’ training was an integral part of many programmes. For example, NIU charity provided different training events once a month. The BCBA.s from NIU charity would pick up different topics for parents when attending workshops. Laura suggested that parents could access online resources to learn ABA.
Professionals’ co-operation was found to be important. Three UK professional interviewees, who were providing EIBI for families, worked together with one or two other therapists or child’s parents. Betty ran the 20 hours EIBI programme with another therapist who was also employed by the child’s family. Jane was working with Mary’s son, and Mary also worked with the child herself.

Anna, in her role as a speech and language therapist, shared an observation that some behaviour analysts were bluntly pointing out shortcomings of professionals who do not use behaviour analysis. These actions caused resentment and resistance to the science of behaviour analysis.

_You imagine, if you have been a teacher in special school, or speech language therapist, OT therapist, and you have done that for a long time and you work very hard, you have a behaviour analyst come and say, oh, this is all useless. That does not make you feel good about your job. I think a lot of behaviour analyst are quite arrogant, they do that, they are very rude and dismissive people, and they hurt people’s feelings... you have to be a diplomat as a behaviour analyst. You cannot serve your science without being extremely diplomatic._ (UK Speech and Language therapist and BCBA, Anna)

Anna used her experience to indicate that speech language therapists understood normal language development and they understood how to divide language up into different parts. Speech language therapist and behaviour analyst used different terminologies.

_We do not say tact, mand, [and] introverbal, we using a more traditional way, non-verbal, nuances, syntax, semantics, and pragmatics._ (UK Speech and Language therapist and BCBA, Anna)

Yet, Anna admitted that speech and language therapy is neither data-driven nor evidence-based.

_We know about language development and we are trying change things, but do not really have the science showing us how things change. Our professional body missed that totally; they say most paediatric speech language therapist interventions are not evidence-based. We do not know_
whether they work or not. That’s rather depressing but it’s rather the truth.
(UK Speech and Language therapist and BCBA, Anna)

In contrast,

Behaviour analysis is about science, is about data, so if you put those two together, a knowledge of language development, combining with behaviour analysis… taking data, manipulating variables… I think you will have something very, very special, so it brings science to a profession… So for me, that’s what behaviour analysis brings to speech language therapists, the science and the rigour. (UK Speech and Language therapist and BCBA, Anna)

Anna raised an important point that speech language therapists were increasingly interested in ABA and it would be a good idea to integrate the knowledge of ABA and to encourage them to be certified as a behaviour analyst.

Often, speech language therapists argue with behaviour analysts, so we try to think ways we can promote behaviour analyst without scaring people.
(UK Speech and Language therapist and BCBA, Anna)

Finally, Anna contributed an important opinion that behaviour analysts should work together with other non-applied behaviour analysts, and help other colleagues, such as physiotherapists and occupational therapists, to learn the knowledge of ABA and be a part of them rather than telling them they are wrong.

I think, to further the cause of ABA, we can’t do things separately from other people. We have to infiltrate; we have to be part of more mainstream organisations. (UK Speech and Language therapist and BCBA, Anna)

6.3.7 Children’s changes

Both professionals and parents stated the goal of the ABA-based intervention programme is to facilitate transition of young children to mainstream schools. Both UK and Chinese parents had a positive feedback about ABA-based interventions and they indicated children’s behaviour and abilities improved. Almost all of the parents reported substantial improvement in the children’s social communication and social interaction.
6.3.7.1 Sleeping and feeding problems, self-injurious behaviours

Mary reported a decrease in inappropriate behaviours and an increase in speech and language ability for her son after ABA-based training.

Every time we [therapist and mother] worked on a specific behaviour, [and] decreased the ones that were causing problems. It is like a little scale. What is happening at the moment, a lot of this are on extinction, a lot of these are coming back. It all seems to happen after that [ABA]...And I can notice with him it’s little developmental things, his speech improves. He asked to wash dishes last night... The work I have done with the child has covered everything including sleeping, feeding problems, self-injurious behaviour, and other difficulties associated with autism. If he could have more EIBI I think the results would be fantastic and it makes me very angry that this is not available. (UK mother, Mary)

6.3.7.2 Academic skills

Linda reported that her son was much better in school than before. Her son started to pick up reading, writing, mathematics and drawing skills.

His behaviour in school has quite improved after starting ABA at home. So he learned a lot. He was good at reading and all that stuff. So basically they are working with him ... all the time to support him all the time. They can work, they can read... He was a good learner. Literally in 2 weeks, we were getting comments from a friend that he is listening to us more. We had results in 2 weeks. Now at 4 months he has made huge progress. ... He was not writing at all before ABA. Although we didn’t teach him writing in ABA, we have taught him to sit at a table and listen to what an adult is saying. So his writing has come up all by itself. He was very good at reading. He’s reading a lot. He’s even doing mathematics. He’s drawing. (UK mother, Linda)

6.3.7.3 Language skills

Jessica and Carol said that their child’s language skills improved significantly.

We noticed, instantly, the first day [therapist] came to see [the child], and she had him doing things that we didn’t know to do. ... And I’m like: Wow,
she had him sitting at a chair at the table. Before ABA, there was [nothing]. He could not talk. He was on what you’d call non-verbal but he didn’t … He wouldn’t communicate and he wouldn’t use speech for communication. And now his eye contact was definitely better and speech was getting better. He was manding and did imitation. He would sing songs. And sometimes, he’ll say something and it’s like: Wow, you just said that. (UK mother, Jessica)

At 3.5 years old, and within three weeks, he said his first words, and within three weeks, I’ve got behaviours under control, like he had refused to walk down to the road holding someone’s hand. ABA sorted that out very quickly, just really basic stuff that was making my life hell. Language and challenging behaviours were the main things where I’ve seen the changes. (UK mother, Carol)

6.3.7.4 Emotional expression

Qian said her daughter could use language to express her emotional feelings.

Her language, cognition and emotional [state] progressed. I felt she enjoyed smiling more than before, because she might develop broader interests than before, or she could express her feelings and emotions. She could somewhat communicate with you, such as by eye contact and using language. When she was able to express her feelings, her mood was better than before. (Chinese mother, Qian)

6.3.7.5 Understanding of norms

Ling said her son learnt the norms of classroom, such as sitting, waiting and imitating.

There was massive progress from before ABA training to after ABA training. For example, when he was two years old in the nursery school, other [typical] children who were one year younger than him were sitting on the seat and were not running around, but he did not know that. He could not even do the very basic imitation. After the ABA training, he learnt to wait, to imitate and to study. All of these abilities appeared and he was catching up. (Chinese mother, Ling)
6.3.7.6 Safety awareness

Mary and Wuling said her son was not aware of traffic when walking on the road. Wuling also told the researcher her son had been lost before.

*Even teaching him how to walk, because he would run away, run into traffic. We had lost him a few times. So it’s everything.* (UK mother, Mary)

*He was running without a purpose, back and forth and running around on the street. He had no situation awareness at all. Now, he at least knew taking Mummy’s hand and walking with Mum. If I had something in my hands, I would let him grab my clothes and [we would] walk together. Sometimes, he was walking in front of me, he would look back to check if I was there; if I was walking in front, he was chasing after me. After the ABA training, I could let him walk independently, [as] he was able to follow me if I gave him an instruction: come on, walk with Mummy step by step. That’s it.* (Chinese mother, Wuling)

At the time of interview at Wuling’s rented apartment, the interview was interrupted for at least half an hour because her neighbour’s son appeared to be lost. Wuling and some other mothers of Beijing AC School living nearby went outside to help to find the child.

6.3.7.7 Social interaction with peers

Meimei talked about her son’s changes in social interaction with his friends and self-management of emotions.

*I would say his change was obvious, now that he was in his 6th month. His social interaction had improved, interacting with his little friends. He knew when he missed his friend and he would tell me he wanted to phone Ziqi [anonymised name of the child’s friend]. He had more emotional communication and his emotions were easier to manage.* (Chinese mother, Meimei)
6.4 ABA and the school

Interviewes reported that ABA was poorly incorporated into school. Significant differences were found between UK and China regarding children with ASD in the school and the relevant support received.

6.4.1 UK: ABA and schools

Depending on child’s ability, school aged children in the UK with ASD would be sent to a mainstream school or a special needs school. It was reported that a special unit would generally be attached to a good mainstream school. One of the professional interviewees, Anna, had been working with children with special needs for nearly 25 years and she said the education for children with special needs in Britain had improved a lot, though there were still many areas needing to be changed.

6.4.1.1 ABA and mainstream school

Those parents whose child enrolled in mainstream nursery or school were facilitated with an assistant to help the child either in class or in extra-curricular activities. The assistant could be one-to-one with a child for the whole day or provide a specified number of assisted hours with the child. For example, Linda’s son had three hours a day from a school assistant.

Many professional interviewees said that a large number of the assistants were poorly trained to handle children with ASD. Many of them did not know the principles or techniques of ABA. Parents reported that most of the school assistants were not trained in ABA and they did not know the function of behaviour.

_He has not done it in the past but did it last week when he crawled underneath the table and would not come out. And both his teachers stood there and [asked]: What do we do? ‘What do you want us to do?’ I was like: ignore him for minutes. We had to tell them [school assistants] what to do, and we have asked them for help! Say he was playing outside and then taken inside when break time was over, and they were doing some work, [he would say] I’m tired. They [school assistants] took the meaning that he was actually tired, rather than just wanting to go outside and to play again. Because he did that with [the home ABA therapist], said ‘I am tired and want to go to sleep’. He did it with me [as well]. So when you put the two together and_
what happened at school. It’s such a missed opportunity because they could work on social skills. (UK mother, Mary)

Mary, the mother who worked as an ABA therapist herself for her son, thought that the assistant was ill-equipped to deal with inappropriate behaviour that arose in her son when he was at school. Some parents like Linda expressed their satisfaction for support received from the school, but they hoped school would introduce a proper behavioural intervention approach.

Some children with ASD were allocated to a special unit/department attached to the mainstream school. Linda’s son was in such a special department with one-to-one help. Those good mainstream schools would have an SEN unit attached for children with different disabilities, including children with physical disability. Supervisor Laura reported that some parents sent their child to units first which were not in the mainstream classroom but in a separate building. Children would be mixed during PE or lunch time so that they were somewhat integrated with other children for certain classes. Many mainstream schools had units attached, which had smaller class sizes and higher staff ratio.

6.4.1.2 ABA and special needs school

Several interviewees indicated teachers from special educational needs (SEN) school had a better understanding of children with ASD compared with mainstream school teachers, and some staff understood the principles of ABA, though that was a small portion.

What happens, most special schools, they are nice people, but it is total chaos, ill disciplined, a mix of different things going on, it’s a waste of time…

I see now in special schools a much greater emphasis on evidence-based practice, a much greater emphasis on data and a much greater emphasis on showing that a child started here and now they’re here. (UK Speech and Language therapist and BCBA, Anna)

However, it was reported that different regions within the UK had different educational systems. In some SEN schools, children with ASD were mixed with other children with different disabilities. They were led to engage with sensory toys, visual schedules and diet.
I am always very worried. They enjoyed the sensory things that they advised but I am always worried about when they are implemented. So instead of doing it when the child has an adverse, effectively reinforcing that behaviour, do it when it is nice and calm, you still do your sensory diet or whatever you to do. It’s having a more positive effect on the behaviour. (UK BCBA, Laura)

Anna was employed by several schools as a freelancer in Wales. She reported that in northern Wales, ABA was firmly established in the state schools. Education authorities were welcoming it and working with universities to further it, which was in stark contrast to the situation in other parts of the UK.

We are the only place in the British Isles where we have ABA firmly established in the state schools and education authorities welcoming it and working well with universities. [In England], the difference is that they are mostly independent schools or free schools, they are schools that have government money but they establish themselves so they are quite independent, quite autonomous. What’s interesting about our schools here is that they are fully under the umbrella of the government. They are very welcoming to ABA. There is a very strong emphasis on the school, and in the university, on working in the medium of Welsh. (UK Speech and Language therapist and BCBA, Anna)

6.4.1.3 Mainstream school versus SEN school

Professional interviewees reported that most of their clients went to mainstream schools. To some extent, parents had stereotypical SEN school students in mind where the disability was very severe and most probably could not follow social interaction or sit by themselves, while mainstream school was for children who could understand and follow instructions.

Parents hoped their children at mainstream school would have more opportunity to become socialised and to imitate the right behaviours. Mother Jessica said, ‘they need positive role model, positive peers.’ For instance, professional interviewee Laura, talking about her experience at SEN, agreed that children in mainstream school could be a positive example for other children. UK mother Lucy originally
preferred mainstream schools, but her opinions changed when she met some children who went to special schools.

Compared with mainstream school, the staff ratio in SEN school is much higher. Rose’s son was considered to be on the severe spectrum of autism disorder, he was allocated to a special needs school. Considering different types of disabilities were in this school, such as physical or people with autism and Down’s syndrome, students with similar type of disability were formed. The class Rose’s son was in had 6 children with autism. Rose invited child’s supervisor Laura, to visit the school and requested her to incorporate ABA for her son in the school.

Other interviewees reported that the schools their children attended did not use ABA-based interventions or follow the principles of ABA. Some did not even accept ABA. Parents said that they would use ABA at home, but the school was applying other things. It was reported by parents that generally, both mainstream and special needs schools did not welcome behaviour analysts to visit.

The school and ABA are totally separate in England. ABA is private. We provide the ABA on our own and [it is] not yet transferred into the school. And the school system doesn’t follow the ABA principle. (UK mother, Linda)

When we started school, they brought out a visual schedule. It is like, right, your son has autism, here [is] the schedule and here is what we will do. It is fine but he does not need that… It’s like they have nothing else. They do not do that [discuss with parents]. They are not trained. They do not know how to get him to take part in other activities or in groups. They [school] will not [use ABA]. I was trying to get them [ABA professionals] into the school but there was a big wall in the way. (UK mother, Mary)

They got small groups and they were playing small games together and encouraged to talk and to learn the names of the small groups. They were trying different things but she [the child] was not very interested. (UK mother, Lucy)

School teachers do not know autism and ABA… In England there are many schools far behind and not willing to see what ABA is about. They have a critical method and they stick to that, and it is very difficult to tell why. They
think it is very intensive, too time-consuming, too difficult, and too expensive. Or it may be a combination of everything. Many local authorities are not very into ABA through misunderstanding of how beneficial it is for children. (UK therapist, Stephanie)

Parents also noted that ABA was not recognised by schools in most parts of the UK. Sometimes, parents would request ABA therapists or supervisors to come to the school to work out problems happening in school or generalise the learnt skills from home-based programmes to school settings, but they were not allowed to come in.

*Because it is not a recognised, umm... sort of intervention such by statutory services in NI... There are a lot of prejudices around ABA so that impacted on schools.* (UK BCBA, Jenifer)

Professional interviewees indicated that a school programme was an important part of the ABA-based programme. If the child had a class assistant, who knows the principles and techniques of ABA, or had a behaviour analyst to work to help the child, he/she would benefit more from the school, such as being with the peer group, learning socially, to imitate, to pick up natural skills and skills’ generalisation. In addition, in order to help the child to get a better outcome in their individualised training programme, it is necessary to keep the training as consistent as possible.

*I went to mainstream primary school with a child and did some trials and a little bit of teaching, [while] another child is actually in a special needs school, and school did not take it on board, so we did not get any generalisation there.* (UK therapist, Nancy)

Professionals also stated that if school teachers could understand the function of the behaviour and principles of ABA, it would be easier for the teacher to control and manage the class.

**6.4.2 China: ASD, school and ABA**

Similar to UK, there were two main types of educational schools for children with ASD, the mainstream school and the intellectual disability school. The intellectual

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33 In Chinese: 启智学校
disability school is for children with special needs, and is mostly supported by the local authority.

Chinese parents reported that children with severe ASD were excluded from mainstream school in some regions of China. Some schools had an assessment before children’s enrolment. As a result, most children with ASD would be precluded by the test. Some head teachers of the class were afraid children with intellectual disability would perform badly in academic assessments, lowering the level of the whole class in the exam. For example, mother Chang reported that her son was persuaded to quit by the mainstream school. Hence, most parents said that they would not tell the school his/her child was with ASD. Furthermore, there would be 30-40 students in a mainstream school class. The teacher had a high workload managing the class and could not adequately cater for children with ASD.

In the intellectual disability school, children with ASD would be mixed with children with other disabilities. Those who were severe might even be rejected by such schools.

Moreover, parents reported that children in China faced the household registration (Hukou\textsuperscript{34}) issue, which means if the child was not from the local province, he/she might not be able to enrol to the mainstream school. For instance, Bing was from Hunan but her family lived in Guangzhou because of her husband’s work. She did not have a Guangzhou Hukou at the time of interview, and she said that their son was not able to enrol in the local mainstream school. There were private schools that did not consider Hukou, but they were costly. Bing said that she would rather teach her son herself when she finished the parents’ training at Beijing AC School.

It was found that ABA had not been brought to the Chinese mainstream and the majority of SEN schools. There were no professionals accompanied the child to school. Several mothers reported that they would like to accompany their child to school to help the child learn and socialise because they had a better understanding of the principles and techniques of ABA comparing to class teachers at typical

\begin{footnote}{34} Hukou (in Chinese: 平, means the household registration. It is an administrative system that decides where citizens should stay in China (Chan, 2009). In this article, the Chinese pronunciation spelling- ‘Hukou’ is going to be applied. \end{footnote}
schools. For example, Chinese mother Qian planned to go to school with her son for a period of time to assist her son adapt to the norms of mainstream schools.

Some Chinese parents said that they would combine autism organisations with school because autism organisation provided training for the child and mainstream school provided the chance to socialise. For instance, Xiang said her son was having three classes in the kindergarten in the morning, and would go to an autism organisation for training in the afternoon.

6.4.3 UK and China: A ‘battle’ with the school

Almost all of the parents, both UK and China, in this study indicated that they had to fight against schools to access education for their child. Parents indicated that when the child started school, a battle started with the teacher and the school. In the UK, it gradually developed into a court case between parents and the local authorities.

Several parents said they had to fight for the assistant to work with and fight for extra support hours from the school.

Several parents said they were in the process of applying for an educational statement to get more support from the local authority. Jessica said that she used to work at an SEN school for 7 years and she used to tell the local authority that it would be more expensive to send children to an SEN school for years than supporting the child with ABA programmes.

>You wanted to spend X amount of money sending him to this school, can you spend this amount on ABA instead. It is actually cheaper than the school and I put it to them in this way, I think, because I had that prior knowledge as to how an expensive special school was. You will spend this sending the child to a special school, can we try ABA instead? And they agreed. And they’ll fund it for a year and then they are going to look at his progress and see if they will continue. So it is a bit like a trial with the local authority. (UK mother, Jessica)

Jessica was one of the mothers who succeeded in getting more support from the government. Carol hired a lawyer to fight with the local authority to get support for her son to enter the ABA school.
I basically got a lawyer on my side on one of the first times I spoke to the local authority, so they could see that I was not going to be messed around with. What’s happening is those who shouted loud do not get money for getting ABA funded by the State. My reason for starting the campaign is that it is not fair. All that means is that there are two tiered systems, autistic kids of rich parents get one thing and autistic kids of poor parents get another thing. It’s not fair and I do not like unfairness. That’s my motivation. (UK mother, Carol)

Carol even started a campaign to help people from the low socio-economic status to have an access to ABA.

However, a number of Chinese parents were still engaged in a battle with mainstream schools and the public to accept their children for education. Parents anticipated an increased application of ABA in the near future as the knowledge spreads.

6.5 ABA and policy context

6.5.1 UK: ABA and policy support

The supervisor participants reported that autism charities had to make a living by themselves. Different counties of the UK had different levels of service. ‘it depends on which Trust you lived in, [and] what access to services you could get’, (UK BCBA, Laura).

Based on interviewees’ feedback, it was reported that England and Wales was a little better than Northern Ireland with respect to public services for children with ASD. For example, a majority of parents in this study said they had to self-fund ABA programmes for their children, while there were two parents from England who were now receiving government funding because they succeeded in a tribunal fight with the local authority. Jessica’s son was the 6th child to receive funding support from her local authority. Her son received 25 hours’ therapy a week paid for by the government and they allowed her to spend £10/hr on hiring a therapist. Hence, they’re funding £250 a week. They also paid the consultancy hours, which is about £1,400 a month.
ABA is not well advertised. If more people knew about it, more people would be asking for it. I think maybe I was lucky because not many people are asking for it and maybe that is why we got it. The local authority, because it is something quite new to them as well, were not 100% sure of how things should be. Sometimes I find myself telling the local authority how things are supposed to be. I think they have still got a long way to come, but I think they are trying. (UK mother, Jessica)

Carol said there is a list of ABA schools which were paid by the government in England. However, parents had to move close to the school and provide a proof that ABA is evidence-based before the local authority would allow access, because government staff did not know much about ABA.

*What I am saying is that, in order to persuade the State to pay, because it’s £62,000 a year in joining this school, I had to have evidence that ABA works and that evidence I had to build up by first paying privately for ABA. They [parents] have to be rich to start with, but then want to pay for ABA and build up evidence-base; you can persuade the State to take over the funding ...They tend to agree with only the more severe kids because the alternative for them is to pay even more if kids go for residential school.* (UK mother, Carol)

Jessica also stated that severe children had a higher possibility of getting funding support from the government, while children who were high or middle-functioning might not.

*Higher functioning kids tend [to] just make their way in normal school. They’d be shipped into normal schools and hope for the best.* (UK mother, Carol)

Several parents from NI stated that they received some funding support from Caudwell Children’s Fund, which helped parents under financial pressure. In addition, the NI mother Lucy said they could get some free service, such as speech therapy from Health Service Care (HSC), when the child received a formal diagnosis, but there were no ABA-based training programmes.
Some of the UK local authorities were not entirely inactive in supporting children with ASD. Participants suggested the government should have more knowledge towards the evidence-based approach for children diagnosed with ASD. Professionals Jenifer from NI and Karen from England believed that the local authorities put money into some therapies which looks ‘nice’ but is not effective for children in reality.

*Usually, the intervention provided from the government would argue against ABA. Schools, nurseries are not very welcoming [of a] ABA for programme. It’s quite difficult. I would say ABA is the best because it’s the evidence proved. I hope it will come true one day. They provided speech therapy, OT, educational psychologists, they addressed some things. It’s like putting drops into a glass that is empty; you won’t get a full glass of water. That’s how much they help. It’s not a holistic approach.* (UK therapist, Karen)

In this regard, Stephanie may represent those mothers whose child was diagnosed with ASD, and she also worked as an ABA therapist as her son moved to residential college.

*The local authority has to look at and accept what parents ask for and what they are trying to say. It’s a big struggle and big fight for the parents to keep this going. It means they have to have ABA privately in their house, to show what these are, the evidence, show my child is progressing, now, I would like this ABA [to] come to school.* (UK therapist, Stephanie)

Mother Jessica said that if the government had spent money at earlier ages, they would not have had to spend that much because as adults of high-functioning they might get a job and support themselves.

*Everybody’s life is going to be much better if you have a way to know how to change behaviour and give them more skills.* (UK BCBA, Laura)

**6.5.2 China: ABA and policy support**

All of the founder interviewees said that it is hard for NGOs to make a living in China. Autism organisations bear the main responsibility for delivering services and training for children with ASD. The majority of autism organisations were not
financially supported by the government, though there had been some changes in recent years. Similar to the UK, there was a lack of understanding about children with ASD.

*These children are special. [If] people with hearing problems, [the government would help to] implant within cochlear; people [who] could not walk, give them a wheelchair. Children with ASD not only need money, but professionals who could really work with them, also [they need] societal support.* (Beijing BC School Founder, Jing)

Professional interviewees mentioned that there were more policies supporting children with ASD and their families now. The Chinese Disabled Persons Federation (CDPF) organises training or workshops for professionals. In addition, in recent years, the CDPF put forward qualification standards and called on all the professionals to pass CDPF’s certification examination to provide a higher quality care for children with developing disorders, including children with ASD.

In China, each region had a different support system for children with ASD and might implement policy differently. Chinese parents said children with ASD who were between 1 and 6 years old could receive some support from the local authority on condition that the child should receive a formal diagnosis, be issued with a Disability Certificate and get training or services in the local area.

Many of the parents reported they were concerned about the Chinese Disabled Certificate because they were afraid of a child’s being tagged as ‘disabled’ or ‘mental disorder’. In China, it was reported that children with developmental or intellectual disability were perceived to have a mental disorder. However, both parent and professional interviewees mentioned, in the mind of Chinese people, the word ‘mental disorder’ has a stigma attached and is considered to be a derogatory term.

*People did not understand what autism is, but people know what mental disorder looked like, so everybody was scared of that. The word ‘mental’ just made people feel unpleasant. I did not apply for the Disability Certificate [for my daughter] because I had the same feeling with other parents.* (Beijing BC School Founder, Jing)
Jing’s opinions had represented the majority of Chinese parents who were not willing to apply for the Disability Certificate. Jing cited a Chinese proverb: ‘Domestic shame should not be made public’. 

Chinese mother Qian talked about her daughter who was issued with the Disabled Certificate at Grade Two. ‘I was a little worried, because in the law of succession, people with mental health may not be able to inherit property’.

In addition, interviewees indicated that Hukou restrictions required parents to take their child to the local appointed autism organisations for services. Chun reported that people from Beijing locally could apply for the reimbursement of ¥ 6,000 (£696) from the local authority if the child went to government designated autism organisations. The mother Chang, who lived in Guangdong province, said that local parents receive ¥ 1000 (£116) a month from the local authority. However, Chang was a registered permanent resident of Hunan province and her son could receive free services at Hunan province. She would not be reimbursed for her son undertaking training programmes in Guangzhou (Guangdong province).

Nevertheless, not all regions of China required children to have such a certificate. Wuling, from Shanxi province, said that the local authority of Shanxi did not require parents to have the Disability Certificate, but a confirmation of diagnosis. Nevertheless, many participants of the local areas indicated the service quality from autism organisations could not be guaranteed and many parents were afraid that would prevent the child from receiving the proper intervention. Therefore, many of the parents refused to apply for a Disability Certificate for their child.

Similar to UK, Chinese parents mentioned they could apply for some support from charities such as the One Foundation.

35 ‘Domestic shame should not be made public’ in Chinese: 家丑不可外扬
36 Currency on 30 Jan. 2017
37 Currency on 30 Jan. 2017
6.6 ASD, ABA, and societal and cultural contexts

6.6.1 Acceptance by the society

Participants reported that the public had a much better understanding of children with ASD than before, but there is a long way to go before society completely understands and accepts them.

Both UK and Chinese participants called on the public to see children with ASD as typical children.

*Society doesn’t know and it assumes that the child is misbehaving and it’s because they are spoilt rather than [that] they are going through some issues.*

(UK mother, Mary)

In the UK, there is conflicted opinion about regarding children with ASD as typical children as some think people with ASD should not be changed. Professionals noted that some people believed people with high-functioning ASD might not want to change, while most children on the autism spectrum need to be taught necessary skills to adapt to the society.

*There are a number of high-functioning adults with autism who write newspapers or magazines, they hate ABA because they say what we are doing is coming to change the children; they are just neurologically different, and we should respect their differences and appreciate them. But that does not make sense logically. Would we apply the same logic to everyone, not just [those with] autism? For example, in a classroom lots of children (age 4 or 5) stand up, run around, or throw things, some draw on the wall; should I leave them like that? That’s ridiculous then. Nobody says, hang on a minute, you shouldn’t stop a child hitting themselves, it’s their right to do it.*

(BACB staff and UK BCBA, John)

The Welsh professional Anna said Welsh culture is different from other UK countries. People from Wales speak the same language and have a similar culture, which unifies them.
Most of us are Welsh speakers, and Welsh is a minority language in Britain. That automatically unites us. If you’re all speaking the same language, it’s much easier to introduce new ideas because you are the same people culturally... I think a major factor is the fact that most of us are Welsh speakers and the cultural link binds us together. And most of us, whether we’re in university or schools, are people who will be here a long time. (UK Speech and Language therapist and BCBA, Anna)

Compared with UK, autism awareness in Chinese society still lags behind. Many respondents reported there was discrimination against children and families. In addition, a number of professional interviewees reported that even a lot of Chinese parents themselves could not accept their child was diagnosed with ASD. Parents would hide the fact that their child was with ASD.

In China, parents will see the difference as a problem: My child is different from others. They thought a child flapping the hands in public was an embarrassing thing as typical children won’t do that. In China, we say ‘mianzi’. Child’s different behaviour made parents lose face. It is a problem, so they want to change it. (Beijing AC School, Lihua)

Lihua raised the important problem that in Chinese culture, the words ‘Mianzi’ (reputation or dignity) influenced people’s minds. Lihua and other teachers from Beijing AC School said the first workshop of the parents’ training at the school was to tell parents to accept that their child is different.

In China, the diagnosis of ASD was beyond a medical diagnosis, it also had a social tag. People did not know much about autism. The Chinese mother Wuling, said her families blamed her parental style for causing the child’s autism.

When he was diagnosed, my family knew the results and their implication, but relatives and friends did not. Close family, friends and neighbours did not realise it is a life-long disability, and thought he would recover. They had no idea what caused autism. They attributed his condition to my nurturing style. They said when he was young; I seldom talked to him, interacted with him, or did not take him outside to play. I was under significant pressure.

38 In Chinese 面子
because not only did outsiders not understand me, neither did my family. That prompted me to take my son away for treatment rather than stay at home. It was like an escape, because when I was in those organisations with my son, I had other parents [whose child was also diagnosed with ASD] to talk to, and to understand [the situation]. But as soon as I went home, no one understood. Blame was placed with me, it’s too much! (Chinese mother, Wuling)

Wuling’s experiences were not unique. Bing mentioned that she did not have the courage to share her son’s diagnosis with relatives and friends due to the pressures they would put on her. The word ‘retarded’ is a commonly used label about a person with an intellectual disability in China.

He did not have many skills. If people called his name, he did not reply. These behaviours implied intellectual ability to those less-informed. If people do not understand the characteristics of ASD, he would be definitely labelled as ‘shazi’ (retarded). (Chinese mother, Bing)

When she talked to other mothers whose children were also diagnosed with ASD, she would feel relief as they understood her plight.

ABA was also not readily accepted by the general public. Several professionals reported some people thought ABA was structured and involved intensive table work, which would ‘kill people’s individuality’. This misunderstanding of ABA was not unique to the UK. Several Chinese professionals reported they were confronted by some people who argued that ABA was like training animals.

There was an appeal from the respondents by both UK and Chinese respondents: ABA is for all, not only for children with ASD.

I have my own child [not with ASD]...since I got into ABA, [I learnt] some rules, like some technical skills. If she [her daughter] has inappropriate behaviour, I would direct to her to an acceptable behaviour. It does work on my own daughter as well. (UK tutor, Sharon)
6.6.2 Eclectic approach

It was found that parents blindly tried therapies, regardless of whether they are evidence based or not. Participants of both countries reported the use of eclectic approaches in autism organizations.

*Often eclectic approaches are that, taking some elements that are effective and blending them with other elements that are ineffective.* (BACB staff and UK BCBA, John)

UK professional interviewees indicated some autism organizations combined ‘therapeutic’ approaches such as art therapy, sensory integration, speech therapists, OT, TEACCH with the ABA-based intervention for children with ASD. Similarly, Chinese professional interviewees used phrases like ‘chaotic intervention systems’ or ‘flowers of every kind are in bloom’ or ‘pandemonium’ to describe the various approaches\(^{39}\) such as sensory integration, floor time, TEACCH and auditory integration combined with ABA-based intervention.

Professionals reported people lacked sufficient knowledge towards evidence-based approaches. UK therapist Betty noted that it is very hard to explain to parents those therapies that would not work for their child. *’I think some of them fear that they’ve got nothing to do since they got the challenge. Everything they see [could be] the life that may work for their child’,* said Betty. The same sentiment was observed in China.

Chinese learnt many approaches from other countries. As a result, no matter what scientific methods, they were brought to China.

*The most important part for us is the application of behaviour analysis. For us, we faced children directly. How to deal with the child is most important. We were not clear about the fundamental elements of behaviour analysis and scientific experiments. After all, they did not come from us, so we did not have the basic theory as premise.* (Cui, Beijing AC School)

Mr Cui contributed an important point that most Chinese autism organisations learnt the application of behaviour analysis but ignored the theoretical background. He

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\(^{39}\)Proverbs from English to Chinese: Chaotic intervention systems: 混乱的干预系统; Flowers of every kind are in bloom: 百花齐放; pandemonium: 乌烟瘴气
indicated that ‘experts’ from developed regions were invited to deliver those ‘effective methods’ or professionals travelled outside to learn ‘advanced knowledge or techniques’.

Many interviewees reported that some autism organisations had to adopt eclectic approaches in order to be supported or funded by local authority. UK mother Carol was aware of eclectic approach is not effective after trying different treatments. However, the ABA school had to combine ABA-based intervention with other approaches, such as OT, PE and SALT.

Chinese professional interviewees indicated the CDPF required organisations to be equipped for these approaches in the programme. There was an annual check. ‘If you followed their requirements to do it, that’s totally contrary to what we do’, said Teng from Beijing AC School.

Most professional interviewees disagreed with eclectic approach because they believed that it is not evidence-based. Several UK professional interviewees pointed out there were no interventions implemented or measurable targets defined in an eclectic programme.

So the problem with the eclectic approach is they mix things that don’t work with things that do work, therefore, just water it down and make the things that do work less effective. (BACB staff and UK BCBA, John)

Sometimes, children with autism and special educational needs need to be taught how to relax and how to play.

Simply stopping what they are doing does not necessarily guarantee that they can relax or take a break because they do not know how to relax or to do something enjoyable or meaningful, which of course [is] a part of the problem when children are engaging in stereotypy [rocking and flapping]...Actually, you have to teach particularly young children via EIBI, teach children how to have a break, how to relax and how to play. (BACB staff and UK BCBA, John)

However, several Chinese professionals claimed that even though other approaches were used in the child programme, they were based/used under the disciplines and
techniques of ABA. The two UK professionals, John and Adam, visited some Chinese autism organisations. They were of the opinion that these ABA autism organisations were not really delivering ABA-based interventions.

They said the service is based on the principles of ABA, but actually what I saw, was one-to-one teaching, and not very good one-to-one teaching in some cases. So you know, like many other places in the world assumed, that firstly ABA is a treatment for autism and secondly, it involves one-to-one discrete trial teaching, so therefore, if you are offering one-to-one DTT or something that looks like that by definition, you must be doing ABA, but as we know that it is not true. (UK BCBA and BACB staff, John)

As in most countries, there needs to be an expose of those who claim to offer ABA-services whilst having little or no training in ABA. This is an affront to science and abuse of parents. (UK BCBA-D, Adam)

6.6.3 Different development of ABA

Professional participants described the different history of the development of ABA in each of the countries, which resulted in the different extent of acceptance by the people.

In the UK, professional interviewees indicated a lot of people still think ABA is just one of many interventions and do not understand the science. Several professionals said that ABA was not recommended by the health services system and the government.

They are talking about things like TEACCH, if you go to the National Autism Society; they talk about all sorts of things like SPELL\(^{40}\) and other things that have very little evidence to support them. So the biggest problem is I think the lack of understanding that ABA is an applied science not just an intervention. (BACB staff and UK BCBA, John)

Three of the UK professionals, Anna, John and Adam believed that it relates to the history of dealing with people with ASD. Those who worked with children with ASD in the UK had already used the ‘old’ approaches for many years and these

\(^{40}\) SPELL means Structure, Positive approaches and expectations, Empathy, Low arousal (National Autistic Society, 2016a).
people believed that ABA was only one of these interventions rather a science. It is hard to tell them to accept a new evidence-based approach like ABA.

Why do you think there are so many obstacles to ABA? This is about professional pride and at the same time it is perfectly understandable. If you have been misinformed about ABA then you will react in a way that is determined by the misinformation. When a new discipline appears, the old discipline that is in power will defend itself and block the new one. In addition, the decision to block the new one, ABA, is influenced by the misunderstanding that exists about ABA. If these professionals, from the old discipline think that ABA is bad, cruel etc., then they will do what they can to block it. That seems reasonable to them. And it would be reasonable if their views on ABA were correct. But they are not correct. (UK BCBA-D, Adam)

Adam pointed out that behaviour analysts should be ready to accept the obstacles and to explain the science to those not familiar with behaviour analysis.

Sometimes it’s easier for me to go to a school and say I’m a speech and language therapist than I’m a behaviour analyst. Because it’s an older profession and new professions are not as accepted so easily. So what we have to do is try and be part of the establishment. Sometimes it’s not good to change things too fast. (UK BCBA and Speech and Language therapist, Anna)

In contrast, ABA has come to China later than the UK. In the words of Jing, ‘The first diagnosis of autism happened in the 1980s, and basically, from the year of 2000, Chinese people started to explore methods for children with ASD’. The Beijing AC School was considered to be one of the first autism organisations to carry out ABA-based intervention for children with ASD and they started parent training in the late 1990s.

There were a lot of people ‘passing off fish eyes as [for] pearls’. We did not have any predecessors[to learn from]. (Beijing AC School, Chun)

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The phrase ‘passing off fish eyes as (for) pearls’ means mixing the fictitious with the genuine. Chun used the word of Chinese martial arts chivalry ‘Jianghu (江湖)’, literally meaning ‘rivers and lakes’, metaphorically referring to the charlatan and quacks of the underworld (Wiki, 2016), to describe different ‘experts’ working the area of ASD.
In China, teachers sought external ABA learning, studying abroad or visiting good quality autism organisations for a short term. For example, professional interviewees of Beijing AC School and Qingdao EC School mentioned that the school had arranged for teachers to go abroad to visit ABA organisations every year. However, many Chinese professionals said they faced language barriers. In addition, some autism organisations would invite foreign experts into China to train professionals and parents. All of the founder interviewees said that they frequently invited foreign experts to China to deliver the knowledge of ABA and give them hands-on guidance. However, experts’ visits were generally brief.

*I think, as with the theory and practice learning of ABA, the practice learning is not a big problem for me, but the theory and knowledge is, because we cannot find professional teachers to train us systematically. When experts came to our school, they would always ask what the biggest problem was. They would help us solve it based on problems we faced. However, it is like what we said: the Dance of the Dragonfly*[^42^]. (Chinese professional, Lihua)

Lihua suggested that there is a need for long-term and systematic ABA training in China. The founder of Beijing AC School, Chun, said that AC School had taken the responsibility for training teachers from around the country since its inception. Beijing AC School set up a Teachers’ Training Class for teachers from around the country. Cui, the trainer of the Teacher’s Training Class, said that the school provided elementary and secondary level of ABA training for Chinese professionals. Because of the long waiting list of parents (parents and children dyad) for entering parents-focused training classes, some parents would also enrol to the elementary level of teachers training to learn ABA. After teachers finished the course, they would be certified in completed systematic training at Beijing AC School. As Beijing AC School has a good reputation in the area of ABA in China, many of the Chinese autism organisations acknowledged this certificate. Cui claimed that ‘previously, at least half of the organisations’ founders from small towns or small cities were trained at our school’.

[^42^]: It means touch on something without going into it deeply. In Chinese: 蜻蜓点水. Lihua used this traditional proverb to describe a phenomenon that experts’ teaching is not long-lasting and was not able to solve the shortage of ABA knowledge and professionals in China from its inside.
With development of autism organisations around the country, a number of workshops were provided by different organisations with them, a number of certification programmes came into being. Almost all of the Chinese professional interviewees said that they had a lot of training certificates and had attended different workshops.

*I now had enough certificates! For example, I was undertaking the BCaBA training while before this, I joined in the CNABA\(^4\) which was organised by China Association of Persons with Psychiatric Disability and their Relatives (CAPPDR). I also participated in level one of Pivotal Response Training (PRT), the level one of Floor Time, consultancy training and various domestic ABA training.* (Beijing BC School Founder, Jing)

The problem with such training is that some of it was not provided by experts in the field. In order to meet the educational requirements of the designated autism organisation, teachers were arranged by organisations to take further education, but:

*Some of the trainers only understood a little bit of ABA, had not done thorough research. For example, I came across a trainer who spelled DTT to DTD. When you pointed out their errors, they would even attack us. Some of the training was provided by government and there were university teachers, but I felt they did not understand ABA. There were no universities teaching ABA in China... If only the trainers were from abroad or study abroad, I would go. It is not that we are not co-operative [with government organizers], but we believed we were at least 10 and 20 years ahead of other organisations. We are more professional.* (Beijing AC School, Meiyin)

Some parents reported they used to take their child to some low quality autism organisations and children learnt a lot of inappropriate behaviours. As a result, Lihua (a teacher from Beijing AC School) said: ‘Parents told me they did not trust ABA or even rejected ABA, because their child developed a lot of problematic behaviours and emotions in the local organisations, and he [the child] had obviously regressed.’

\(^4\)Chinese Applied Behaviour Analysis certification by China Association of Persons with Psychiatric Disability and their Relatives (中国精协孤独症工作委员会行为分析师)
John and Adam visited some autism organisations in China. John expressed his opinion that Chinese people would like to know therapies which were effective for children with ASD. ABA-based intervention was welcomed by the majority of Chinese. However, there is a risk of bringing in ‘experts’ who were not well trained which might mislead people.

*What I observed and what I think [is that] there is no history and there is a pressing need to offer something because there’s a growing number of children with autism or there is growing awareness of it as a problem. The Chinese just want something that works and they want it now, they are not interested in the rationale for it or explanation of whether there is a huge amount of research evidence or whether someone says different because there is not anything different, there has never been anything different. So they just want it and they want it now, so they don’t want to mess around and wait a long time. And that’s a good thing in a way. But there’s a problem because there’s not enough people in China that offer it and that is going to result in many people in China, as in rest of the world, appearing and saying, oh oh, I can do ABA and charge a lot of money and probably they cannot, because they are not trained.* (BACB staff and UK BCBA, John)

The autism organisation I visited is keen to embrace the best of what modern science has to offer. Translation difficulties, however, make it difficult to fully appreciate what is needed. ABA [was] not yet being used [in the autism school]. The mark of a science is the collection of data and associated data-based decision making. This is not yet happening to the extent that would be typical for an ABA school. My experience of China is that it is virgin territory with respect to ABA. There is virtually no understanding of ABA but this will change. This is the same as many European countries. Also, like these other countries, when parents find out what has been denied to them they fight for their children. That is how it should be. China is very good at having all-family involvement. The UK tends to leave it solely to mothers. (BCBA-D, Adam)
Adam stated, from an international perspective, that there are going to be changes in the future for people in other countries, including UK and China, leading to an increased acceptance of the science of ABA.

6.7 Chapter summary

Results demonstrated the similarities as, in addition to ABA-based interventions, parents took their children to try different kinds of therapists or ‘treatments’ and sometimes got lost along the way. Both, UK and Chinese parents were looking for a ‘cure’ to ‘treat’ their child with ASD.

There was a difference in health care norms for children with ASD between UK and China. In China, children with disability were cared for by the family. Those children who had severe symptoms mostly stayed at home, but children on the middle- or high-functioning end might be taken by parents for ‘treatment’ or training.

Detailed differences of service delivery of ABA-based programme were specified. Three types of ABA-based programme were found in the UK: Home-based programmes professionals-led, clinical-based programmes professionals-led and school-based professionals-led. Professionals played a leading role in children’s ABA-based programmes. Data collection was a very important part of the home-based ABA programme and professionals were requested to take data before, during and after the intervention for a targeted behaviour. In China, four types of ABA-based programmes were found, i.e., school-based programme parents-focused; clinic-based programmes professionals-led and parents-assisted; school-based programmes professionals-led; and clinic-based programmes professionals-led. Parents were considered to have one of the important roles in the service delivery. The individualised ABA training was considered as one-to-one DTT training and ‘group actives’ involved parents taking an active part. There was a lack of data collection on child’s targeted behaviour in China, especially the first two Chinese service delivery modes.

Interviewees reported little use of EIBI services in the UK and China.

There was a big difference in the application of ABA into schools between UK and China. In the UK, ABA was better established in special unit/department of mainstream school than SEN school. Chinese parents expected their child with ASD
to be included in mainstream schools and hoped ABA would be applied in school in the near future.

Challenges faced by children with ASD in the use of ABA were found to arise from political, societal and cultural factors. Eclectic approaches were utilised in some autism organisations, especially in China. The different history of the development of ABA in each country had resulted in the different extent of acceptance by people.

Systematic training in ABA is very necessary. The improper application of ABA leads parents to doubt ABA. When parents thought the ABA-based programme was ineffective, it was not the programme itself but the professional delivering it. There was an appeal from both UK and Chinese respondents: ABA is for all, not only for children with ASD.
Chapter 7. Results of direct observations

7.1 Overview

In this chapter, the results from Study 3 are reported. In total, 5 parents (2 from the UK and 3 from China) and 3 professionals (1 from the UK and 2 from China) were involved in this study. In addition to quantitative data collected during direct observations of the parents’ and professionals’ work with children with ASD, substantial informal data were collected during conversations with these participants. These data were included as field notes. Some file archives of the organisations were also obtained. The results of the direct observations aim to answer this research question: Is the application of Discrete Trial Training (DTT) the same across cultural divides?

7.2 Parents

Given that DTT was individually tailored, the tasks during the DTT observations were different for each child. The details of each parent-child dyad in the direct observations of parents were as follows:

7.2.1 UK parents

7.2.1.1 Daisy – David

Daisy’s son David had difficulties with language and communication. When he was not able to get the things he wanted, he exhibited tantrum behaviour such as screaming and crying. However, David also screamed when he was playing something he enjoyed or when he was excited by the external environment. Daisy worked on David’s language and communication skills (e.g., pronunciations), mobility skills (e.g., finger strength) and social interaction skills (e.g., waving goodbye, saying hi and waiting).

Treatment fidelity was measured as accuracy levels of discrete trials across four 20-minute observation periods. Table 7.1 shows a clear increase in accuracy from Stage 1 to Stage 4. As such, treatment fidelity in delivering DTTs increased across the 4 observation sessions. The number of tasks completed in 20 minutes also seemed to
increase, although this does not necessarily reflect increased fluency, as the tasks were different at each stage.

Table 7.1: Summary of accurate trials instructed by Daisy

<table>
<thead>
<tr>
<th></th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of trials</td>
<td>60</td>
<td>82</td>
<td>86</td>
<td>90</td>
</tr>
<tr>
<td>Number of inaccurate trials</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Mean score for trials</td>
<td>9.17</td>
<td>9.45</td>
<td>9.67</td>
<td>9.63</td>
</tr>
<tr>
<td>Total trials</td>
<td>63</td>
<td>85</td>
<td>88</td>
<td>91</td>
</tr>
<tr>
<td>Percentage of accurate trials</td>
<td>95.24%</td>
<td>96.47%</td>
<td>97.73%</td>
<td>98.9%</td>
</tr>
</tbody>
</table>

**Stage 1**

Prior to the research, Daisy had little knowledge of ABA-based intervention and how to conduct DTT because David’s home-based ABA programme was started only 2 months prior to the study. Daisy carried out the DTT with David every day.

The task in this session was to discriminate visual cards (e.g., fruits or animals), to identify shapes (in different colours), to recognise 24 alphabet blocks, to match toys (e.g., to match a cat toy with a cat card; to assemble a strawberry toy that came in two parts into a whole ‘strawberry’) and to use some handmade instruments (e.g., to match coloured lids with coloured boxes; to open and close a small plastic bottle). If David was able to follow Daisy’s instructions correctly, Daisy gave David verbal praise. When each task was completed (B), a small piece of cookie was given as a reinforcer (C).

The first observation session contained 63 trials within the 20-minute session. 60 of the trials scored above the threshold of 6 for accuracy described in the methodology (ref Chapter 4- Table 4.15). The average score for the accurate trials was 9.17. During this observation period, 3 trials were scored below this threshold with an average score of 1.67. The ratio between accurate to inaccurate trials was 90:3; 95.24% of trials in this stage were accurate.

For the 3 inaccurate trials (Figure 7.1, Stage 1), there were 2 instances of using a prompt without the reinforcer being delivered i.e., A-P-B, without C. There was 1
instance where Daisy presented the Consequence (C), i.e. the potential reinforcer, by itself without the A or the B.

In this session, it was observed that Daisy asked David to open a plastic bottle’s lid, but David could not open it. Daisy prompted David to open the bottle and David opened it, but Daisy did not give David the reinforcer. In the next trial, when Daisy asked David to open the bottle’s lid independently, David did not open it. The task of opening the plastic bottle’s lid was ended because Daisy thought David could not make it. As David started the ABA programmes recently, Daisy prepared a lot of small tasks for him, for example, to train David to ‘say hi’, sit quietly and point to body parts under instructions. During the visual card discrimination task, Daisy also prompted the child to pronounce and imitate the items on the card. When Daisy asked David to match a cat toy with a cat card, instead of saying ‘where is the cat’, Daisy asked: ‘where does the animal making the sound of Meow Meow go to’? After David matched the right cards, Daisy asked David to pronounce the word (cat).

Between Stage 1 and Stage 2, Daisy attended workshops and conducted online self-learning to increase her knowledge of ABA-based interventions. A child support programme manager from NIU charity came to supervise for two hours every week and to give Daisy feedback on her work with David.

**Stage 2**

The tasks of this stage were similar to Stage 1. Training instruments included visual cards, pictures, toys and some other handmade instruments. Daisy added academic training about counting in this stage. Daisy presented a handmade instrument which was a series of 10 clothes pins that were pasted with 10 silvered colour stars with numbers of 1 to 10 drawn on. During the process, Daisy prompted David to pronounce numbers. The reinforcers used in this stage were the same as with Stage 1, i.e., verbal praise and a cookie at the end of the 20 minutes.

The second observation session contained 85 trials within the 20-minute session; 82 of the trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.45. During this observation period, 3 trials were scored below this threshold with an average score of 3.67. The ratio between accurate to inaccurate trials was 82:3. 96.47% of trials in this stage were accurate.
Of the 3 inaccurate instances (Figure 7.1, Stage 2), the first inaccurate instance was the non-delivery of the consequence despite occurrence of the behaviour (B), i.e., A-B, without C. The second inaccurate instance was the application of C was delivered before Behaviour (B). The third inaccurate instance was the incorrect application of the learn unit with prompt, but C was not delivered.

In this session, David was asked to choose the task he wanted to do first. Daisy continued to study ABA interventions online and receive supervision between Stage 2 and Stage 3.

**Stage 3**
The tasks of this stage began with pointing to the body’s parts, and identifying the colour and the shape of blocks (circle, triangle, square, rectangle and diamond). Daisy also introduced academic learning, such as differentiating between ‘big’ and ‘small’ by presenting different sized bows. Although the instrument was similar, the instructions (A) and prompts (P) given by Daisy to David were changed. Daisy’s physical or gestural prompts were gradually reduced. For example, instead of pointing to her own nose first and saying ‘touch the nose’, Daisy said to David ‘touch the nose’ without any other visual modelling and prompts. The reinforcers used in this stage were the same as with Stage 1 and Stage 2.

The third observation session contained 88 trials within the 20-minute session. 86 of the trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.67. During this observation period, 2 trials were scored below this threshold with an average score of 3. The ratio between accurate to inaccurate trials was 86:2. 97.73% of trials in this stage were accurate.

The 2 inaccurate instances (Figure 7.1, Stage 3), were related to the non-delivery of the consequence despite occurrence of the behaviour, i.e., A-B, without C. Daisy continued with studying ABA-based interventions between Stage 3 and 4.
**Stage 4**

In the final observation, visual items, colour shapes and toys/cards were provided. Daisy introduced some household items for David to discriminate door and table. Daisy also introduced more daily living skills, such as drinking water appropriately (open the bottle’s lid-drink water-close the bottle), differentiating between Mum’s water cup and child’s water bottle, putting the spoon into the bowl. Tasks were broken down into several units in this session. The reinforcers used in this stage were the same as with the previous three stages.

The final observation session contained 91 trials within the 20-minute session; 90 of the trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.63. During this observation period, 1 trial scored below the threshold with a score of 1. The ratio between accurate to inaccurate trials was 90:1; 98.9% of trials in this stage were accurate.

The inaccurate trial was the one where Daisy presented the Consequence (C), i.e. the potential reinforcer, by itself without the A or the B (Figure 7.1, Stage 4).

In this session, Daisy learnt to make the imitation tasks more complicated for David. For example, Daisy gave an instruction and said ‘Do this’! She did the following steps: pointing to her head, pointing to her ears, knocking the table, and then standing up, which meant David had to remember what Daisy just did and to imitate. In addition, Daisy moved the work of the table-top tasks. She walked to the door and showed David how to close and open the door, and then, David was asked to close and open the door. Daisy took David’s hand to close the door (physical prompt) when he was not able to close it.
Figure 7.1: Accuracy levels during discrete trials for Daisy
7.2.1.2 Mary - Mark

Mary’s son, Mark, had a good language competency. However, it was hard for Mark to interact with peer groups in school. Mary worked on developing Mark’s social communication and interaction skills (e.g., waiting, turn-taking, asking for help) and improving his basic academic skills and imagination.

The data collected here was after Mary carried out the parents’ training for Mark for around 12 months. Mark was mostly trained using Natural Environment Training (NET, using the principles of ABA to teach in a natural setting; (Sundberg & Partington, 1998) by an ABA therapist at this stage but he was also trained using DTT in academic skills. Mary was asked to show the researcher how she conducted DTT with Mark.

Treatment fidelity was measured as accuracy levels of the discrete trials across four 20-minute observation periods. Table 7.2 shows Mary maintained accuracy delivering DTTs across the 4 observation sessions.

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<thead>
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<th></th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of accurate trials</td>
<td>49</td>
<td>35</td>
<td>17</td>
<td>15</td>
</tr>
<tr>
<td>Number of inaccurate trials</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mean score of accurate trials</td>
<td>8.92</td>
<td>9.71</td>
<td>9.23</td>
<td>9.07</td>
</tr>
<tr>
<td>Mean score of inaccurate trials</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Total trials</td>
<td>49</td>
<td>35</td>
<td>17</td>
<td>15</td>
</tr>
<tr>
<td>Percentage of accurate trials</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Stage 1**

Prior to the research, Mary had enrolled in a part time MSc (ASD) programme at a local university in the UK. She had a good knowledge of ABA-based interventions. Mary carried out the ABA-based intervention with Mark every day.

The tasks in this session were copying pictures using crayons. Mary presented a drawing book depicting a clear shape on each page (Figure 7.2) and she asked Mark which picture he would like to copy. Mark chose the submarine picture. Mary waited for him to mand the crayon he needed. In this task, Mary gave Mark instructions (A),
for example, what colour do you need/want; what is the next step, and what is the colour of the sea.

Figure 7.2: Submarines captured from the internet (AZ Colouring, 2012)

Mary presented two token boards for Mark to display reinforcers. The token (C) was given after each of Mark’s target responses. A ‘star’ token board was introduced after Mark received 10 tokens and he earned 1 star for every 10 tokens. After obtaining 5 stars, Mark was allowed to take a 10-minute break and select a gift to play with from a ‘surprise bag’. The ‘surprise’ bag was specially prepared by Mary and it contained Mark’s favourite toys.

The first observation (Figure 7.5, Stage 1) session contained 49 trials within the 20-minute session. All of the 49 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 8.92. The percentage of accurate trials was 100%.

In this session, Mary also trained Mark to colour-in within the lines and to use the necessary strengths, pressing down on the crayons, to deposit colour onto the paper. It was observed that Mary gave Mark many physical prompts during the colouring.

Between Stage 1 and Stage 2, Mary attended workshops and continued her MSc course at the University. An ABA therapist came to work for Mark every week and Mary could watch the therapist’s work with Mark and listen to the therapist’s advice.
**Stage 2**

The task in this session was drawing pictures. Mary aimed to help Mark to generalise the skills learnt from copying pictures (in Session 1) to drawing pictures freely on blank sheets. Mary prepared a small blackboard and chalks for Mark to copy the image. Mary gave Mark oral instructions, e.g., ‘what is the window of the submarine?’ and ‘how about the telescope?’ After Mark finished drawing the submarine on the blackboard, Mary provided Mark with several blank sheets of paper. Mark was then able to draw a picture from his imagination (Figure 7.3). The reinforcers used in this stage were the same as with Stage 1.

![Submarine copied from drawing book](image1.png)  ![Submarine drawn by imagination](image2.png)

**Figure 7.3:** Mark’s drawing generalisation procedure

(Permission was granted for the use of this photo)

The 2\textsuperscript{nd} observation (Figure 7.5, Stage 2) session contained 35 trials within the 20-minute session. All of the 35 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.71. The percentage of accurate trials was 100%.

In this session, it was observed that DTT was used in a natural environment. The physical and oral prompts were gradually faded when Mary found that Mark was doing the task of drawing correctly. In addition, Mary gave instructions to Mark when he paid attention. For example, Mary asked Mark during his drawing: ’where can you find the submarine?’ Mark answered, ‘the sea’. Mary said, ‘you know what, I would definitely give a token for such an excellent say’.
Between Stage 2 and Stage 3, Mary continued with her professional development.

**Stage 3**
The task of this session was academic learning, arranging 24 alphabets from A-Z. Mary scattered all the blocks on the table. Mark was asked to pick from the blocks and to place them in order (Figure 7.4). The reinforcers used in this stage were the same as with Stage 1 and Stage 2.

![Image of alphabet blocks](image)

Figure 7.4: Example of 24 alphabet blocks (My Wooden Toys, 2016)

The 3rd observation (Figure 7.5, Stage 3) session contained 17 trials within the 20-minute session. All of the 17 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.23. The percentage of accurate trials was 100%.

In this session, Mary placed three alphabet blocks (e.g., letter I, letter S, letter T) for Mark and asked Mark to finish the rest. After that, Mary placed two alphabet (e.g., letter H and letter I) blocks for Mark and asked Mark to finish the rest.

Between Stage 2 and Stage 3, Mary continued with her professional development.

**Stage 4**
The task of Stage 4 was the same as with Stage 3. Though the same instrument was used, the way of presenting instructions (A) by Mary was different (described below). Specifically, Mary started by placing the first two letters of the alphabet for Mark,
then reduced to one letter of the alphabet and finally used oral instructions only. In the end, arrangement of alphabet blocks was achieved without physical instructions but by oral instruction only, for example, ‘Mark, let’s build alphabet blocks! What is the next after letter E’? Mary also reduced the physical prompt but with more verbal prompt.

The reinforcers used in this stage were the same as with the previous three stages.

The final observation (Figure 7.5, Stage 4) contained 15 trials within the 20-minute session. All of the 15 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.07. The percentage of accurate trials was 100%.
Figure 7.5: Accuracy levels during discrete trials for Mary
7.2.2 Chinese parents

7.2.2.1 Ling - Yun

Ling’s son, Yun, had difficulties with language and social communication. When Yun wanted something but could not get it immediately, he expressed this by crying and screaming rather than using vocal expressions. Ling worked on Yun’s verbal communication and academic skills.

Treatment fidelity was measured as accuracy levels of discrete trials across four 20-minute observation periods. Ling’s treatment fidelity in delivering DTTs showed clear improvement across the 4 observation sessions from Stage 1 to Stage 4 (Table 7.3). The speed in finishing a task in 20 minutes was not taken into account (i.e., the increases in number of trials completed could not necessarily be considered increases in fluency) because tasks were different at each stage.

Table 7.3: Summary of accurate trials instructed by Ling

<table>
<thead>
<tr>
<th></th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of accurate trials</td>
<td>16</td>
<td>18</td>
<td>31</td>
<td>32</td>
</tr>
<tr>
<td>Number of inaccurate trials</td>
<td>9</td>
<td>14</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Mean score of accurate trials</td>
<td>9.25</td>
<td>9.28</td>
<td>8.87</td>
<td>9.38</td>
</tr>
<tr>
<td>Mean score of inaccurate trials</td>
<td>3.00</td>
<td>2.57</td>
<td>4.13</td>
<td>3.00</td>
</tr>
<tr>
<td>Total trials</td>
<td>25</td>
<td>32</td>
<td>39</td>
<td>37</td>
</tr>
<tr>
<td>Percentage of accurate trials</td>
<td>64.00%</td>
<td>56.25%</td>
<td>79.49%</td>
<td>86.49%</td>
</tr>
</tbody>
</table>

Stage 1

Prior to the research, Ling had little knowledge of ABA-based intervention and how to conduct a DTT. She had begun parent training one week before the first observation took place at Stage 1.

The task in this session was visual cards discrimination. Ling presented cards about places (e.g., hospital, school and police station). First, Ling asked Yun to give her one card. Secondly, Ling requested Yun to give her two cards, and subsequently Ling requested Yun to give her three cards. If Yun was able to correctly answer
Ling’s request or be able to correctly follow Ling’s instruction, Ling praised Yun directly. If Yun finished one task, Ling gave him access to the reinforcer, for example, a cup of water (C).

The 1st observation (Figure 7.6, Stage 1) had 25 trials in the 20-minute session: 16 of the trials scored above the threshold of 6 for accuracy described in the methodology (Chapter 4- Table 4.15). The average score for the accurate trials was 9.25. During this observation period, 9 trials were scored below this threshold with an average score of 3.00. Thus, accurate to inaccurate trials were conducted at a ratio of 16:9. The percentage of accurate trials was 64.00% at this stage.

At Stage 1, DTT was conducted under close supervision of a teacher and focused on visual cards discrimination. While the treatment fidelity was relatively high, the main cause for inaccuracy was that the consequence, i.e., the reinforcer was not delivered. In one of the trials, drinking water was used as a reinforcer. The child opened the lid of the bottle and drank some of the water but subsequently played with the bottle. Mother turned to the teacher and said: “He is not willing to return the lid to me!”

Between Stage 1 and Stage 2, Ling was trained regularly by ABA teachers (Chapter 4- Table 4.15) at AC school, which mainly focused on the A-B-C sequence of DTT.

**Stage 2**

At this session, the parent-child dyad in the class gradually got familiar with each other. The teacher asked the parents to lead their own child to the front to introduce themselves to everybody. Ling’s son Yun, jumped to the front, with his mum standing behind him. Ling modelled the sentence by speaking slowly and Yun imitated by echoing: ‘Hi! Everyone! My name is Yun. I am 4 years old. I hope you will like me!’ After that, Ling began the DTT with her son.

The DTT task in this session was still focussing on visual cards discrimination. The difference from Stage 1 was that the consequence was presented with a time delay, as Ling waited for a few seconds to allow the child to echo rather than presenting reinforcers directly. For example, she held a toy or a piece of chocolate in the child’s view for a few seconds and said ‘Yun, say, I want chocolate’. Once Yun echoed ‘I want the chocolate’, he received the piece of chocolate and was allowed to eat it.
The 2\textsuperscript{nd} observation (Figure 7.6, Stage 2) had 32 trials in the 20-minute session, of which 18 trials scored above the threshold of 6 for accuracy described in the methodology. The average score for the accuracy during these trials was 9.28. During this observation period, 14 trials were scored below this threshold with an average accuracy score of 2.57. Thus, accurate to inaccurate trials were conducted at a ratio of 18:14. The percentage of accurate trials was 56.25% at this stage.

Of the 14 inaccurate trials in this stage, there were 2 instances of incorrect manipulation by presenting the consequence before the behaviour had occurred (i.e., A-C-B rather than A-B-C). There were 5 instances of non-delivery of the consequence despite occurrence of the behaviour, i.e., A-B, without C. There were 2 instances of using a prompt without the reinforcer being delivered i.e., A-P-B, without C. There were 5 instances where Ling presented the consequence (C), i.e. the potential reinforcer, by itself without the A or the B, and Yun did not pay any attention to the ‘reinforcer’.

Interestingly, when the teacher asked Ling how many inaccurate trials she had conducted during this session, Ling was unable to recall and she said “did not remember”.

Between Stage 2 and Stage 3, Ling was trained regularly by ABA teachers (Chapter 4- Table 4.15) at AC school, which mainly focused on the A-B-C sequence of DTT.

**Stage 3**

During this session Ling aimed to train the child to identify different body parts and to tell different facial expressions, verbal language, and cards discrimination (venues, animals and food). Ling presented antecedent (A) instructions such as ‘Yun, where is your hair’ or ‘Can you do this’. Ling also asked Yun to give her smiling face, angry face or anxious face. As with the visual cards discrimination, Ling prompted the child to echo, i.e., Ling said ‘follow me, say car’, and the child said ‘car’. At this stage, Ling also let the child choose the reinforcer that he wanted (C) from a box of toys.

The 3\textsuperscript{rd} observation (Figure 7.6, Stage 3) session had 39 trials in the 20-minute session, of which 31 scored above the threshold of 6 for accuracy described in the
methodology. The average score for the accurate trials was 8.87. During this observation period, 8 trials were scored below this threshold with an average score of 4.13. Thus, accurate to inaccurate trials were conducted at a ratio of 31:8. The percentage of accurate trials increased to 79.49% at this stage. The accuracy score of the inaccurate trials also increased, slightly.

At Stage 3, there were 8 inaccurate trials. To be specific, there were 3 instances were A-C-B procedures were used, thus evidencing incorrect manipulation, because consequences were given before behaviour. There were 5 instances of A-B, without C procedure indicating inaccurate manipulation because the consequence, i.e., the reinforcer, was not delivered. For example, Yun kneeled on the chair rather than sat on it and Ling gave him a toy to play with and asked him to sit well. The child did not follow the request but, when the mother took away the toy, he began to scream. He quietens down when the mother left the toy beside him.

Between Stage 3 and Stage 4, Ling continued with her professional development.

**Stage 4**

The tasks for this session were instructions like ‘Do this’, ‘what is he doing’, and matching to the right pictures. At this stage, antecedent instructions (A) had become a warm-up session, because the child was able to achieve these goals. Then, Ling prepared some real items, such as fruit, so the child could learn to match it with the real pictures. This generalisation procedure allowed the child to identify real life items, thus the trial was not restricted to pictures.

The final observation (Figure 7.6, Stage 4) had 37 trials in the 20-minute session, of which 32 trials scored above the threshold of 6 for accuracy described in the methodology. The average score for the accurate trials was 9.38. During this observation period, 5 trials were scored below this threshold with an average score of 3.00. Thus, accurate to inaccurate trials were conducted at a ratio of 32:5. The percentage of accurate trials increased to 86.49% at this stage.

At Stage 4, there were 5 inaccurate trials, in which the procedure of A-B, but without C, was manipulated, because the consequence, i.e., the reinforcer, was not delivered.
Figure 7.6: Accuracy levels during discrete trials for Ling
7.2.2.2 Meimei – Cheng

Meimei’s son, Cheng, had difficulties with vocal language and social communication. Meimei aimed to improve Cheng’s language development and his social skills, such as asking for help and sharing toys with peers.

Treatment fidelity was measured as accuracy levels of discrete trials across three 20-minute observation periods. Table 7.4 shows Meimei maintained the accuracy of DTTs across the 3 observation periods.

Table 7.4: Summary of accurate trials instructed by Meimei

<table>
<thead>
<tr>
<th></th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of accurate trials</td>
<td>56</td>
<td>50</td>
<td>79</td>
</tr>
<tr>
<td>Number of inaccurate trials</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mean score of accurate trials</td>
<td>9.09</td>
<td>9.56</td>
<td>9.78</td>
</tr>
<tr>
<td>Mean score of inaccurate trials</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Total trials</td>
<td>56</td>
<td>50</td>
<td>79</td>
</tr>
<tr>
<td>Percentage of accurate trials</td>
<td>100 %</td>
<td>100 %</td>
<td>100 %</td>
</tr>
</tbody>
</table>

Stage 1

Prior to the research, Meimei had little knowledge of ABA-based intervention and how to conduct DTT. She had begun parent training three weeks before the first observation took place at Stage 1. Three observation sessions of Meimei and Cheng were completed.

The task of this session was imitation, visual cards discrimination and recognising household items. Meimei prepared the household items, such as toothbrush, cup and toothpaste. In addition, Meimei aimed to train Cheng to speak louder as his voice was low when answering questions. If Cheng was able to answer Meimei or be able to correctly follow Meimei’s instruction, Meimei praised and kissed Cheng. After each completed task (B), Meimei let Cheng play on the cell phone for 1 minute. A timer was placed beside it to count down the time as a reminder.

The 1st observation (Figure 7.7, Stage 1) contained 56 trials within the 20-minute session. All 56 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.09.
In this session, Meimei presented visual cards to match with common household items, for example, after Cheng correctly pronounced toothbrush, cup and toothpaste on the cards. Meimei asked Cheng to pass her the real toothbrush, cup and toothpaste. Meimei engaged Cheng’s attention to teach him new skills. For example, Meimei found that Cheng was very interested in the cups he picked up. Meimei utilised this interest to teach Cheng the steps in brushing his teeth, i.e., grabbing a cup, filling it with tap water and squeezing toothpaste onto the toothbrush. In addition, Meimei alternated simple motor skills into the task so Cheng could build up his confidence. For example, follow me and make a circle (hands) or touch the belly.

Between Stage 2 and Stage 3, Meimei was trained regularly by ABA teachers at AC school. The teaching content was chaining and DTTs. The content of DTTs was reviewed as homework.

**Stage 2**

In the second observation, Meimei prepared plasticine to train Cheng in academic skill and prepared an airplane toy to develop his imagination. All of these tasks involved vocal expressions. The reinforcers used in this stage were the same as with Stage 1.

The 2nd observation (Figure 7.7, Stage 2) contained 50 trials within the 20-minute session. All 50 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.56.

At the beginning of this session, Cheng was crying and resisted sitting down for work because he was playing with colouring pens on the table. Meimei asked Cheng to put all the pens back into the box, but Cheng would not listen and kept crying. Meimei ignored Cheng’s crying and insisted that he put the pens back into the box. After 10 minutes, Cheng packed up the colouring pens and Meimei started the session.

Meimei started by asking Cheng to point to eyes, hair and clap hands. Then Meimei moved to playing with plasticine. She let Cheng choose the colour of plasticine he wanted to play with. Then, Meimei divided the plasticine into several small parts and asked the child to count numbers and to identify between small and big. Meimei also asked, ‘Cheng, can you show Mummy five pieces of plasticine’ (A). Meimei also
alternated some smaller tasks into it, for example, she would ask Yun, ‘what’s your age/mother’s name/father’s name’. In the imagination development task, Meimei pretended that there was a fireman on the airplane and the forest was on fire. Meimei prompted and triggered Cheng to continue the next scene of this story. During this procedure, it was observed that Cheng was able to speak a lot of words and finished the story.

Between Stage 2 and Stage 3, Meimei continued with her professional development.

**Stage 3**

The aim of this session was to improve Cheng’s intraverbals skill (conversational language). Meimei prepared visual cards, household items and toys in this session. The reinforcers used in this session were the same as with Stage 1 and Stage 2.

The 3rd observation (Figure 7.7, Stage 3) contained 79 trials within the 20-minute session. All of the trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.78.

In this session, Meimei asked, ‘what is it (spoon)’? After the child gave the right answer, Meimei would continue to ask, ‘what is spoon used for’, ‘is it (spoon) long or short/big or small’? Meimei also presented cards (animals, household items and food) for Cheng to identify, but this time, she generalised the item showing on the card to real items around the house. For example, one picture showed a light bulb and Meimei asked, ‘Cheng, can you show Mummy where else you could find a light bulb in this room?’ Cheng looked around and pointed to a light bulb on the ceiling.

When Cheng identified the animal visual cards, Meimei also asked him to show her the corresponding animal toys around the room. Meimei taught Cheng direction words (up and down). For example, Meimei asked: ‘where are your feet’. Cheng answered: ‘under the table’!

Stage 3 was the last observation. Meimei told the researcher that she ranked No. 1 in her exam in Friday’s morning assessment.
Figure 7.7: Accuracy levels during discrete trials for Meimei
7.2.2.3 Wangjun – Xiaobao

Wangjun’s son, Xiaobao, had difficulties with language and social communication. Wangjun’s homework was recorded by videos (ref. procedure section of Chapter 4: Methodology) and four observations were selected with a one week interval between each observation.

Treatment fidelity was measured as accuracy levels of discrete trials across four 10-minute observation periods. Table 7.5 shows an increase in accuracy from Stage 1 to Stage 4. Wangjun’s treatment fidelity in delivering DTTs increased over 4 observation sessions.

Table 7.5: Summary of accurate trials instructed by Wangjun

<table>
<thead>
<tr>
<th></th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of accurate trials</td>
<td>16</td>
<td>18</td>
<td>34</td>
<td>14</td>
</tr>
<tr>
<td>Number of inaccurate trials</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Mean score of accurate trials</td>
<td>9.25</td>
<td>8.67</td>
<td>8.97</td>
<td>9.5</td>
</tr>
<tr>
<td>Mean score of inaccurate trials</td>
<td>2</td>
<td>5</td>
<td>4.5</td>
<td>N/A</td>
</tr>
<tr>
<td>Total trials</td>
<td>18</td>
<td>22</td>
<td>36</td>
<td>14</td>
</tr>
<tr>
<td>Percentage of accurate trials</td>
<td>88.89%</td>
<td>81.82%</td>
<td>94.44%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Stage 1

Prior to the research, Wangjun had little knowledge of ABA-based intervention and how to conduct DTT.

The task in this session was visual cards discrimination (one showing a child drinking water and the other showing a child brushing the teeth) and a drinking bottle. If Xiaobao was able to follow Wangjun’s instruction or answer his question correctly, Wangjun praised him. Wangjun gave Xiaobao a toy to play with for around 30 seconds after finishing 3-4 trials during the visual cards discrimination task. Xiaobao was also given the opportunity to choose the toy he wanted to play with.

The 1st observation (Figure 7.8, Stage 1) contained 18 trials within the 10-minute session: 16 of the trials scored above the threshold of 6 for accuracy described in the
methodology. The average score for the accurate trials was 9.25. During this observation period, 2 trials scored below this threshold with an average score of 2.00. Thus, accurate to inaccurate trials were conducted at a ratio of 16:2. The percentage of accurate trials was 88.89% at this stage.

The 2 inaccurate instances, were the incorrect application of the learning unit with prompt (A-P-B), because no Consequence (C) was delivered. Wangjun helped Xiaobao pick up the right card, but did not give him reinforcers.

In this session, Wangjun taught Xiaobao to discriminate the drinking water cards and brushing teeth card. At first, Wangjun placed four cards in front of Xiaobao and asked him to give two of them but Xiaobao did not follow the instruction. Then, Wangjun realised he needed to reduce the level of difficulty and took away two cards. Wangjun asked the child to give the drinking water card first and then to give the brushing teeth card. After the visual cards discrimination section, Wangjun presented a real drinking water bottle and asked Xiaobao: ‘what is this and what is this used for’?

Between Stage 1 and Stage 2, Wangjun was trained regularly by ABA teachers at AC School, in which the A-B-C sequence of DTT was reviewed as homework.

**Stage 2**

The tasks in this session were imitation skills and visual cards discrimination (plate, watering can, telescope and football). The reinforcers in this session were the same as in Stage 1.

The 2nd observation (Figure 7.8, Stage 2) contained 22 trials within the 10-minute session: 18 of the trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 8.67. During this observation period, 5 trials were scored below this threshold with an average score of 5.00. Thus, accurate to inaccurate trials were conducted at a ratio of 18:4. The percentage of accurate trials was 81.82% at this stage.

Of the 4 inaccurate instances, there were 3 instances of incorrect application of the learn unit without prompt because Consequence (C) was delivered before Behaviour
(B) and 1 instance of application of the learn unit without prompt because no Consequence was delivered (A-B, no C).

In this session, Wangjun asked Xiaobao to imitate knocking on the table three times, but Xiaobao was not able to follow the rhythm (two quick knocks first and one slow knock). During the imitation skills training, Wangjun alternated 4 visual cards and asked him to name the items on cards. If Xiaobao answered wrongly, Wangjun corrected it. There was one card showing telescope. Wangjun took out a real telescope and asked Xiaobao to match them.

Between Stage 2 and Stage 3, Wangjun continued with her professional development.

Stage 3

The tasks of this session were identifying daily use items (shampoo), visual cards discrimination and name/age answer. The reinforcers in this session were the same as Stage 1 and Stage 2.

The 3rd observation (Figure 7.8, Stage 3) contained 36 trials within the 10-minute session: 34 of the trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 8.97. During this observation period, 2 trials were scored below this threshold with an average score of 4.50. Thus, accurate to inaccurate trials were conducted at a ratio of 34:2. The percentage of accurate trials was 94.44% at this stage.

Of the 2 inaccurate instances, there was 1 instance of incorrect application of the learn unit without prompt, because no Consequence (C) was delivered (A-B, no C) and the other was the incorrect application of the learn unit without prompt because Consequence (C) was delivered before Behaviour (B).

In this session, Wangjun presented the shampoo in front of Xiaobao and asked him questions of ‘What is this and what is this used for’. It was observed that the task was not oriented to child’s interest because Xiaobao knew each answer but did not answer to the corresponding question. For example, Xiaobao answered shampoo when asked ‘what is this used for.’ When Wangjun gave him a toy for completing one task, Xiaobao shook his head, which indicated that Xiaobao was not interested in the reinforcer, so Wangjun gave him a box of toys and let him choose. In the visual
cards discrimination, Wangjun presented cards of flowers (sunflower, lily and rose) and cards of stationery (notebook and stapler) so Xiaobao could categorise the cards. Finally, Wangjun asked Xiaobao questions like, ‘what is your name/age’?

Between Stage 3 and Stage 4, Wangjun continued with his professional development.

**Stage 4**

The tasks of this session were visual coloured blocks (triangle, square and circle) discrimination and recognition of everyday items (pen). The reward for finishing a task was playing on an electronic device.

The 4th observation (Figure 7.8, Stage 4) contained 14 trials within the 10-minute session. All of the trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.50.

In this session, it was observed that Xiaobao was interested in doing the task. He was able to finish the coloured blocks with different shapes.
Figure 7.8: Accuracy levels during discrete trials for Wangjun
7.3 Professionals

The work of four professionals was recorded in the data analysis. In the UK, the direct observation was carried out between Jane and Lily. In China, direct observations were carried out between Xiaohong and Yun. Observations of other classes in Beijing AC School are also reported here.

7.3.1 UK professional

Jane’s (the therapist) client, Lily (Lucy’s daughter), had difficulties in social communication and social interaction. Lily’s parents bought the needed instruments based on the Independent Education Plan (IEP) and the supervisor’s advice.

Treatment fidelity was measured as accuracy levels of discrete trials across three 20-minute observation sessions. Table 7.6 shows Jane maintained accuracy in the delivery of DTTs across the three observation sessions.

<table>
<thead>
<tr>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of accurate trials</td>
<td>60</td>
<td>75</td>
</tr>
<tr>
<td>Number of inaccurate trials</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mean score of accurate trials</td>
<td>9.07</td>
<td>8.89</td>
</tr>
<tr>
<td>Mean score of inaccurate trials</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Total trials</td>
<td>60</td>
<td>75</td>
</tr>
<tr>
<td>Percentage of accurate trials</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

**Session 1**

At the beginning, the child, Lily remained silent and looked away when Jane asked her questions. Jane switched to easy tasks. She said “Hi, Lily.” And Lily said “Hi” back. Jane started asking what her name/mother’s name was.

In the first observation, two types of visual cards were presented. The first were regular visual cards and the second were visual card pairs. The regular cards consisted of a graphic with corresponding words to describe the graphic, for example, a figure of a building followed by the word ‘building’. Visual card pairs were pairs
of visual cards with the same graphics used for the tasks such as identifying matching pairs. Jane also performed speech therapy with Lily. Jane used training sheets provided by a speech therapist to practise pronouncing words such as ‘snowman, sheep, snail and sleep’. Jane used some of body parts to prompt Lily for an answer, for example, touch your ear/hair/head.

The 1\textsuperscript{st} observation (Figure 7.9, Session 1) contained 60 trials within the 20-minute session. All of the 60 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.07. The percentage of accurate trials was 100%. There was one week between Stage 1 and Stage 2.

\textbf{Session 2}

In the second observation, Jane presented Lily with cards containing two pictures to show the concept of ‘before’ and ‘after’. For example, the dog was dry before it stepped into the water but it was wet after it stepped into the water. Jane also presented cards indicating a graphic with corresponding words to describe the category which it belonged to, for example, a figure of a school/house/hospital belonged to building or a figure of carrot belonged to vegetables. Again, body parts were used to prompt Lily for an answer, for example, touch your ear/hair/head.

The 2\textsuperscript{nd} observation (Figure 7.9, Session 2) contained 75 trials within the 20-minute session. All of the 75 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 8.89. The percentage of accurate trials was 100%.

There was one week between Stage 1 and Stage 2.

\textbf{Session 3}

In the third observation, Jane presented Lily with picture cards that represented stories. For example, if asked, ‘What is she doing’, the picture showed a girl sitting on the chair. Again, body parts were used to prompt Lily for an answer.

The 3\textsuperscript{rd} observation (Figure 7.9, Session 3) contained 91 trials within the 10-minute session. All of the 91 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 8.85. The percentage of accurate trials was 100%.

276
Jane prepared stickers showing Lily’s favourite cartoon images as reinforcers. A cartoon token board was introduced after Lily received 10 stickers and she earned 1 star for every 10 stickers. After obtaining 5 stars, Lily was allowed to take a long break (10-15 minutes) and have a chocolate button.

Finally, it was observed that the supervision meeting happened once a month (2 hours) in this ABA home-based programme, where the supervisor (Jenifer, BCBA, see UK participants of Chapter 4-Methodology), the therapist Jane and Lily’s mother Lucy would work to review and discuss the IEP and made decisions for the next stage. After this supervision meeting, Jenifer also summerised their discussion and deribed what was going on in that supervision meeting and emailed everybody.
Figure 7.9: Accuracy levels during discrete trials for Jane
7.3.2 Chinese professionals

The direct observations at the Chinese sample site were different from those of the UK, because the type of service delivery was different (See Pilot study). In Beijing AC School, one teacher managed a class of 10 students. For example, the teacher Lihua asked one of the students to the front of the classroom for a practical demonstration of ABA-based intervention. It was not possible for the researcher to record data at one-week intervals between the teacher and the student like the UK therapist Jane and her client Lily. Hence, the data recorded here was continuous data from day 1 to day 2.

7.3.2.1 Xiaohong- Yun and Cheng

Yun and Cheng were students from Class X which included children with moderate autism spectrum disorder. The majority of the 10 children showed difficulties in language and social communication.

Xiaohong (the teacher) demonstrated ABA-based practice for Class X, in which 10 parents brought their child to the class. The teacher asked one of the children to come to sit in front with her and demonstrated to the whole class how she conducted an intervention based on the child’s IEP.

Treatment fidelity was measured as accuracy levels of discrete trials across two observation periods. Table 7.7 shows Jane maintained accuracy delivering DTTs across the two observation sessions.

Table 7.7: Summary of accurate trials instructed by Xiaohong

<table>
<thead>
<tr>
<th></th>
<th>Session 1</th>
<th>Session 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of accurate trials</td>
<td>17</td>
<td>61</td>
</tr>
<tr>
<td>Number of inaccurate trials</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mean score of accurate trials</td>
<td>8.82</td>
<td>9.36</td>
</tr>
<tr>
<td>Mean score of inaccurate trials</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Total trials</td>
<td>17</td>
<td>61</td>
</tr>
<tr>
<td>Percentage of accurate trials</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>
**Session 1: Xiaohong-Yun**

The first time when the researcher recorded was between Xiaohong and Yun (Ling’s son). Xiaohong brought her own teaching instruments (reinforcers, such as toys and candies) with her and she also asked for the reinforcers brought by Yun’s mother. These reinforcers were a part of their homework instruments. This teaching demonstration happened after the practical demonstration between Ling and Yun (See Section 7.2.2.1 of this chapter, Ling-Yun: Stage 1). Xiaohong’s teaching demonstration was finished in 15 minutes so it was not possible to record a 20-minute observation.

In the 1st observation (Figure 7.10), Xiaohong was working with Yun. The instruments presented by Xiaohong were visual cards. Visual cards showed a graphic with corresponding words to assorted categories, for example, flowers/animals/buildings.

It was observed that Xiaohong also presented 5 coins for Yun to insert into a hand-made box during the waiting period so that Xiaohong was able to prepare other materials.

The 1st observation (Figure 7.10) contained 17 trials within the 15-minute session. All 17 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 8.82. The percentage of accurate trials was 100%.

![Figure 7.10: Accuracy level of discrete trials for Xiaohong (Session 1)](image-url)
If Yun correctly answered Xiaohong’s request or was able to correctly follow Xiaohong’s instruction, Yun was rewarded by being allowed to play with a toy for 1 minute.

After this demonstration, Xiaohong explained why she did that and the key points parents should pay attention to when working with their child. As Xiaohong’s teaching demonstration happened after mother Ling’s practical demonstration, Xiaohong also gave Ling feedback that reinforcers are not limited to toys and candies but also include social activities. She told the whole class that mothers could use social activities as reinforcers, for example games involving body movement. Xiaohong also pointed out parents should change the way they placed cards in front of the child because when placing cards in one row, the child made fewer mistakes. When cards were placed in two rows, the child made more mistakes. The learning procedure should be changed occasionally in order to make sure the child had really mastered the target behaviour.

**Session 2: Xiaohong-Cheng**

This session was between Xiaohong and Cheng (Meimei’s son). Similar to the previous session, Xiaohong had her own teaching instruments as well as reinforcers brought by Meimei. This teaching demonstration was more than 20 minutes. A 20-minute session was randomly selected for observation.

In the 2nd observation, Xiaohong was working with Cheng. The instruments presented by Xiaohong were visual cards. Visual cards showed a graphic with corresponding words, for example, flowers/clothes/animals. If Cheng correctly answered Xiaohong’s request or was able to correctly follow Xiaohong’s instruction, he was rewarded by being allowed to play with a toy for 1 minute.

The 1st observation (Figure 7.11) contained 61 trials within the 20-minute session. All of the 61 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.36. The percentage of accurate trials was 100%.

Xiaohong counted down from 10 to 1 when asking Cheng to return the toy. When Cheng returned it immediately, Xiaohong would reward him with another 30 seconds to play with it and she said: ‘Because you returned the toy to me very well, I will let you play for a while.’
In addition, it was observed that Cheng was distracted by the noisy toys of other children during the demonstration. Parents brought the children to the class and teachers required parents to control their child to maintain the classroom order. It was observed that Yun (same class with Cheng) was playing with a noisy toy. Cheng’s attention was on Yun’s toy and he did not listen to Xiaohong’s instruction. Xiaohong noticed this and asked Yun’s mother, Ling, to take back the noisy toy. Ling smiled and said: ‘it is not easy for him [Yun] to play with himself and I could [watch your demonstration and] make notes now.’

![Figure 7.11: Accuracy level of discrete trials for Xiaohong (Session 2)](image)

### 7.3.2.2 Liumei-Hua

There were many Chinese organisations which differed from Beijing AC School because they did not offer intensive behavioural training programmes. Schools/organisations provided individualised ABA trainings, but they were largely based on an eclectic approach, i.e., integration into non-behaviour analytic programmes.

Liumei (the teacher) conducted individualised training with Hua (the child) on a table (Table 7.8). Hebei GC School indicated the individualised training as ABA-based intervention. It was observed that training was merely based on therapist delivered DTTs for 30 minutes in a closed room.
Hua was a student undertaking school-based training at Hebei GC School. He is a local resident of Hebei province. Hua had difficulties in social communication and social interaction.

Figure 7.12: Individualised training at Hebei GC School

(Permission was granted for the use of this photo)

Treatment fidelity was measured as accuracy levels of discrete trials across the randomly selected 20-minute session. Table 7.8 shows Liumei maintained accuracy delivering DTTs across the two observation sessions.

Table 7.8: Summary of accurate trials instructed by Liumei

<table>
<thead>
<tr>
<th>Session 1</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of accurate trials</td>
<td>57</td>
</tr>
<tr>
<td>Number of inaccurate trials</td>
<td>0</td>
</tr>
<tr>
<td>Mean score of accurate trials</td>
<td>9.26</td>
</tr>
<tr>
<td>Mean score of inaccurate trials</td>
<td>N/A</td>
</tr>
<tr>
<td>Total trials</td>
<td>57</td>
</tr>
<tr>
<td>Percentage of accurate trials</td>
<td>100%</td>
</tr>
</tbody>
</table>

In this observation session, Liumei conducted four tasks with Hua. The instruments presented by Liumei were visual cards and puzzles. Task 1 was visual cards
discrimination which showed a graphic with corresponding words, such as transportation (car, train and airplane) and profession names (doctor, teacher and policeman). Task 2 was doing puzzles. Liumei placed a puzzle in front of Hua which he finished with some physical prompts. Task 3 was also visual cards discrimination. In task 4, Liumei instructed Hua to pronounce the words on the cards, such as cup, bowl and clothes. If Hua correctly responded to Liumei’s request or was able to correctly follow Liumei’s instruction, Hua was rewarded by a piece of snack or allowed to blow bubbles.

It was observed that task 1 and task 3 were similar. It was hard to assess whether the teacher repeated the task to reinforce an existing skill or to teach a new skill. In task 4, Liumei asked the child to pronounce words such as ‘Qianbi’ (pencil), ‘Shuzi’ (comb) and ‘Jiandao’ (scissors). Hua was able to do so with the help of Liumei’s vocal prompts. Alphabetic pronunciation of these words was complicated and the child was not able to pronounce them correctly. In addition, the researcher also observed the child had not finished the snack before the instructor moved on to the next task. Hua was not listening to Liumei’s instruction but kept on chewing the snack.

This observation (Figure 7.13) contained 57 trials within the 20-minute session. All of the 57 trials scored above the threshold of 6 for accuracy. The average score for the accurate trials was 9.26. The percentage of accurate trials was 100%.

![Figure 7.13: Accuracy level of discrete trials for Liumei](image-url)
7.4 Chapter summary

Results from direct observations (Study 3) indicated the application of DTT (a fundamental and popularly used approach of ABA-based intervention) was similar despite cultural differences between the UK and China. The treatment fidelity by parents working with their child increased or was maintained across trials due to parent training. The treatment fidelity by professionals working with children was consistently high. However, there were some differences observed between the UK and China. It was observed that the two UK participants, mother Mary and therapist Jane, collected data during the intervention. The new learner, Daisy who is from the UK, and all of the Chinese parents and professionals, did not collect data during the intervention. Instead, Chinese parents used video recordings as data collection tools which was regarded as daily homework and would be submitted to the head teacher for feedback. In addition, it was found that Chinese parents and professionals lacked preference assessment before the intervention. One of the Chinese professionals, Liumei, did not have a clear intervention goal identified in terms of targeted behaviour.
Chapter 8. Discussions and recommendations

8.1 Chapter overview
Three studies were conducted to explore the differences and similarities of ABA-based early interventions between the UK and China. Surveys (Study 1) and semi-structured interviews (Study 2) were conducted with parents and professionals. Substantial similarities in ABA-based interventions were found between UK and China, despite the vast differences in history, culture, policy and society. However, there were also substantial differences which can be attributed to the local environment. Study 3 was based on direct observations of parents and professionals working with children with autism conducting Discrete Trial Training (DTT) and showed that the application of DTT was similar despite the two contrasting geographically and culturally diverse regions.

This chapter presents the discussion of findings, and draws out practical recommendations. This chapter also illustrates contributions and limitations of this research.

8.2 Discussions
Based on findings from the study results, this section illustrates the applied behaviour analytic interventions for children diagnosed with ASD in both countries in the contexts of diagnosis and health care system, treatments, therapies and eclectic approach, ABA-based intervention programmes, school and policy support.

8.2.1 Diagnosis and health care
The results from the surveys and semi-structured interviews showed some similarities and differences on pre-diagnosis and diagnostic process reported by UK and Chinese parents. In the pre-diagnosis period, both UK and Chinese parents thought that their children would grow out of ASD. However, Chinese parents were influenced by the proverb: ‘Great minds mature slowly’, while UK parents were advised by professionals to take a watch and wait approach. Both UK and Chinese parents reported a delay in the diagnostic process, but there was a big difference in understanding towards diagnosis and different health care systems between the two countries.
8.2.1.1 ASD and diagnosis

Even though both UK and Chinese participants indicated children with ASD should be viewed as typical children, there was different cultural understanding towards them.

In UK, a difference of opinion about the best response to a diagnosis of autism was confirmed by findings of the present study. Some advocates in the ‘neurodiversity’ movement (Silberman & Sacks, 2015) said that there should be no attempt to change or ‘normalise’ children with ASD so that they are like other children. They argue, for example, that difficulties with eye contact or lack of vocal speech should not be targeted for intervention, but rather accepted as different and equally valid expressions of humanity. This opinion is reflected in some of the anti-ABA literature (e.g., Socially Anxious Advocate, 2015; Kupferstein, 2016). However, others argue that proponents of this view do not appreciate the heterogeneity of the autism spectrum. Children who are diagnosed with Asperger’s syndrome (AS) and high-functioning autism (HFA) are different from those affected by more severe forms of ASD. Children diagnosed with AS/HFA generally display a normal range of intellectual and language skills (APA, 2013), but their cognitive skills and social communications needs improvement (Rao, Beidel, & Murray, 2007). An interviewee pointed out that the idea of ‘should not be changed’ is problematic for children with AS/HFA as well as those with typical ASD as they need to be taught necessary skills to adapt to the society. This was confirmed by Bauminger, Shulman and Agam (2003) that the AS/HFA group may have difficulty maintaining friendship and experience loneliness. Most of the parents and professionals interviewed supported the view that children with typical ASD would fare worse without intervention as they would experience difficulties in vocal, social communication, repetitive behaviour and even challenging behaviours (Friedman, 2015).

In China, children with ASD are included under the mental disability category (Sun, et al., 2013). According to CCMD-3 (Psychosis Branch of Chinese Medical Association, 2001), only psychiatrists were licensed to diagnose autism. Children with autism in the present study were diagnosed under a range of different categories, in addition to the different types of Pervasive Developmental Disabilities defined in DSM-IV (APA, 2013) or ICD-10 (WHO, 2011), including ‘autistic features’, ‘suspected autism’ and ‘autism tendency’. This finding is consistent with other
research (e.g., Sun et al., 2013; Zhou et al., 2014). One of the reasons for this ambiguity was shortage of qualified diagnosticians (Huang, Jia, & Wheeler, 2013), especially in smaller cities and rural areas from which a number of the participants originated. This diversity of the diagnosis lead to an underestimation of the prevalence of ASD (Li, Chen, Song, Du, & Zheng, 2011). Children diagnosed with mental or cognitive disability were labelled as ‘shazi’, which means stupid or retarded, leading to a general reluctance to obtain a diagnosis. This was confirmed in some of the Chinese parents’ interviews where some parents were not willing to obtain a formal ASD diagnosis. In addition, a prominent cultural phenomenon, ‘mianzi’, which means reputation or dignity (Buckley, Clegg, & Tan, 2006), influenced parents so that the diagnosis of autism is viewed as a ‘domestic shame and should not be made public’. A number of the Chinese parents confirmed these feelings in this study.

This view was not present in the UK, where most parents were keen to receive early diagnosis for their child. They believed that early diagnosis would enhance chances for early intervention. Both in the UK and in China, some of the parents did not wait for a final diagnosis, sending their child for early intervention prior to receiving the diagnosis. This scenario is not well represented in the intervention literature, where diagnosis usually precedes intervention. However, more recently the term ‘at risk’ of autism diagnosis has been used in the field of very early intervention, i.e., before the age of 2 years of age (Rogers, 2014).

8.2.1.2 Health care system, ASD and ABA

The UK health care system is different from that of China. In the UK, the National Health Service (NHS) provides services that are free at the point of delivery for people in the UK (Beveridge & William, 1942; Public Health England, 2014). Services for children with disability are an important aspect of the provision (Emerson & Baines, 2010). However, parents reported that compared with other types of disabilities, such as dementia, there was a lack of adequate NHS services for families of people diagnosed with ASD. This finding is consistent with other UK studies (Keenan, Dillenburger, Doherty, & Byrne, 2007; Dillenburger, Keenan, & Gallagher, 2015; Wills & Evans, 2016). Parents also said that, when working with children with disability and their families, co-operation among professionals of specialist teams was not adequate (McConachie, Salt, Chadury, McLachlan, &
Logan, 1999), and the structure and service process of NHS required improvement. This was confirmed by the findings of this study, in particular in relation to children with ASD experiencing long waiting times for getting formal diagnosis.

In China, the health care system for the disabled, as well as the physicians’ awareness and knowledge of autism, requires significant improvement (Sun, et al., 2013; Huang, Jia, & Wheeler, 2013). The burden of care was placed firmly on the extended families (parents as well as grandparents) to take on the responsibility of looking after the needs of their children with ASD. This was in contrast to the UK, where industrialisation and urbanisation pushed families to seek and use public health service and professionals’ services rather than relying on intra-family care (Demetria, Durodoye, & Harris, 2013; Liao, Dillenburger, & Buchanan, 2016). It is entirely possible that parents from rural, low socio-economic areas were not aware of neurodevelopmental disorders, including ASD, let alone the initiative to take children for services and intervention (Huang et al., 2013). Hence, it was unsurprising that Chinese professionals from Beijing AC School mentioned that children who had severe symptoms were mostly made to stay at home, but children on the middle or high-functioning spectrum might be taken to ‘treatment’ or training by parents.

The results of the study indicated that the most popular service received by UK parents from the health care system was speech and language therapies, though the length of time was not enough (30 minutes per visit). This finding was not surprising. Despite the National Institute for Health and Care Excellence (NICE, 2013) including behaviour intervention in support and management of ASD, ABA-based interventions were not well known and generally not recommended by professionals of the health care system. Equally, neither the National Autistic Society (NAS, 2016) nor the NHS (NHS Choices, 2016) recommend ABA-based interventions on their treatment options. Only voluntary autism organisations recommended ABA in the UK. In China, on the other hand, results showed that ABA-based interventions were recommended by a large proportion of doctors during and after autism diagnosis. However, overall, China has a severe lack of mental health diagnostic professionals (Clark & Zhou, 2005; Standaert, 2006), and hence recommendations for interventions rest on the shoulders of a relatively small number of professionals.
8.2.2 Treatment, therapies and eclectic approach

Most parents had tried different types of therapies, not all of which were evidence-based. This finding was consistent with previous research (e.g., Green et al., 2006; McPhilemy & Dillenburger, 2013; SAS, 2013; Deng et al., 2014; Wills & Evans, 2016) and showed that SALT, ABA-based intervention, sensory integration and TEACCH were popular interventions undertaken by both UK and Chinese parents.

In addition, UK parents reported they had taken their child to try OT and TEACCH, diet, art therapy and music therapy, and medication therapies. These were recommended by NAS (2016) or NHS Choices (2016). However, some UK parents also sought non-recommended therapies such as hyperbaric oxygen therapy and Rapid Prompt Method (RPM; Tostanoski, Lang, Raulston, Carnett, & Davis, 2014). On the other hand, a quarter of the Chinese participants reported trying sensory integration, around fifteen percent of them received play therapy and less than ten percent of the participants were undertaking TEACCH, music therapist or auditory integration. A small number of children had undertaken acupuncture and massage, bio-therapy, occupational therapy or hyperbaric oxygen therapy. These findings were inconsistent with the study by Shenzhen Autism Society (SAS, 2013). Sensory integration, auditory and motor integration, and traditional Occupational Therapies were proved to be with limited evidence (Dawson & Watling, 2000). It was not until 2015 that the official guidance about autism diagnosis and treatments was released nationwide by the Chinese Disabled People Federation (CDPF, 2015).

Similiarly, both UK and Chinese interviewees indicated that some parents were looking for a ‘cure’ and expected their child to be ‘cured’ by the ABA-based interventions. This results is in consistent with the literature (Tzanakaki et al., 2012).

Parents of both countries reported trying different approaches and getting confused by the services available. Since there was a lack of information from the health care system, autism organisations were the main place where parents could find out about ABA-based programmes. A number of autism organisations providing an eclectic approach for children with ASD. As summarised by one of the interviewees: ‘taking some elements that are effective and blending them with other elements that are ineffective ’ (BACB staff and UK BCBA, John). Such an eclectic approach was used frequently by parents and combined different types of therapies, such as ABA-based
intervention, TEACCH and sensory integration therapy for children with autism. However, previous empirical research (Eikeseth, Smith, Jahr, & Eldevik, 2002; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005) had shown its ineffectiveness, especially when compared with ABA-based interventions.

The results reported here indicate that in both, the UK and China, some autism organisations had to adopt eclectic approaches in order to be supported or funded by the local authority. In the UK, the ABA school combined ABA-based intervention with other approaches, such as OT, arts therapy and SALT due to governmental requirements. It is confirmed by Grindle et al. (2012) that in the UK, the state-funded schools need to follow the National Curriculum, which stipulates the subjects and knowledge to be taught. For example, at an SEN school in Wales, physical education and Welsh language learning are part of the teaching subjects (Foran et al., 2015). Similarly, some Chinese professional interviewees indicated the CDPF required autism organisations to use these approaches in programmes, since the programmes was checked annually for compliance with guidelines. Only organisations that passed the annual inspection checks were approved as designated autism organisations, where families could receive government financial reimbursement for the interventions (See below, Section 8.2.6 for more detail). Policies requiring an eclectic approach meant that ABA specific schools or autism organisations could not apply an entirely evidence-based approach.

In general, more of the Chinese autism organisations utilised eclectic approaches compared to those in UK. This result was consistent with rapid reviews of ABA-based interventions in China, where 29 studies were identified using eclectic approach (See Chapter 3). The history of ABA in China is much shorter than that in the UK, which might explain the gap between the current Chinese practice and the current accepted practice in the UK. China has imported many autism interventions from other developed countries, including many approaches that are non-scientific. Many Chinese professional interviewees described various approaches utilised by autism organisations in phrases such as ‘chaotic intervention systems’ or ‘flowers of every kind are in bloom’ or ‘pandemonium’. Some parents indicated they were reluctant to engage with yet another new intervention, i.e., ABA-based interventions, because they had not seen expected changes in their child from the eclectic programmes they had been using. In addition, the eclectic approaches had wasted a
lot of parental time and money and, most importantly, they had delayed timely intervention.

8.2.3 ABA-based intervention programmes

Results indicated some similarities between UK and China where communication skill was the most commonly addressed area in the ABA-based programmes, along with social skills and independent life skills which were being taught in these programmes. However, the service delivery format of ABA-based intervention programmes was different between the UK and China, but the application of ABA-based intervention (specifically, the use of Discrete Trial Training, DTT) was similar.

8.2.3.1 Roles involved in the ABA-based programme

Parents and professionals in China and the UK played differing roles in the delivery of ABA-based programme. The reasons for these differences were related to the substantially different local environment in the two countries, especially related to family and service delivery structures and roles.

In the UK, mainly professionals delivered ABA programmes for families. The role of consultants/supervisors and therapists/tutors were clearly defined in the service delivery. Semi-structured interviews showed that professionals led the programmes, while parents became involved, if requested. These findings were consistent with several UK studies on services providing early behaviour interventions in the UK (Griffith, Fletcher, & Hastings, 2012; Wills & Evans, 2016). Due to the industrialisation and urbanisation of the UK, there had been great changes in family structure, where mothers are no longer responsible solely for the main household role, but took part in the workforce (BITC, 2013). Hence, there has been an increased use of professionals in the ABA-based programme (Liao, Dillenburger, & Buchanan, 2016). In contrast, the present economic status in China meant that the gender roles remain more clearly defined and especially the mothers took up domestic duties and played the role of therapist/tutor in ABA-based programmes.

Results of the present study found that parents took an active role in Chinese autism organisation. This finding correlated well with the previous research (McCabe & Tian, 2001; McCabe, 2008b; Liao, Dillenburger, & Buchanan, 2016). The parent-focused training in Beijing AC School utilised the power of parents to train their
child. Teachers (professionals) were there to demonstrate the knowledge of ABA rather than directly performing intervention on the children. A large number of Chinese autism organizations implement a ‘parenting class’, like Beijing BC School or Qingdao EC School, which require parents to assist or to prompt the child to engage in social communication and interaction with group activities. The emphasis on parents was driven by lack of service in the local area which forced the parents to take their child to big cities. Financial and other constraints meant that they could not remain indefinitely in the larger cities. Hence, parents felt that they had to gain sufficient knowledge to be able to apply this knowledge with their child themselves once they returned home. This was true for most students in Beijing AC School and Qingdao EC School who were not local Beijing or Qingdao residents. This was also reflected in the research by (SAS, 2013) where 55.88% of the autism organisations’ founders’ own children were diagnosed with autism and the main reason for starting the organisations was the lack of access to ABA-based training.

In China, within its philosophy of Confucianism, a child’s education is viewed as an embodiment of the family’s obligation and responsibility, which implies that the failure of the child academically or career-wise is a disgrace to the family (Clayton, 2011; Huang & Gove, 2012). The collectivism of Chinese culture expected parents to devote their energy and sacrifice their time to help their children lead a better life (Xu, Farver, Zhang, Zeng, Yu, & Cai, 2005; Huo & Yuan, 2015), especially for those family who only had one child (McCabe, 2007). Those families whose children are HF/AS might generally expect to pursue mainstream education following on from an intervention programme or training, just like typically developing children. This phenomenon was reflected by several Chinese interviewees (e.g., mother: Xiang and Meimei). This is in contrast to the UK or other European/American cultures, where individualism leads to the relationship between parents and children being considered nearly equal and parents expect autonomy and independence from their children (Triandis, McCusker, & Harry, 1990).

Many mothers in this study left their job to access quality ABA-based intervention programmes. This is consistent with the report by McCabe (2010). In contrast to most Chinese parents, UK parents in this study, such as Lucy and Rose, were employed full-time and thus were unable to conduct much of the intervention themselves. They relied on professionals to carry out these tasks. In addition, the
majority of the UK parent interviewees had more than one child in the family and indicated that they had to care for their other children as well as their child with autism. This obviously contrasted with the Chinese One-child policy (relaxed to two-child policy in 2015, Xinhuanet, 2015) and might have been another factor leading to the increased likelihood of hiring professionals in the UK.

Overall, the population contexts in the UK are very different from those of China. Obviously, China has a larger population than the UK and fewer ABA-trained professionals. In the whole of mainland China, there are 44 BCBAs (BCBA-D) or BCaBAs, in contrast to 246 in the UK (BACB, 2016a). Not surprisingly, therefore, results of the present study found that Chinese professionals had greater workloads than UK professionals. It was reported that each UK supervisor worked with approximately 10 boys and 2 girls and each UK therapist worked with 5 boys and 1 girl, whereas each Chinese professional worked with 17 boys and 3 girls. This resulted in the Chinese parents stepping into the role of training their child as parent therapist or involved in an assistant role in the programme, while experienced teachers designed the IEP and demonstrated the knowledge and techniques of ABA, effectively performing a supervisory role. It would be expected that the effectiveness of a programme delivered by professionals would be higher than that delivered by parents. Even though the present study did not directly compare the effectiveness of the outcomes between professionals and parents, findings from the participants’ experiences reflected some issues, such as that the insufficiency of parents’ educational background would negatively affect the outcome. This is consistent with the study by Johnson and Hastings (2002) that poorly trained professionals (including parent therapists) would reduce intervention efficacy. Hence, the large number of children requiring intervention and great workloads faced by Chinese professionals were compounded by the shortage of qualified professionals. As a result, the professionals cannot spend sufficient time to be able to work directly with individual children but rather must act in a supervisory capacity in order to help more children.

8.2.3.2 The service delivery of ABA-based intervention programmes

Different modes of service delivery were found between UK and China. UK and Chinese participants showed a difference in understanding towards home-based
ABA programmes. In the UK, home-based programmes of a professionals-led mode were more popular. Results of this study showed more than half of the UK parent respondents (66.7%) indicated their child was undertaking home-based ABA programmes. More than half of supervisor participants (70.0%) and a majority of therapist participants (84.6%) reported they delivered home-based 1:1 programmes. The type of service delivery is consistent with previous literature (Keenan, Dillenburger, Doherty, & Byrne, 2007) in the UK; the census results in Australia (Horiguchi, 2014); and the research in the US (Love et al., 2009). In China, a majority of parents (93.9%) and professionals (133.3%, i.e., 72.7% of one-to-one and 60.6% of group format) reported the service delivery of ABA-based interventions was through centre-based programmes. This finding correlated well with findings by SAS (2013) where 64.53% of Chinese parents indicated children with autism were undertaking training in autism rehabilitation organisations.

However, it should be noted that in the present survey of Chinese parents, the one-to-one training/practice was between parent and their child rather than between the professional and the child, which was the case in the UK. This was evident in one of the semi-structured interviews: ‘insufficient quality therapists to provide home-based ABA training’ (Juan, Beijing FC Centre). It is likely that parents brought home knowledge of ABA from autism organisations (e.g., Beijing AC School and Qingdao EC School) and practised it on their child.

The difference in how service is delivered may be due to different stages of ABA-based programme development and the difference in the availability and distribution of resources between the UK and China.

First of all, historically, development of ABA-based interventions has been different between UK and China. UK and other English speaking countries (e.g., Kanner, 1943; Asperger, 1944) recognised autism in official publications around 40 years before the Chinese (e.g., Tao, 1987). Specifically, the diagnosis and classification of autism was defined in DSM-3 (APA, 1980) and ICD-10 (WHO, 1992), which were translated and adopted by many other countries, including China. Subsequently, the second edition of Chinese Classification and the Diagnosis Criteria of Mental Disorder (CCMD-2-R, PBCMA & BHNMU, 1995) outlined autism diagnosis for
Chinese people, and thereafter, CCMD-3 (Psychosis Branch of Chinese Medical Association, 2001) has been utilised by psychiatrists to diagnose children with ASD.

On the other side, in the UK, the parental pressure for the recognition and adoption of interventions to help children with autism has grown since the 1960s (Wolff, 2004). With the publication of UCLA YAP model by Lovaas (1987) and his colleagues (Smith, Eikeseth, Klevstrand, & Lovaas, 1997), there has been substantial research to replicate the intensive ABA-based intervention programme in a research setting (e.g., Green, Brennan, & Fein, 2002; Remington et al., 2007; Klintwall & Eikeseth, 2015) or in practice (e.g., UK YAP, 1994) since the 1990s. Hence, the exploration of treatment therapies in the UK began earlier than in China. However, a number of autism organisations in China were started after the 1990s because of increasing concern from parents whose children were diagnosed with autism but who were not able to help (McCabe & Tian, 2001). According to several founders from the research, the number of autism organisations increased greatly in the 2000s in China.

Second, compared with UK, China faced a bigger shortage of resources, particularly in regional areas. Results from the survey showed a majority of UK parent participants (63.60%) indicated there was no travel required to access ABA-based services because it was carried out by therapists/supervisors at home and a small proportion of parents had to travel less than 30 minutes (18.2%) or 30-60 minutes (18.2%) to receive the supervision.

This was in stark contrast to more than half of the Chinese parent respondents (51.2%) in this survey who indicated they had to take their child out of their local place of residence to access ABA-based programmes. This finding is in contrast to the survey by SAS (2013) where only 10.07% of parents reported that their child was undertaking the training outside of the local province. It should be noted that the survey by SAS (2013) focused on southern China (72.08%), while the present study had a wider geographical spread of respondents (see Chapter 4 Methodology).

Third, there was an imbalance of resources in different regions in both UK and China, but overall the availability of resources was a little better in the UK than in China. For example, Johnson and Hastings (2002) reported that there were around 250 Lovaas-style programmes set up in the UK. In the first census of ABA Schools
around the UK, Griffith, Fletcher and Hastings (2012) identified 14 ABA schools and classes, with most of the ABA schools located in England or Wales. In fact, results of the semi-structured interviews showed that different counties of the UK had different level of services. One of the interviewees commented: ‘It depends on which Trust [area] you lived in, [and] what access to services you could get’. Based on interviewees’ feedback, England and Wales was a little better than Northern Ireland in terms of public services for children with ASD.

In China, autism organisations in the economically developed regions such as north eastern, eastern coast or southern China had better resources (Zhou et al., 2014). ABA-based intervention programmes were first brought into China by autism organisations (Stars & Rain, 2003; Qingdao Yiling, 2015) in the Northern China and that resulted in earlier establishment of services and exploration of training approaches for children with autism and their families in the North, especially in cities like Beijing, Qingdao and Shanghai. In contrast, there had been a shortage of services in remote and rural areas. For example, Chinese mother Ling was from Shanxi province (northern China) and Wuling was from the countryside of Shanxi province. Unfortunately, there is a lack of literature on services for families who were from Tibet (southwest autonomous region) or Xinjiang (northwest autonomous region).

Despite these differences, the application of DTT was found to be similar in direct observation study in each country. The treatment fidelity by parents who worked as therapist with their child increased or maintained across trials due to consistent parent training. The treatment fidelity by professionals working with children was maintained by both UK therapists and Chinese teachers. This finding was confirmed by Symes, Remington, Brown and Hastings (2006), that the delivery of discrete-trials is influenced by characteristics of therapists and children, on-going training and supervision and intervention techniques. For both parents and professionals, continuing training improved knowledge and intervention techniques were honed through feedback from supervisors/experienced teachers. In addition, results of direct observations indicated Chinese participants lacked preference assessment and target behaviour identification. Pre-intervention preference assessment had been shown by Elliott and Dillenburger (2016) to improve motivation and intervention outcome for the child. Since the present study is focussed on treatment fidelity as
measured by how well the intervention steps were followed, the outcome for the children was not included.

8.2.3.3 ‘ABA’ or not

There is debate on whether the intervention that some autism organisations provided was ABA-based intervention or not. There were two observations from the study related to this debate. The first one is that ABA-based intervention was mixed with other approaches in the programme, as noted in the earlier discussion about eclectic approach in both countries (See the above Section 8.2.2). The other one is that when some Chinese professionals claimed they delivered ABA-based intervention, what they called individualised ‘ABA’ training was actually restricted to DTT training on a table. This ignored a broad range of other principles and techniques of the science of ABA. Both issues were compounded by the lack of data collection in the intervention process. The importance of data collection in the ABA-based intervention was emphasised by Adam (UK BCBA-D): ‘The mark of a science is the collection of data and associated data-based decision making.’

Nevertheless, data collection was not always conducted during the delivery of ABA-based interventions by Chinese professionals. Findings from the survey showed a large proportion of UK parent respondents (70.0%), supervisor participants (100%) and therapist participants (100%) reported collecting of data by continuous measurements (e.g., frequency, duration or intensity). Most Chinese parent participants reported their child had an evaluation assessment (52.5%) and parents’ interviews/questionnaires (31.3%) as data collection but more than twenty percent of parents (22.5%) did not know; nearly half of professional participants reported by the use of duration (42.2%) and interval recording (40.6%), and a small percentage of professionals were unknown (17.2%). In addition, it was observed that a number of Chinese professionals did not know when to, and how to, take data. The Beijing AC School in this study made parents record videos and submit their daily homework, practising the learned techniques with their children, to teachers for data collection. Teachers presented feedback the next day.

The reason behind this phenomenon can be traced to the different application of Individualised Educational Plan (IEP) in practice in each country. In the UK, findings from the survey showed that the majority of the supervisor participants
(60.0%) reviewed the IEP for a child/family every month. 22.2% of the supervisor participants provided supervision weekly, fortnightly (44.4%) or monthly (33.3%). These findings were similar to that of Love, Carr, Almason and Petursdottir (2009) from the US. As reported by more than half the UK supervisor participants in this study, the duration of ABA-based programmes were typically more than 36 months (60%). This indicated UK children in the sample received supervision regularly and mostly had a long duration of IEP.

However, most programmes in China were short-term, lasting for around three months. For example, the parents-focused programme from Beijing AC School offered entry-level knowledge in ABA-based intervention for parents through an 11-week-long ‘crash course’. Children would be taken by parents to a local autism organisation once that finished. In addition, the heavy financial burden often means parents could not afford a longer programme. The large number of children, and professionals’ workloads in one class was reported by teachers, rendering data collection on an individual basis impossible. Furthermore, Juan’s words raised another reason for the lack of data collection: ‘Chinese parents may not understand your long-term plan; they would prefer to know the present.’ Hence, data collection in China was not very consistent and varied substantially between programmes.

8.2.4 Early intensive behaviour intervention

The surveys and semi-structured interviews returned contradictory results due to a difference in the understanding toward early intensive behavioural intervention (EIBI) between UK and China.

In the UK survey, it was found that nearly three-quarters of supervisor participants and half of UK therapist respondents reported they offered EIBI programmes to families. The findings of the present study, in terms of techniques and features addressed in the EIBI programme, age of commencement, duration of the programme and parents’ perception of its effectiveness, were broadly inconsistent with the literature (e.g., Green et al., 2002; Eldevik, Hastings, Hughes,ahr, Eikeseth, & Cross, 2009; Howlin, Magiati, & Charman, 2009; Reichow, 2012; Reichow, Barton, Boyd, & Hume, 2012). However, there were differences in hours delivered. Professionals reported an average intensity of 18.29 hours per week, specifically a minimum of 14 hours (Mean =14.00, Min=2, Max=35) to a maximum 23 hours
(Mean =22.58, Min=3, Max=35) per week. This result was higher than that recorded by the census in Australia (Mean = 16.5 hours), lower than some UK studies (e.g., Mudford, Martin, Eikeseth, & Bibby, 2001, Mean =32.0 hrs; Symes, Remington, Brown, & Hastings, 2006, Mean =20.2 hrs; Remington et al., 2007, Mean =25.6 hrs) and much lower than the recommended ‘well-established’ practice of 20-40 hours per week (Lovaas, 1987). In the semi-structured interviews, UK professionals referred to early ABA-based intervention rather than EIBI because of the inability of delivering the suggested intensive hours.

On the other hand, around ninety percent of Chinese professional participants indicated they provided EIBI programmes to families. However, subsequent results from the interviews revealed a different understanding of EIBI by Chinese participants, because none of the Chinese professional interviewees said they were doing EIBI. In fact, Chinese professionals mainly utilised DTT and did not encompass the basic elements of EIBI such as Natural Environmental Training (NET) and did not collect data in the intervention. However, they generally labelled their practice as EIBI. The potential explanation could be derived from a typical mode of service delivery in China. For example, in Beijing AC School, the programme is comprehensive (covered different domains of child’s skills), intensive (9 am-4pm, 5 days per week) and at earlier ages (2-6 years of age), which would satisfy some elements of EIBI. This unawareness of the data collection requirement and other principles and techniques of ABA in addition to DTT was likely the cause of the over reporting of EIBI adoption rates. In reality, the ratio of low qualified staffs to high number of students made it impossible to meet the Lovaas model.

Results of the semi-structured interviewees revealed a low popularity of EIBI services in the UK and China, which is in agreement with the pilot study (Liao, Dillenburger, & Buchanan, 2016). It was found that a small number of professional interviewees in both countries had heard about the EIBI programme, but none of the UK and Chinese parent interviewees said their child was undertaking an EIBI programme. It was found that the lower extent of the EIBI programme in the UK and China was due to insufficient understanding of EIBI, funding, time, energy, distance and other resource constraints. This result was confirmed in the research by Mudford, Martin, Eikeseth and Bibby (2001), who also indicated the Lovaas model could not be replicated in the UK.
Nevertheless, a significant number of UK professional interviewees indicated they were working towards the EIBI model and a large number of Chinese respondents expressed their desire for learning the EIBI model and more systematic training in ABA.

**8.2.5 School involvement**

Both the UK and China parent participants reported that school teachers, speech therapists, occupational therapists and psychologists were poorly incorporated into their child’s ABA-based programmes, although UK was a little better than China. There were many challenges faced by children in schools reported by both UK and Chinese parents.

A large number of UK interviewees reported that special units of mainstream schools or some SEN schools did not apply the science of ABA or follow the principles of ABA in the child’s educational programme, and some schools did not even accept behaviour analysts to visit. Schools applied other approaches which might not be as effective as ABA so parents had to purchase ABA services privately. This was confirmed by other UK researchers (Foran et al., 2015). Almost all of the UK parents indicated that they had to fight against the school for more hours of assistance. In order to get their child’s ABA-based programme funded by the local authority, some of them had to bring the educational authority to a tribunal. Similar results were reported by Johnson and Hastings (2002). Unfortunately, this situation did not improve after more than ten years.

In China, ABA-based intervention has not been established in mainstream schools, but available in many NGOs and a small number of SEN schools (e.g., Guangzhou Cana School). The biggest challenge that Chinese parents faced was that their child was at the risk of being excluded from mainstream education. This result was consistent with several previous studies (Clark & Zhou, 2005; McCabe, 2007; Huang & Wheeler, 2007; Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013). Chinese parents reported that some schools had pre-enrolment assessment. The head teachers feared the child with autism would perform badly academically, resulting in lowering the average of the whole class in the exam and affecting the whole class’s higher education enrolment rate. As a result, those who failed the test would be removed. Furthermore, there was a non-acceptance of children with ASD in the
mainstream system. For example, mother Chang reported that her son was persuaded to quit by a mainstream school. That is one of the reasons that most of the parent interviewees said they would not reveal to the school that their child was affected with autism. However, there were some regions of China where progress was being made. For example, Foshan city of Guangdong province provided support to people with autism until senior high school and allowed them to undertake schooling out of the city (The Government Information Publicity of Foshan city, 2015). The present process for education for children with disability in China is called ‘suibanjiudu’⁴⁴, which means learning within the general classroom or attending regular schools (Huang & Wheeler, 2007; Chen & Lan, 2014). This policy put forward by the State Department of Education, was to include children with disability into mainstream education and remove enrolment tests for children with disability (Huang & Wheeler, 2007). However, it failed to consider the individualised education needs of children with ASD (McCabe, 2008b).

**8.2.6 Policy support and ABA**

Generally, both UK and Chinese parents self-funded their child’s programme, with government financial support only constituting a very low proportion. In addition, different regions of the UK or different provinces of China had different levels of services.

Due to regional restrictions, both UK and Chinese parents relocated from in the place of residence with their child in order to access free or better resources. For example, the UK mother Carol moved to an ABA school in England and many Chinese parents from different provinces travelled to Beijing to access the parents-focused training. This was in contrast with the US, where the Public Laws 94-142 in 1975 (Department for Education, 2016) and the Education of the Handicapped Act in 1986 (Education of the Handicapped Act, 1986) stipulated public education and services needed to cater for children with disabilities and their families. Up to December 2015, 43 states and the Districts of Columbia had announced laws introducing insurance coverage to meet the needs of these children and families (National Conference of State Legislaters, 2015).

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⁴⁴ ‘Suibanjiudu’ In Chinese 随班就读
In the UK, public service care and treatment from the NHS across various settings has been set up for people with disability since 1948. The 2009 Autism Act and the Autism Strategy Fulfilling and Rewarding Lives (2010) have largely promoted public autism awareness and improved the lives of people with ASD. At least one quarter of pupils who had a statement of Special Needs Education (SNE) or an Education, Health and Care (EHC) plan were children with ASD (Department for Education, 2016). The EHC is from the local authority and aims to provide additional support for children and young people if current needs are not met at school (National Autistic Society, 2016b). However, it was reported by parents that local authorities had little knowledge of evidence-based approaches like ABA. The schools did not integrate ABA-based interventions into their educational programmes either, and behaviour analysts were not included in the educational system. Hence, ABA-based interventions lack enough support from the local authority and most parents must hire therapists/tutors privately.

In China, the 1987 Reform and Opening-up policy has prompted significant policy development for children with autism. The 2008 Viewpoints on Promoting the Career Development of the Disabled was issued by (The Central People’s Government of the P. R. C., 2008). More specific policies (General Office of the State Council, 2009, 2010) were released to promote its implementation. Children with autism, who: were under 6 years (inclusive) of age, had a formal diagnosis from a medical institution, and were issued with a Disability Certificate from the local authority, could apply for the government funding to undertake services or training at a local designated autism organisation. The implementation of these policies was varied. Some parents of this study indicated they were unwilling to apply for the Disability Certificate for their child due to concern about social stigma, especially those parents whose child was with HFA/AS. Children with ASD also faced Hukou (registered permanent residence) restrictions because they must undertake services at the local designated autism rehabilitation organisations in order to access subsidised services. It should be noted that the autism rehabilitation organisations from undeveloped provinces or small cities lacked good quality services and professionals (Clark & Zhou, 2005; Huang et al., 2013).

45 In China, ‘disability rehabilitation organisation’ is a common saying, so as the ‘autism rehabilitation organisation’, though the word ‘rehabilitation’ is not a common word in the UK and areas of ASD.
As a result, over half the Chinese parent respondents temporarily moved from their hometown to big cities to access better quality services, just as parents of this study who had moved to Beijing AC School and Qingdao EC School to access the ABA-based intervention programmes. In addition, parents reported that different regions had different policy support systems. Some well-developed provinces or cities supported children with ASD beyond 6 years of age. For example, Suzhou city supports children until 14 years (inclusive) of age (Government Information Publicity of Jiangsu Province, 2013), but one of the essential criteria is people must be from Suzhou city and need to go to local designated rehabilitation organisations. However, the Disability Certificate is not a prerequisite in Jiangsu province, though a formal diagnostic assessment from a professional organisation is required. This was the same as Shanxi province (Shanxi Province Disabled Federation, 2015) and Tianjin city (Tianjin city Disabled Federation, 2013). This was confirmed by parent interviewees who were from Shanxi province.

Interestingly, although the health care and educational system were more developed in the UK when compared to China, the evidence-based approach of ABA-based intervention was not as widely endorsed in the UK. One potential factor, as discussed earlier, was due to the differing time when autism was recognised and different stages in the adoption of treatment therapies for children with ASD. The other reason might be traditional treatments reported by UK participants included SALT, OT and TEACCH. The professionals who worked in these areas had already been established under the health care system or educational system (Health Careers, 2015). These treatments have a long history in the UK and have been rooted in people’s minds, so it is hard for them to accept ABA-based intervention which, although having a long history in the USA, is more recently established in the UK. Despite China having a shorter history than UK in the establishment of ABA-based interventions, parents indicated a strong willingness to learn all kinds of therapies that might be effective for their child. Proponents of ABA-based interventions were promoted popularly and directly by a number of local Disability Federations (e.g., Beijing Disabled Persons’ Federation, 2011; CDPF, 2016; Jilin Province Disabled Persons’ Federation, 2016).
8.2.7 Changes and trends of autism organisations

The UK professionals were working towards the ‘well-established’ practice. This survey showed that supervisors provided an average of 8.70 supervision hours per child and therapists delivered an average of 26.79 hours of ABA-based therapy per week. This was somewhat better than the study in Australia (Horiguchi, 2014) but still significantly lagged behind the UK study by Mudford, Martin, Eikeseth and Bibby (2001) and international levels (Lovaas, 1987). In addition, half the UK parent respondents had team meetings with programme supervisors or therapists once a month. As the research by Lovaas (1987) was not repeatable in the UK (Mudford et al., 2001), several studies suggested that a lower intensity school-based ABA programmes might work for children with ASD in the UK (e.g., Remington et al., 2007; Grindle et al., 2012; Foran et al., 2015) and other parts of the world (e.g., Eldevik, Eikeseth, Jahr, & Smith, 2006; Peters-Scheffer et al., 2010). In order to achieve the best outcome for children and families, an increasing number of UK behaviour analysts realised the importance of individualised training and utilising different techniques within the science of ABA.

On the other hand, Chinese autism organisations were working on a transition from traditional parents-founded towards professional-founded or -led service. Jing, the founder of Beijing BC School and a mother whose daughter was diagnosed with autism, admitted: ‘We [parent founders] lacked technical expertise.’ An increasing number of Chinese organisation founders or school principals were recruiting experts and professionals. Beijing FC Centre was one of the first autism organisations founded by a BCBA and set out to train more behaviour analysts qualified by BACB. The Chinese training could be summarised as the strategy of ‘going out’ and ‘bringing in’. The ‘going out’ means teachers participated in ABA learning, studying abroad or short-term visits to good quality autism organisations. This ‘going out’ is expensive and most Chinese professionals faced language barriers. The ‘bringing in’ means foreign experts were invited to China to train professionals and parents. Under this arrangement, professionals’ ability to deliver ABA-based intervention might influence parents’ perception towards the effectiveness of ABA. Overall, there is a transfer from traditional parent-led programmes towards professionals-led programmes.
Finally, results of the survey found a large proportion of UK professional participants were qualified in or working towards qualifications approved by the BACB, which offer a professional qualification in the field of behaviour analysis. In contrast, most Chinese professional participants held or working towards a teaching qualification, either at mainstream schools or special schools, or qualification as a social worker. In addition, some of the Chinese participants had no professional qualifications or did not participate in training to gain qualifications.

A large number of the UK and Chinese participants longed for systematic and professional training in ABA. Particularly, professional interviewees expressed their willingness to be certified in the field of behaviour analysis, where the BCaBA and BCBA certifications were highly recognised in both countries. For example, there was a 118% growth in demand for behaviour analysts from 2012 to 2014 in the US, in which the demand for BCBA was up 116% (Burning Glass Technologies, 2015) and 94.71% of Chinese professionals hoped to be similarly qualified (Shenzhen Autism Society (SAS, 2013).

It is anticipated that more professionals from different fields would join in to do better for children with ASD and their families. For example, Anna, a speech and language therapist and a BCBA from Wales, said ‘We [speech language therapists] know about language development and we tried to change things, but do not really have the science showing us how things [are] changed, ...So you put these two [speech language therapy and behaviour analysis] together... it brings science to a profession.’
8.3 Recommendations
In order to advance autism awareness and the use of an evidence-based approach of ABA-based interventions, several recommendations are put forward.

8.3.1 Parents who worked as therapists and parental involvement
Results of this study found around 70% of the UK and Chinese parent respondents ran ABA therapy sessions for their child. Parents could benefit considerably from working as an ABA therapist for their child because learning the function of behaviour would help them better understand their child. However, parents indicated there were time, energy and emotional constraints. The mother was generally the one who left the workforce for the sake of family. It was found that, to some extent, fathers were also involved in the programme, and sometimes, grandparents of the children as well. In the UK, siblings were also involved.

Empirical studies suggest that parents’ involvement, and even that of friends, siblings and neighbours, in the early stages of an ABA-based programme was beneficial to children with ASD (Hastings & Johnson, 2001).

8.3.2 Systematic training of ABA professionals and their qualifications
There is a need for more well-qualified diagnostic services for ASD both in UK and in China, especially since early diagnosis and intervention can make such a big difference in the life of children with ASD (Harris & Handleman, 2000; Fein et al., 2013).

A large number of Chinese professionals assessed their work skill to be low. All UK supervisor respondents and around four-fifths of UK therapist professionals assessed their skills of working with children with ASD to be ‘somewhat high’ or above, while only a very small proportion (6.2%) of Chinese professionals made the same assessment. In addition, the entirety of supervisor respondents and the majority of therapist respondents (67.3%) self-evaluated their application of ABA-based techniques to be ‘somewhat high’ or above, while only an even smaller number (4.5%) of Chinese professionals made that same evaluation. However, it is arguable whether a self-assessment is accurate. For example, a recent study by Fennell and Dillenburger (2016) showed teachers in Ireland self-rated their skills ‘competent’ in
ABA and ASD, but when asked a factual question, were not able to answer it correctly.

In addition, it would be greatly beneficial if the local university could co-operate with autism organisations to train more ABA professionals. Currently, there was only one university in China and only 5 universities in the UK provided BACB approved course sequence; there were only 3 organisations qualified to train BCBAs or BCaBAs in China (BACB, 2017b). In contrast, 215 universities or institutions in the US provided training for ABA professionals (BACB, 2017b).

Professionals reflected that it is not the effectiveness of the ABA intervention that the parents were unsure of, but whether the professionals can adequately deliver this intervention. Undoubtedly, there is a need to train more behaviour analysts due to a huge demand from families and professionals. However, the key is that therapists/teachers needed to be supervised by good, certified supervisors.

Parents and professionals should work together to achieve the best outcome for children. This is important because professionals are focused on attainment of skills, whereas parents are more concerned with daily life and communication in practice. Professional interviewees indicated that consistent training by professionals during the session and by parents at home is pivotal. Otherwise children would be confused if professionals discouraged actions which the parents allowed. Therefore, professionals encouraged parents to learn about ABA and to apply the principles and techniques of ABA to their child’s everyday life. It is believed that as parents are the ones who spend the most time with their child, they are best positioned to continue practising at home or using the learnt skills in daily life.

8.3.3 Cost-effective ABA-based interventions within school settings
It is necessary to make parents aware that early commencement of behavioural intervention brings better outcomes for their child. Some parents, especially parents from the UK sample area, reported they did not know autism organisations could intake children who did not receive a final diagnosis. It would be helpful if autism organisations could advise parents that they could accept children who were still waiting to be diagnosed.
The duration of the programme should depend on children’s needs. It could be seen from this study that intensive hours were the parents’ key concern when undertaking EIBI programmes due to financial, time, energy, distance and resources constraints. It is highly recommended that the school, either mainstream or SEN schools, should take behaviour analysts on board to achieve a better outcome for children and families because several interviewees from this study indicated it is important to generalise the learnt skill from the home setting to the school environment. If a child’s ABA-based programme could be integrated with the child’s school education, this child would not only benefit significantly in both academic learning and social skills, but also save a lot of financial expenditure.

Both UK and Chinese teachers or school assistants should improve their knowledge of ASD and ABA. Chinese education system can learn from the UK, organising special units attached to mainstream schools or providing support for more SEN schools.

**8.3.4 More involvements of health service system and policies**

It is recommended that diagnosticians and other medical staffs learn more about ASD and understand the families’ needs. Most importantly, medical staff should be able to provide more information on evidence-based treatment therapies and on where these can be accessed for parents. People with ASD would benefit from timely diagnosis alongside rich supporting information. In China, only psychiatrists are qualified to make autism diagnoses (Clark & Zhou, 2005). Small cities lack psychiatrists, so parents usually took children to big cities, such as Beijing, for a diagnosis. It is recommended that more qualified diagnosticians should be trained in China, especially in remote regions and small cities.

Further efforts should be made by policy makers to raise autism awareness and to improve the lives of people with ASD and their families. It is essential for people with ASD to master basic living skills and aim to be able to live or work independently. Perhaps it might be a good idea to get adults with ASD involved in the local community, especially in decision-making, because they were easily ignored (Department of Health, 2014).
8.3.5 The dissemination and collaboration of behaviour analysis

Both UK and Chinese respondents recognised that ABA is for all, not only for children with ASD. Convincing the public about the power of behaviour analysis may take some time. However, the behaviour analysts have an obligation to disseminate the science of behaviour analysis to the general population through workshop, conference or social media (BACB, 2016b). Behaviour analysts should be aware that professionals, who have been working with children with ASD for decades and had become established under the local authority’s system, are slow to understand and accept the newly established ABA-based intervention. Hence, behaviour analysts should be ready to accept those who did not agree behavioural analytic intervention and take the responsibility to disseminate to those who were unaware of or misunderstood it.

The BACB guidelines, examination and other relevant documents have been translated from English to simplified and traditional Chinese language. However, the delivery of the science of behaviour analysis globally should consider its linguistic appropriateness and national usage habits (Jones et al., 2011). More books, papers and other literatures should be translated in a culturally-adapted manner into other languages to meet the needs of people internationally. For example, China Association of Persons with Psychiatric Disability and their Relatives (2016) co-operated with SEEK education (USA) and Guangzhou CANA autism school to promote an indigenous qualification called CNABA. In addition, in order to meet the supervisory needs of overseas therapists/teachers, it is necessary to consider developing online courses and capitalising on advances in communication and other technologies.
8.4 Contributions and limitations of the study

8.4.1 Contributions

The research undertaken for this thesis has made contributions to a range of areas. The majority of cross-national studies in the literature are in topics such as politics, economy and ethnography. This study offered rich empirical data on exploration of psychology and education aspects. This cross-national study offered an extension to research methods in education and sociology, and develops a generalisation and replication methodology which did not focus on a single case nation. The use of mixed method in this cross-national research was meaningful in exploring topics that lack sufficient literature, such as determining the popularity of the use of EIBI in China.

This study made a number of contributions to the practice and application of ABA-based intervention programmes in the UK and China. As far as the author is aware, this was the first study to explore the similarities and differences of ABA-based interventions between UK and China. Particularly, as the literature indicated, there was no empirical research specifically studying ABA-based interventions and the application of DTT across two contrasted cultural settings.

The three rapid reviews of ABA-based interventions in the UK and China provided information for researchers to identify gaps in empirical research. There are currently few published studies exploring topics of ABA-based interventions, specifically in China. In China, the Shenzhen Autism Society (SAS, 2013) reported 56 organisation founders/principals, 510 professionals and 988 parents whose child was with ASD. This survey focused on southern China (72.08%), but ABA formed a very small part of the study and was considered as a type of intervention. In addition, SAS (2013) mainly focused on southern China.

Study 1, the survey replicated the census study in Victoria, Australia (Horiguchi, 2014), which contributed to an international comparison. This empirical research served to probe people’s knowledge towards EIBI away from its origin of place, the US, and to understand the current provision of its practice across three countries, i.e., UK, China and Australia. This might provide researchers and practitioners with a benchmark for replicating the EIBI model (Lovaas, 1987) in other parts of the world.
Although the present survey main sample site was in Beijing, the majority of the 
participants were from different regions and congregated in Beijing for training. 
Hence, the survey in China added new knowledge for practitioners and researchers. 
The survey in the UK, built on existing surveys, namely (Keenan et al., 2010; 
McPhilemy & Dillenburger, 2013). As such, the relatively small UK sample size in 
Study 1 served mainly to reaffirm these earlier findings.

In addition, this study addressed a series of issues regarding children with ASD and 
ABA which yields empirical and practical data for researchers, practitioners and 
policy-makers. For example, findings around the ‘diagnosis and health care system’ 
should be useful for doctors in understanding the parents’ experiences and consider 
other professionals’ suggestions. Listen to the feedback from parents and ABA 
professionals are important during the adoption of evidence-based approaches by the 
health care system, autism organisations, and policy makers.

8.4.2 Limitations

The study has a number of possible limitations. As Lijphart (1971) indicated, 
comparative research is time-consuming and expensive. It requires a lot of energy 
and a large sample size. One of the main limitations of this study was the sample size. 
The UK survey could not represent a broader population of UK parents, children and 
ABA professionals, despite two additional rounds of calls for participants during the 
data collection period (See Chapter 4 Methodology). However, an earlier UK census 
study had identified 382 ABA staff members in 14 ABA schools/classes in 2010 
(Griffith et al., 2012). An earlier study included 96 parents (Keenan et al., 2010). 
Given that there were no authoritative data on number of ABA therapists in the UK 
(Symes et al., 2006), the representativeness of the present sample remained unknown. 
As such, Study 1 is best considered a confirmation study of existing data, rather than 
a full census in its own right.

The first census study on EIBI from Victoria, Australia, reported the same difficulty 
in reaching a large sample (38 therapists, 15 supervisors, and 72 parents took part 
(Horiguchi, 2014). The earlier UK survey about ABA staff members’ psychological 
issues by Griffith, Barbakou and Hastings (2014) included 45 therapists 
(representing 10% of the 2010 UK census size) from ABA schools and also admitted 
difficulty in reaching a large size. Earlier, Symes et al. (2006) had 19 therapists in
their study exploring the facilitating factors and difficulties that therapists considered to influence the delivery of home-based applied analytic behavioural interventions.

Hence, the results of data related to the UK survey were reported with caution. For example, the sample from Study 1 showed that children in the UK (4.20 years-of-age) received their formal diagnosis 11.76 months later than their Chinese children (3.22 years-of-age). This was unexpected and might be due to the average age of UK children (8.02 years-of-age at time of study) being approximately 3 years higher than their Chinese counterpart (4.84 years-of-age at time of study). Another factor may be that a certain number of Chinese children were reported not diagnosed at the time of the survey but might be diagnosed at a later stage, increasing the average age of diagnosis.

In China, no nation-wide data were available to indicate the prevalence of ASD (Zhou et al., 2014), consequently, the number of parents of children with ASD was unknown. In addition, there were no nation-wide data available about the number of ABA professionals. Hence, there was no reference point to indicate the representativeness of the Chinese sample.

Nevertheless, results indicated a boy to girl ratio of 4.63:1 in the UK and 5.30:1 in China. The average ratio of boy to girl was estimated to be 5:1, which is consistent with the CDC report (2015).

The sampling strategy of the UK survey was selective sampling, which created a selective bias in as far as that those who had a good knowledge of EIBI or ABA-based intervention programmes may have been more inclined fill in online questionnaires. Another possible risk was that, as in all self-reported studies, there were no verification of the responses’ accuracy and genuineness.

The UK online questionnaires were sent by the researcher, or staff, to those consenting autism organisations, on the researcher’s behalf, through their mailing list or social media. The online questionnaire was very comprehensive and thus many were returned incompletely as the respondents could end it at any point. In addition, a number of respondents were removed from the final analysis because they did not meet the selection criteria - not from the UK (See Chapter 4 Methodology). It is clear that some of the participants did not carefully read the information on the front page.
of the questionnaire. This was not the same in China due to its unique geography and language.

Study 2, the qualitative study had its own limitations. For example, it was observed that some mothers’ mood affected their view of a range of entities ranging from the health service to school education. Of course, one can argue that this was a true reflection of the individual’s experience and that, after informed consent had been sought before the interview, the interviewee was willing to share her/his feelings.

Finally, the instruments of the treatment fidelity of application of DTT in Study 3, direct observations, were developed by the researcher and her supervisor. Since there was little existing literature for reference, a few shortfalls were identified. For example, the researcher only focused on the fidelity of parents and professionals’ manipulation of DTT, i.e., the appropriate use of antecedents (A), prompts (P) and consequence (C) rather than child’s behaviour (B). If the correct behaviour was presented, the entire trial was recorded. If either no reaction or the incorrect behaviour was presented, only the antecedent (A), prompt (P) or consequence (C) was recorded.

8.5 Chapter summary

Based on the research aims, this chapter discussed findings in conjunction with the literature review. Five recommendations were put forward to facilitate a wider delivery of the effective science-based approach—ABA-based interventions. Contributions and limitations of the research were addressed.
Chapter 9. Conclusions

9.1 Chapter overview
This chapter provides a summary of the thesis and outlines key sections. The original topic is revisited along with the evolution to the current topic. This is followed by the overview of the results and discussion associated with each of the six research aims. The implication of this research on future works is then assessed, followed by the final concluding remarks.

9.2 Revisit of the original topic
Before the field work and data analysis, the original topic focussed on early intensive behaviour intervention (EIBI). However, results indicated a low popularity of EIBI in the UK and China, due to a low-intensity delivery of ABA-based interventions in the UK and a different understanding towards EIBI in China. This was consistent with the pilot study (Liao, 2013; Liao et al., 2016). In addition, findings showed that there were more factors impacting ABA-based interventions in the two countries, such as cultural, historical and population reasons in addition to political and practical reasons. The initial proposal and original topic restricted the research because it was not able to provide the real status of EIBI and also failed to provide an overview of ABA-based interventions in the UK and China. Hence, a broader topic focusing on ‘early applied behaviour analytic interventions for children diagnosed with autism spectrum disorder’ was adopted. This allowed the study to encompass EIBI as well as lower intensity interventions and enabled the researcher to achieve the stated research aims. In addition, the ‘cross-national study of the UK and China’ emphasised the inclusion of the overall landscape in exploring ABA-based interventions in each country.

9.3 Review of research aims
This research compared early applied behaviour analytic interventions in the UK and China to address six research aims: (1) understand the current provision of health care for children with ASD; (2) identify the categories of service delivery of ABA-based intervention programmes in each country; (3) explore the extent to which children with ASD have access to EIBI; (4) understand changes observed in the child’s behaviour and the relationship with other professionals during or after
involvement in programmes; (5) explore parents’ and professionals’ experience with local ABA provisions; and (6) explore difficulties faced, to understand intrinsic reasons and to put forward recommendations.

First, parents’ reactions towards a diagnosis of ASD were found to be different in the two countries due to a different cultural background and social awareness. UK parents mostly relied on public health care and professionals’ services, while Chinese parents mostly relied on intra-family care.

Second, different modes of service delivery in ABA-based interventions were found in the UK and China. Results of the survey showed home-based programmes were the most popular services used by UK parents while the majority of Chinese parents utilised services through autism organisations. The qualitative interviews uncovered differences in who delivered the programmes, i.e., in the UK, professionals took a leading role in delivering ABA programmes while in China, parents took an active role in the training programmes. The reasons for the difference in service delivery were the different level of ABA-based programme adoption and the availability of resources in the two countries. However, results from the direct observations indicated that despite the different categories of service delivery reported, the application of Discrete Trial Training (a fundamental and commonly used approach of ABA-based intervention) was similar.

Third, lack of knowledge about EIBI programmes was reported in the UK and China. Possible causes included participants’ insufficient understanding towards EIBI, as well as funding, time, parenting energy, distance and other resources constraints. However, a significant number of UK professional interviewees indicated they were working towards the EIBI model and a large number of Chinese respondents were seeking systematic training in ABA. Recommendations towards a cost-effective EIBI model, taking into consideration the child’s age, intensity, duration, techniques addressed in the programme and professionals’ performance, were put forward to better match real world circumstances.

Fourth, both the UK and Chinese parents reported in the survey that their child’s quality of life improved. Semi-structured interviews showed that their child had made substantial improvements, including:
1. Improved language skills, social communication and social interaction;
2. Improved academic skills, emotional expressions, safety awareness and understanding of social norms;
3. Reduced sleeping and feeding problems; and reduced self-injurious behaviours.

Fifth, a large proportion of the UK and Chinese parent participants indicated that professionals from their child’s ABA-based programmes were supportive. More than half of the UK professional participants self-rated their skills highly, but two fifths of the Chinese professionals self-reported their skills as low. A large number of professionals from both two countries indicated their willingness to receive more training and attain certified qualifications.

Finally, both UK and Chinese participants reported that they faced a number of challenges ranging from health care system to school education system. Results showed a different health care system and educational system in each country. Parents of both countries reported a lack of information on evidence-based interventions from the health care system. The biggest challenges UK participants faced was that the child’s social skills were not being generalised from home settings to school settings because some schools, both mainstream and SEN, did not understand the science of behaviour analysis or did not integrate the principles and strategies of ABA into the child’s programme. Some schools did not allow behaviour analysts to visit and work with the child. The biggest challenge that some Chinese parents faced was the exclusion of their child from mainstream education because of societal non-acceptance and the attached cultural stigma.

In addition to reporting findings in line with the research aims, several recommendations were put forward. A cost-effective model is necessary to roll-out real world evidence-based practice. There should be systematic training in ABA for professionals and those who work as a parent therapist. A more integrated approach, involving and incorporating the health care system, schools and policy makers, is required. Finally, there should be more international collaboration to disseminate the science of behaviour analysis across countries.
9.4 Implications for future research

Future larger scale studies are required, especially of the UK population. Future studies should consider cultural and societal norms within the design to increase comparability at a cross national level.

Since EIBI is not widely used in either the UK or China, future research should pave the way for a cost-effective and time-effective intervention programme model. The present research showed that the model from the US cannot be simply replicated across other cultures, and the cultural, economic, social and practical reasons for this should be considered. In the UK, a number of researchers believed that a low-intensity applied behaviour analytic model can be incorporated within the educational system. For example, Foran et al. (2015) reported success in providing individualised early behavioural intervention for children of younger ages at an SEN school in Wales; Grindle et al. (2012) and Eldevik et al. (2012) indicated children enrolled at UK mainstream schools who received a low-intensity ABA-based intervention showed optimal outcome. A low intensity of 13.6 hours per week on average also produced significant change of a child’s IQ and adaptive behaviour (Eldevik et al., 2011). In addition, Peters-Scheffer et al. (2011) put forward a low intensity behaviour treatment (average 6.5 hours per week) which could be integrated in the preschool service in the Netherlands. Perhaps such a cost-effective model can be replicated in a wider region of both UK and China. Chinese researchers are encouraged not only to replicate the Western model, but also to work on indigenous models that are adapted to the local educational system.

The present study revealed a lack of fundamental knowledge in the science of behaviour analysis. The rapid reviews identified a deficiency in the knowledge of Chinese researchers, which was concerning. It is imperative for Chinese researchers to conduct and publish experimental and non-experimental research in a more rigorous and well-designed manner. In particular, studies on the current status of ABA-intervention and its delivery are welcome in order to adapt evidence based methods to the local environment. As these studies become more widespread, they provide evidence for the behaviour analytic approach, which would help dispel misinformation surrounding eclectic approaches and guide policy development.
It would be interesting to examine treatment fidelity of DTT in more sample sites via direct observations. For example, in China, Beijing AC School was the main sample site in this study. As Beijing AC School is regarded as a well-developed autism organisation and its service is mainly on parents-focused training, it would be interesting for future researchers to conduct direct observations in professional-led autism organisations or in those who apply an eclectic approach. A comparison between these approaches would be meaningful. In addition, it would be interesting to explore gender differences in therapists, e.g., in the Chinese sample of Study 3, both father and mother worked as behaviour therapists and observations of differences in their training deliveries would be interesting.

Finally, the progress of globalisation has promoted exchange of ideas and knowledge. This flow of information brings about many challenges. Technology, educational teaching method and language differences result in cultural divides that influenced the spread of the knowledge of ABA and autism interventions to different countries (Käck et al., 2014). Hence, it is important for future researchers and practionners to consider the practice and research on the science of behaviour analysis in different cultural and language media, and to develop technologies and teaching methods with a global perspective, for example, via the virtual presence.

9.5 Concluding remarks
Quantitative and qualitative techniques were combined to study the current provision of early applied behaviour analytic interventions for children diagnosed with ASD. Participants were parents and professionals who worked with the children with ASD (founders, supervisors and therapists). Results showed different categories of service delivery of ABA-based programmes in the UK and China. Professionals played a leading role in the UK while parents took the lead role in China. The different types of service delivery were due to different levels of adoption of ABA-based programmes and availability of resources between the UK and China. It was established that ABA-based interventions can be improved quite easily in China, e.g., by addressing a lack of data collection in the intervention. Though the EIBI model was not fully applied in practice in the two countries, the UK professionals were working towards the ‘well-established’ practice and Chinese autism organisations were transitioning from parents-founded organisations towards professional-led services and programmes. Participants of the two countries sought more integration
of ABA-based intervention services and the involvement of behaviour analysts in the child’s programme, and hoped for government policies which would support children and their families because significant improvements were observed after ABA-based programmes were carried out.

Children with ASD require support from many levels. Figure 9.1 shows a model of relationships for children with ASD. The parents of the child with ASD are pivotal in terms of the provision of care, support and intervention. Alongside parents, professionals are also vital as they directly provide intervention services to the child, as well as advice to the parents. The effectiveness of intervention services was greatly dependent on parents and professionals. On the next level is the education system which is a platform for the child with ASD to interact with the outside world as well as being a potential pathway towards integration with mainstream society. The health system also plays an important role as it is the system through which the support and intervention services are provided. Public policy forms the framework for the operation of the health and education system and sets out their operation. Finally, public policy is strongly influenced by the society and its culture. The acceptance of ABA and individuals with ASD are dependent on an inclusive society and a diverse culture. Hence, the dissemination of the science of behaviour analysis should occur cross national boundaries to benefit a wider population.

Figure 9.1: A model of relationship for children with ASD
Clearly, ABA-based intervention programmes need to be tailored not only to the child, but also the entire system of delivery. Supporting policies and infrastructure must be tailored to the local environment to achieve the best results. Hence, ABA should be viewed as the Milliarium Aureum (Golden Milestone, Schaff, 1867): ‘There are many roads that lead to good ABA-based interventions’.
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### Appendix 1  Search terms of ABA-based interventions in the UK

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Appendix: 352
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Appendix: 353
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Appendix: 354
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Appendix: 355
Appendix: 356

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Appendix: 356
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*Searched on 16-21 January 2017
## Appendix 2  The detail of journal papers of ABA-based interventions in the UK

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<td>Study Title</td>
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<td>---------</td>
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<td>--------------------------------------------------------------------------------</td>
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<tr>
<td>10</td>
<td>Eldevik, Hastings, Jahr &amp; Hughes</td>
<td>2012</td>
<td>Experiment</td>
<td>ABA group; 26 post-ABA group (conducted ABA in the past, but currently no longer); 61 control families did not in any ABA</td>
<td>UK</td>
<td>Children</td>
<td>Behavioural interventions for children with ASD within mainstream school</td>
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<tr>
<td>11</td>
<td>Griffith, Fletcher, &amp; Hastings</td>
<td>2012</td>
<td>Census</td>
<td>44 children: 31 children received behavioural intervention and 12 children receiving treatment as usual</td>
<td>UK</td>
<td>Staffs</td>
<td>ABA in school provision, current situation, characteristics an staffing structures</td>
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<tr>
<td>12</td>
<td>Dillenburger, Keenan, Doherty, Byrne &amp; Gallagher</td>
<td>2012</td>
<td>Questionnaire</td>
<td>14 UK ABA schools/classes</td>
<td>NI &amp; ROI **</td>
<td>Parents and professionals</td>
<td>Parents and professionals experiences in schools provided ABA and non-intensive ABA-based home programmes</td>
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<td>13</td>
<td>Grindle et al.</td>
<td>2012</td>
<td>Experiment-based</td>
<td>95 parents and 67 professionals</td>
<td>NI &amp; ROI ***</td>
<td>Children</td>
<td>ABA-based interventions in a mainstream school</td>
</tr>
<tr>
<td>14</td>
<td>Tzanakaki, Grindle, Hastings, Hughes, Kovshoff &amp; Remington</td>
<td>2012</td>
<td>Qualitative interview</td>
<td>30 mothers</td>
<td>UK</td>
<td>Mothers</td>
<td>Process of how and why choose EIBI</td>
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<tr>
<td>15</td>
<td>Sowden, Perkins &amp; Clegg</td>
<td>2011</td>
<td>Experiment</td>
<td>8 children</td>
<td>UK</td>
<td>Children</td>
<td>Children with ASD in naturalistic behaviour-based interventions</td>
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<tr>
<td>16</td>
<td>Jones, Hoerger,</td>
<td>2011</td>
<td>Experiment-</td>
<td>One ABA school</td>
<td>Wales</td>
<td>Staffs</td>
<td>Delivering an ABA curriculum within</td>
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Appendix: 359
<table>
<thead>
<tr>
<th>ID</th>
<th>Authors</th>
<th>Year</th>
<th>Study Type</th>
<th>Sample</th>
<th>Location</th>
<th>Participants</th>
<th>Findings</th>
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<tr>
<td>17</td>
<td>Kovshoff, Hastings &amp; Remington</td>
<td>2011</td>
<td>Experiment</td>
<td>41 Children: 23 children in the intervention group and 18 of the treatment as usual group</td>
<td>UK</td>
<td>Children</td>
<td>Examine early gains can be maintained after intervention ceases</td>
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<tr>
<td>18</td>
<td>Reed, Osborne &amp; Corness</td>
<td>2010</td>
<td>Experiment-based</td>
<td>33 children</td>
<td>South-east of England</td>
<td>Children</td>
<td>Examine effectiveness of three local authority early teaching interventions</td>
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<tr>
<td>19</td>
<td>Hayward, Eikeseth, Gale &amp; Morgan</td>
<td>2009</td>
<td>Experiment study</td>
<td>44 Children (two groups): 23 Children in the clinic-based group and 21 children in the parent managed group</td>
<td>UK</td>
<td>Children</td>
<td>One year outcome of replicating the UCLA ABA treatment</td>
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<tr>
<td>20</td>
<td>Grindle, Kovshoff, Hastings &amp; Remington</td>
<td>2009</td>
<td>Qualitative interview</td>
<td>53 Parents</td>
<td>UK</td>
<td>Parents</td>
<td>Parents' experiences of home-based applied behaviour analysis programs</td>
</tr>
<tr>
<td>21</td>
<td>Eikeseth, Hayward, Gale, Gitlesen &amp; Eldevik</td>
<td>2009</td>
<td>Experiment</td>
<td>20 Children</td>
<td>UK</td>
<td>Children</td>
<td>Examine supervision is associated with outcome in preschool aged children with autism</td>
</tr>
<tr>
<td>22</td>
<td>Trudgeon &amp; Carr</td>
<td>2007</td>
<td>Qualitative interview (Focus group)</td>
<td>16 parents from 9 families</td>
<td>UK</td>
<td>Parents</td>
<td>Impacts and the stressors experienced by families running EIBI programmes</td>
</tr>
<tr>
<td></td>
<td>Authors</td>
<td>Year</td>
<td>Study Type</td>
<td>Participants</td>
<td>Location</td>
<td>Participants Type</td>
<td>Study Description</td>
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<tr>
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<td>-------------------------------------------------------------------------------</td>
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<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>23</td>
<td>Remington et al.</td>
<td>2007</td>
<td>Experiment</td>
<td>44 children: Intervention group (n=23) and comparison group (n=21)</td>
<td>UK</td>
<td>Children</td>
<td>RCT on EIBI</td>
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<tr>
<td>24</td>
<td>Magiati, Charman &amp; Howlin</td>
<td>2007</td>
<td>Experiment</td>
<td>44 children: 28 in EIBI home-based programme; 16 in autism specific nurseries</td>
<td>UK</td>
<td>Children</td>
<td>Compare outcome for pre-school children with ASD receiving home-based EIBI programme or autism-specific nursery provision</td>
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<tr>
<td>26</td>
<td>Symes, Remington, Brown &amp; Hastings</td>
<td>2006</td>
<td>Semi-structured interview</td>
<td>19 therapists</td>
<td>South of England</td>
<td>Therapists</td>
<td>Factors and barriers that therapists consider to influence the delivery of EIBI</td>
</tr>
<tr>
<td>27</td>
<td>Farrell, Trigonaki, Webster &amp; Peter Farrell</td>
<td>2005</td>
<td>Retrospective cohort</td>
<td>13 children: 8 children in LUFA group and 5 children in ABA group</td>
<td>UK</td>
<td>Children</td>
<td>A discussion of the impact of two contrasting early intervention programmes for a small number of young children with autism</td>
</tr>
<tr>
<td>29</td>
<td>Dillenburger, Keenan, Stephen &amp;</td>
<td>2004</td>
<td>Questionnaire</td>
<td>22 parents: 12 parents in long-term ABA programmes</td>
<td>NI</td>
<td>Parents</td>
<td>Examination of parents’ perception of ABA outcome</td>
</tr>
<tr>
<td>#</td>
<td>Author(s)</td>
<td>Year</td>
<td>Method/Instrument</td>
<td>Sample Size</td>
<td>Location</td>
<td>Group/Role</td>
<td>Summary</td>
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<tr>
<td>----</td>
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<td>------------------------------------------------------------------------</td>
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<tr>
<td>30</td>
<td>Hastings</td>
<td>2003</td>
<td>Behaviour-rating questionnaires</td>
<td>18 married</td>
<td>UK</td>
<td>Parents</td>
<td>Interrelationships between mothers' and fathers' psychological well-being</td>
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<tr>
<td>31</td>
<td>Hastings</td>
<td>2003</td>
<td>Questionnaire</td>
<td>79 mothers</td>
<td>UK</td>
<td>Parents</td>
<td>Siblings of children on intensive ABA</td>
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<tr>
<td>32</td>
<td>Johnson &amp; Hastings</td>
<td>2002</td>
<td>Questionnaire</td>
<td>141 parents</td>
<td>UK</td>
<td>Parents</td>
<td>Facilitating factors and barriers to the implementation of intensive home-based behavioural intervention</td>
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<tr>
<td>33</td>
<td>Hastings &amp; Symes</td>
<td>2002</td>
<td>Questionnaire</td>
<td>65 mothers</td>
<td>UK</td>
<td>Parents</td>
<td>Self-efficacy of parents’ therapists</td>
</tr>
<tr>
<td>34</td>
<td>Salt, Shemilt, Sellars, Boyd, Coulson &amp; McCool</td>
<td>2002</td>
<td>Experiment</td>
<td>20 children: 14 children in the experiment group and 6 children in control group</td>
<td>Scotland</td>
<td>Children</td>
<td>Examine effectiveness of a developmentally based early intervention programme</td>
</tr>
<tr>
<td>35</td>
<td>Hastings &amp; Johnson</td>
<td>2001</td>
<td>Questionnaire</td>
<td>141 parents</td>
<td>UK</td>
<td>Parents</td>
<td>Stress in UK families conducting intensive home-based behavioural intervention</td>
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<tr>
<td>36</td>
<td>Mudford, Martin, Eikeseth &amp; Bibby</td>
<td>2001</td>
<td>Assessment tests (IQ) &amp; interviews</td>
<td>Children (n=75)</td>
<td>England</td>
<td>Parents</td>
<td>To examine how closely do parent-managed EIBI programmes in the UK follow the UCLA protocols</td>
</tr>
</tbody>
</table>

*Also included in the rapid reviews of ABA-based interventions in China
**Included because UK participants occupied 80% of the participants.
***Included because 73% parents and 31% of professionals were from NI: 27% of parents and 69% of professionals were from ROI.
****The above articles can be found in the bibliography.
### Appendix 3  Search terms of ABA-based interventions in China (EN)

<table>
<thead>
<tr>
<th>No.</th>
<th>Databases</th>
<th>Search terms</th>
<th>Records</th>
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<tbody>
<tr>
<td>1</td>
<td>Education Abstracts</td>
<td>TX ( autis* OR PDD OR &quot;pervasive developmental disorder*&quot; OR &quot;pervasive developmental delay*&quot; OR &quot;pervasive developmental disabilit*&quot; OR &quot;global developmental delay*&quot; OR asperger* OR ASD OR HFA OR HFASD OR HF-ASD OR Rett* OR &quot;childhood disintegrative disorder*&quot; OR &quot;triad of impairments&quot; OR &quot;Fragile X&quot; OR PDDNOS OR PDD-NOS OR PDD/NOS OR savant OR &quot;reactive attachment disorder*&quot; OR AS/HFA OR Kanner* OR aspies OR &quot;childhood schizophrenia&quot; OR &quot;atypical personality development&quot; ) AND TX ( &quot;early intensive behavio* intervention&quot; OR EIBI OR “comprehensive ABA-based early intervention” OR “intensive behavio* intervention” OR “early behavio* intervention”OR “early applic* behavio* intervention” OR &quot;applied behavio* analysis&quot; OR ABA OR &quot;applied behavio* analysis&quot; OR “ABA-based intervention” OR “behavio* analysis” OR “behavio* intervention” OR “behavio* treatment*” ) AND TX ( China OR Chinese OR “P.R.C.” OR “People’s Republic of China” OR “Mainland China” )</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>ERIC</td>
<td>TX ( autis* OR PDD OR &quot;pervasive developmental disorder*&quot; OR &quot;pervasive developmental delay*&quot; OR &quot;pervasive developmental disabilit*&quot; OR &quot;global developmental delay*&quot; OR asperger* OR ASD OR HFA OR HFASD OR HF-ASD OR Rett* OR &quot;childhood disintegrative disorder*&quot; OR &quot;triad of impairments&quot; OR &quot;Fragile X&quot; OR PDDNOS OR PDD-NOS OR PDD/NOS OR savant OR &quot;reactive attachment disorder*&quot; OR AS/HFA OR Kanner* OR aspies OR &quot;childhood schizophrenia&quot; OR &quot;atypical personality development&quot; ) AND TX ( “early intensive behavio* intervention” OR EIBI OR “comprehensive ABA-based early intervention” OR “intensive behavio* intervention” OR “early behavio* intervention”OR “early applic* behavio* intervention” OR &quot;applied behavio* analysis&quot; OR ABA OR &quot;applied behavio* analysis&quot; OR “ABA-based intervention” OR “behavio* analysis” OR “behavio* intervention” OR “behavio* treatment*” ) AND TX ( China OR Chinese OR “P.R.C.” OR “People’s Republic of China” OR “Mainland China” )</td>
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Appendix: 363
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<th></th>
<th>“P.R.C.” OR “People’s Republic of China” OR “Mainland China” )</th>
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<td>3</td>
<td>Web of Science</td>
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<tr>
<td>4</td>
<td>ProQuest Education Journals</td>
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<td>5</td>
<td>SCOPUS</td>
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Appendix: 364

*Searched on 22-25 January 2017
**Appendix 4  The details of journal papers of ABA-based interventions in China (EN)**

<table>
<thead>
<tr>
<th>No.</th>
<th>Author</th>
<th>Date</th>
<th>Methods</th>
<th>Sample</th>
<th>Area</th>
<th>Participants</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Liao, Dillenburger &amp; Buchanan*</td>
<td>2016</td>
<td>Semi-structured interview</td>
<td>10 professionals and 5 parents</td>
<td>UK and mainland China</td>
<td>Parents and professionals</td>
<td>Cultural differences in the UK and China in relation to ABA-based interventions for children with autism</td>
</tr>
<tr>
<td>2</td>
<td>Zhang, &amp; Spencer</td>
<td>2015</td>
<td>Structured-interview</td>
<td>2 principals</td>
<td>Mainland China</td>
<td>Organisation's principals</td>
<td>Addressing the needs of students with autism and other disabilities in China</td>
</tr>
<tr>
<td>3</td>
<td>Zhou, Ye, Sun,Tian, Pu, Wu, Wang, Zhao, Lu, Yang &amp; Wei</td>
<td>2014</td>
<td>Students’ registration data and survey</td>
<td>Stars and Rain with 2,222 registration children; 100 member centres of Heart Alliance</td>
<td>Mainland China</td>
<td>NGOs</td>
<td>Statistical analysis of twenty years (1993 to 2012) of data from mainland China's first intervention centre for children with autism spectrum disorder and survey 100 autism organisations</td>
</tr>
<tr>
<td>4</td>
<td>Wang</td>
<td>2008</td>
<td>Evaluation</td>
<td>27 families</td>
<td>Mainland China</td>
<td>Families</td>
<td>Compare individualised training and parents’ training</td>
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</tbody>
</table>

*Also included in the rapid reviews of ABA-based interventions in the UK

**The above articles can be found in the bibliography
### Appendix 5  Search terms of ABA-based interventions in China (CN)

<table>
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<th>Databases</th>
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<td>CKNI (知网)</td>
<td>All text (自闭症 OR 孤独症) and (应用行为分析 OR ABA)</td>
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<tr>
<td>VIP (维普)</td>
<td>Title or key words(自闭症) OR title or key words (孤独症) And Abstract (应用行为分析)</td>
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</table>

*Search on 26-28 January 2017; 4-5 February 2017*
### Appendix 6  The details of journal papers of ABA-based interventions in China (CN)

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<th>Sample</th>
<th>Indicated Area</th>
<th>Participants</th>
<th>Topic</th>
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<tr>
<td>1</td>
<td>Zhong</td>
<td>2016</td>
<td>Experiment</td>
<td>1</td>
<td>Mainland China</td>
<td>One boy (11y)</td>
<td>Case study of child's challenging behaviour</td>
</tr>
<tr>
<td>2</td>
<td>Dong</td>
<td>2015</td>
<td>Experiment</td>
<td>1</td>
<td>Mainland China</td>
<td>One boy</td>
<td>Case study of task analysis to teach child's vocational skills</td>
</tr>
<tr>
<td>3</td>
<td>Hu, Xu, Xu &amp; Feng</td>
<td>2015</td>
<td>Experiment-single subject design</td>
<td>3</td>
<td>Mainland China</td>
<td>Three children</td>
<td>Explored immediate learning, generalization and maintaining effects</td>
</tr>
<tr>
<td>4</td>
<td>Ding, Zhong, Cheng &amp; Jiang</td>
<td>2015</td>
<td>Assessment evaluation</td>
<td>66</td>
<td>Mainland China</td>
<td>66 Children</td>
<td>Child's quality of life by ABA training</td>
</tr>
<tr>
<td>5</td>
<td>Hu &amp; Fan</td>
<td>2014</td>
<td>Experiment-single subject design</td>
<td>1</td>
<td>Mainland China</td>
<td>One boy (4y)</td>
<td>Use PECS to mand</td>
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<tr>
<td>6</td>
<td>Shao, Xu &amp; Zhang</td>
<td>2014</td>
<td>Experiment</td>
<td>1</td>
<td>Mainland China</td>
<td>One boy (2y3m)</td>
<td>PECS on low-functioning children with autism</td>
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<tr>
<td>7</td>
<td>Liu &amp; Chen</td>
<td>2012</td>
<td>Assessment evaluation</td>
<td>41</td>
<td>Mainland China</td>
<td>43 children</td>
<td>Speech and language skills by ABA</td>
</tr>
<tr>
<td>8</td>
<td>Xiong et al.</td>
<td>2010</td>
<td>Assessment evaluation</td>
<td>76</td>
<td>Mainland China</td>
<td>Mothers</td>
<td>Clinic symptoms of children with autism and psychological condition of their mothers</td>
</tr>
</tbody>
</table>

*The above articles can be found in the bibliography*
Appendix 7 UK parents’ questionnaire

Questionnaire for parents of children with ASD

ABA-based intervention for children diagnosed with autism spectrum disorder

I. Participant information
You are invited to take part in this Doctoral research project by the Centre for Behaviour Analysis of the School of Education at Queen’s University Belfast. If you would like further information regarding any aspect of this project, you are encouraged to contact the researcher via the phone number or email address listed below.

The aim of the study is to find out more about the current situation of children diagnosed with ASD and compare the application of early ABA-based interventions in practices and policies between the UK and China.

Parents/Guardians should meet the following criteria:
- Have one or more children with ASD
- At least one child is involved in ABA programmes

The survey should take approximately 20-25 minutes.

II. Storage of data
After the study is completed, data will be kept securely at the School of Education data storage facility for 5 years, before being destroyed. Your name or identity will not be disclosed to anyone other the researcher and her supervisor. For all other purposes, you will be given a substitute code and the key to this code will be kept in a separate file and destroyed immediately after the study is completed.

This study was approved by the School of Education Research Ethics Committee and is conducted under QU research governance guidelines.

If you have further questions, feel free to contact me at

Yini Liao (PhD candidate)
Tel: +44 (0)7927284030
Email: yliao05@qub.ac.uk
Or my supervisor Prof. Karola Dillenburger
Email k.dillenburger@qub.ac.uk
School of Education
Queen’s University Belfast
69-71 University Street, Belfast BT7 1HL

Note:
**Applied Behaviour Analysis (ABA)-based interventions programs:** any programmes that involve ABA-based interventions or the use of Applied Behaviour Analysis strategies or principles. The programme may be comprehensive (covering many targeted areas) or target-specific (e.g. Social Skills training using ABA), intensive or non-intensive, home-, clinic- or school-based.

### III. Consent form

I have read the attached information letter which explains the research process.

I understand that the letter is asking me to participate in an online survey.

I understand that all the information gathered will be kept strictly confidential and that my name and the name of my child / the organisation/school where I work will not be included in any reports.

I understand that participation is voluntary and that I am free to withdraw my consent at any time during the interview or until submission of the anonymous survey.

I understand that this research will be published in the form of a Doctoral dissertation and journal articles.

Please tick one of the following boxes to indicate whether or not you agree to take part:

- ☐ Yes
- ☐ No

### Section 1: Demographic information:

Q1.1 Relationship to the child (children) doing ABA

- o Mother (1)
- o Father (2)
- o Grandparents (3)
- o Other Guardians (4)
- o Other(Specify:________________)

Q1.2 Gender

- o Male
- o Female

Q1.3 What is your marital status?

- o Single, that is, never married
- o Married and living with husband/wife
- o A civil partner in a legally-recognised Civil Partnership
- o Married and separated from husband\wife
- o Divorced
- o Widowed
Q1.4 Which age group are you in?
- 0-17 (1)
- 18-24(2)
- 25-44 (3)
- 45-64(4)
- 65-74 (5)
- 75+  (6)

Q1.5 In which country do you live currently?
- England (1)
- Wales (2)
- Scotland (3)
- Northern Ireland (4)
- UK, Britain (not sure about country) (5)
- Republic of Ireland (6)
- Other(Specify:_____________)  (7)

Q1.6 How would you describe your national identity?
- English (1)
- Welsh (2)
- Scottish (3)
- Northern Irish (4)
- British (5)
- Irish (6)
- Other(Specify:_____________)  (7)

Q1.7 Which of following applies to your current working status?
- Looking after home or family full-time (1)
- Going to school full-time (2)
- Going to college full-time (3)
- In paid employment or self-employed full-time (4)
- In paid employment or self-employed part-time (5)
- On a Government scheme for employment training (6)
- Doing unpaid work (7)
- Looking for paid work or a Government training scheme (8)
- Intending to look for work but prevented by temporary sickness or injury (9)
- Permanently unable to work because of child’s disability (10)
- Retired from paid work (11)
- Other(Specify:_____________)  (12)

Q1.8 What is your highest education level? (Tick all that apply)
- If your UK qualifications is not listed, tick the box that contains its nearest equivalent
- If your qualifications gained outside the UK, tick the ‘Foreign qualifications’ box and the nearest UK equivalents (if known)

- Secondary school qualification (e.g., Standard Grade, Intermediates, O Levels, GCSE) (1)
- Advanced secondary school qualification (e.g., Highers, A levels) (2)
- University or college qualification below a degree (e.g., HND, HNC, City and Guild advanced certificate, nursing diploma, primary school teaching diploma) (3)
Section 2: Parents’ information:

Q2.1 In total, how many hours per week do you spend providing help or care for your child (children) diagnosed with ASD

- 1 - 4 hrs (1)
- 5 - 9 hrs (3)
- 10-14 hrs (4)
- 15-19 hrs (5)
- 20-34 hrs (6)
- 35-49 hrs (7)
- 50+ hrs (8)
- Continuous (at all times of the day ) (9)

Q2.2 Where did you find out about ABA-based interventions/therapy in general? (Tick all that apply)

- Paediatrician (1)
- Psychiatrist (2)
- Psychologist (3)
- Speech Pathologist (4)
- Occupational therapist (5)
- Other health professionals (eg., Audiologist) (6)
- Family / friends (7)
- Autism guidelines / handbooks (8)
- Social media (9)
- Websites (10)
- Diagnosis / assessment teams (11)
- Community Health (12)
- Autism Awareness (13)
- National Autistic Society (14)
- PEACH (Parents for the Early Intervention of Autism in Children) (15)
- PEAT (Parents for the Early Intervention for Autism in Children) (16)
- Other autism organisations/societies (17)
- Others (Specify:___________ ) (18)

Q2.3 Was ABA-based interventions/therapy recommended to you? If so, by whom? (Tick all that apply)

- Paediatrician (1)
- Psychiatrist (2)
- Psychologist (3)
- Speech Pathologist (4)
- Occupational therapist (5)
- Other health professionals (eg., Audiologist) (6)
- Family / friends (7)
- Autism guidelines / handbooks (8)
Social media (9)
- Websites (10)
- Diagnosis / assessment teams (11)
- Community Health (12)
- Autism Awareness (13)
- National Autistic Society (14)
- PEACH (Parents for the Early Intervention of Autism in Children) (16)
- PEAT (Parents for the Early Intervention for Autism in Children) (17)
- Other autism organisations/societies (15)
- Others (Specify: __________) (18)
- Not recommended (19)

Q2.4 How many of your child/children are currently doing ABA programmes?
- 0 (1)
- 1 (2)
- 2 (3)
- 3 (4)
- 4 (5)
- More than 4 (6)

Q2.5 How many of your child/children have completed ABA programmes in the past?
- 0 (1)
- 1 (2)
- 2 (3)
- 3 (4)
- 4 (5)
- More than 4 (6)

Q2.6 Family income per annum (Pre-tax)
- Less than £16,000 (1)
- £16,000 to £25,000 (2)
- More than £25,000 (3)
- I would rather not say (4)

Q2.7 Approximately how much do you currently spend on your child/children’s ABA-based programmes per year? (per child, including cost of materials etc.)
- £0-£500 (1)
- £501-£1,000 (2)
- £1,001-£2,000 (3)
- £2001-£3,000 (4)
- £3,001-£4000 (5)
- £4,001-£5,000 (6)
- £5,001-£10,000 (7)
- £10,001 + (8)

Q2.8 What forms of financial support do you receive for your child/children's ABA programmes? Include prior payments if applicable.
- The Disability Living Allowance (DLA) (1)
- Personal Independence Payment (PIP) (2)
- Carers Allowance (3)
- Child Tax Credits (4)
Appendix:

Q2.9 How do you pay / have you paid for the ABA programme? (Tick all that apply)

- Government financial support (1)
- Salary (2)
- Investment (3)
- Took on additional employment (4)
- Cashed in leave entitlements (5)
- Loan (6)
- Borrowed funds from family / friends (7)
- Superannuation (8)
- Inheritance (9)
- Sold assets (10)
- Fund raising (11)
- Gifted money (12)
- Re re-mortgaged house (14)
- Others (Specify:___________ ) (13)

Section 3: Parents’ knowledge and understanding on autism

Q3.1 How much do you agree with the following statements about the causes of autism?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely</th>
<th>Probably</th>
<th>Don’t know</th>
<th>Probably not</th>
<th>Definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism is caused by vaccines like MMR (1)</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>Autism is caused by something in the environment (2)</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>Autism can be inherited (3)</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
<tr>
<td>Autism is caused by poor parenting skills (4)</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
<td>![ ]</td>
</tr>
</tbody>
</table>

Appendix: 375
Q3.2 How much do you agree with the following statements about the treatment of autism?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely</th>
<th>Probably</th>
<th>Don’t know</th>
<th>Probably not</th>
<th>Definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>There are drug treatments that are effective in helping people with autism (1)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>There are behavioural interventions that are effective in helping people with autism (2)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>There are other non-drug related therapies and supports that that are effective in helping people with autism (3)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>There is nothing that can help with autism (4)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>People with autism do not need help (5)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Q3.3 Here are some statements that have been made about people with ASD. How much do you agree or disagree with each of these?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism is a life-long disability and you can do nothing about it (1)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>When child/ren has autism their own choices are not respected enough (2)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>It is better for people with</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Appendix: 376
severe autism if they are cared for in a residential unit (3)

It is better for the *family* of someone with severe autism if the person is cared for in a residential unit (4)

Q3.4 Here are some statements: Could you please tell me whether you think people with autism have...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely</th>
<th>Probably</th>
<th>Don’t know</th>
<th>Probably not</th>
<th>Definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>...A brain disorder (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>...A mental illness (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>...A behavioural problem (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>...A type of learning disability (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>...Special abilities, for example in maths, music, art (5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q3.5 How much do you agree with the following statements about the *socialisation* of children diagnosed with ASD? When child/ren has autism they…

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely</th>
<th>Probably</th>
<th>Don’t know</th>
<th>Probably not</th>
<th>Definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>… may have no chance in mainstream education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…may have no chance in getting a job</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>…may not be able to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
spend life outside except at home
…may not be taken care by anyone else except parents/guardians
…may personally not be able to enjoy life as other parents

<table>
<thead>
<tr>
<th>Section 4: Child profile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please answer the following questions for your child that is currently involved in ABA programme.</td>
</tr>
<tr>
<td>[If more than one child has been diagnosed with ASD in the family, unless you wish to do otherwise choose the one who is doing the most intensive ABA-based intervention programmes.]</td>
</tr>
<tr>
<td>Q 4.1 Number of children in the family diagnosed with ASD</td>
</tr>
<tr>
<td>o One child</td>
</tr>
<tr>
<td>o Two children</td>
</tr>
<tr>
<td>o Three children</td>
</tr>
<tr>
<td>o Four children</td>
</tr>
<tr>
<td>o More than four children</td>
</tr>
<tr>
<td>Q4.2 Gender</td>
</tr>
<tr>
<td>o Male (1)</td>
</tr>
<tr>
<td>o Female (2)</td>
</tr>
<tr>
<td>Q4.3 Age of the child (eg., 7 years 3 months --&gt; 7, 3)</td>
</tr>
<tr>
<td>o Years (1)</td>
</tr>
<tr>
<td>o Months (2)</td>
</tr>
<tr>
<td>Q4.4 Age of the child when ASD was identified/suspected, i.e., by yourself/family/others (eg., 7 years 3 months --&gt; 7, 3)</td>
</tr>
<tr>
<td>o Years (1)</td>
</tr>
<tr>
<td>o Months (2)</td>
</tr>
<tr>
<td>Q4.5 Does your child have a formal ASD diagnosis?</td>
</tr>
<tr>
<td>o Yes (1)</td>
</tr>
<tr>
<td>o No (3)</td>
</tr>
<tr>
<td>Q4.6 Which of the following applied to your child? (Tick all that apply)</td>
</tr>
<tr>
<td>o Autism Spectrum Disorder (1)</td>
</tr>
<tr>
<td>o Autistic Disorder (2)</td>
</tr>
<tr>
<td>o Asperger's Syndrome (3)</td>
</tr>
<tr>
<td>o Pervasive Developmental Disorder-Not otherwise specified (PDD-NOS)</td>
</tr>
<tr>
<td>o Rett's Disorder (5)</td>
</tr>
</tbody>
</table>
○ Cerebral palsy (6)
○ Epilepsy (7)
○ Attention deficit hyperactivity disorder (ADHD) (8)
○ Learning disability (9)
○ Others (Specify:___________  ) (10)

**Answer If Does your child have a formal ASD diagnosis? (All Loops) Yes Is Selected**

Q4.7 Age of the child when ASD was formally diagnosed

○ Years (1)_______
○ Months (2)_______

**Answer If Does the child have a formal diagnosis? (All Loops) Yes Is Selected**

Q4.8 diagnosed/assessed by a...

○ Paediatrician (1)
○ Psychiatrist (2)
○ Psychologist (3)
○ Speech pathologist (4)
○ CAMHS team (Child and Adolescent Mental Health Services) (5)
○ Others (Specify:___________  ) (6)

**Section 5: Child’s ABA-based behavioural intervention**

Q 5.1 Age of the child when commenced ABA programme

○ Years (1)_______
○ Months (2)_______

Q5.2 How long was your child on a wait-list for the current ABA programme?

○ Months (1)_______

Q5.3 Type of current ABA programme (Tick all that apply)

○ Home-based 1:1 programme (1)
○ Centre-based 1:1 programme (2)
○ School-based 1:1 programme (3)
○ Centre-based group programme (4)
○ School-based group programme (5)
○ Multi-disciplinary programme (ABA + Speech +Occupational Therapy) (6)
○ Kindergarten / School ABA consultation (7)
○ Kindergarten / School support from ABA therapists (8)
○ ABA playgroup (9)
○ ABA Sports programme (10)
○ Others (Specify:___________  ) (11)

Q5.4 How many hours of ABA programme does your child currently do per week?

_____ hrs at Home-based 1:1 programme (1)
_____ hrs at Centre-based 1:1 programme (2)
_____ hrs at School-based 1:1 programme (3)
_____ hrs at multi-disciplinary programme (ABA + Speech + OT) (4)
_____ hrs at Kindergarten / School consultation & support (5)
_____ hrs at ABA playgroup (6)
_____ hrs at ABA Sports programme (7)
_____ hrs at others (Specify:___________ ) (8)

Q5.5 Which statement best represents your child's current ABA programme?

- Intensive and comprehensive (i.e., targeting a number of skill areas) programme (1) (Skip to Q 5.6)
- Intensive programme targeting one specific skill (eg., Social Skills Training programme) (2) (Skip to Q 5.6)
- Intensive and comprehensive programme that moved to a less intensive one (3)
- Comprehensive programme that started as non-intensive (4)
- Non-intensive programme targeting one specific skill (5)
- Other (Specify) (6) ________________

Q 5.5.1 What are the reasons for currently having a non-intensive programme for your child? (Tick all that apply)

- The child does not need an intensive programme (1)
- Financial reasons (2)
- Time constraints (3)
- Transition to school (4)
- Nature of the programme (5)
- No particular reason (6)
- Others (Specify:___________ ) (7)

Q5.6 What areas does your child's early ABA-based programme currently address? (Tick all that apply)

- Communication skills (1)
- Social skills (2)
- Play skills (3)
- Academic skills (eg., reading, writing) (4)
- General knowledge & Reasoning (5)
- Difficult/ problematic behaviours (6)
- Obsessions and rituals (7)
- Sensory issues (8)
- Motor skills (9)
- Dietary issues (10)
- Sleeping issues (11)
- Emotional issues (eg., anger, anxiety) (12)
- Independent daily life skills (eg., toileting, dressing) (13)
- Skills needed for group learning environment (14)
- Others (Specify:_____________ ) (15)
Q5.7 What other services does your child currently access? (Tick all that apply)

- Speech Therapy (1)
- Occupational Therapy (2)
- Medical treatment (3)
- Sports programme (e.g., Swimming, gymnastics) (4)
- Music programme (e.g., Music therapy) (5)
- Early Intervention programme (non-behavioural) (7) specify ____________
- None (8)
- Others (Specify:___________ ) (9)

Q5.8 Does your child currently attend any of the followings? (Tick all that apply)

- Childcare (1)
- Early education / intervention programme (2)
- Kindergarten (3)
- ABA-preschool (4)
- Primary school (Mainstream, Regular class) (5)
- Primary school (Mainstream, Special Education class/programme) (6)
- Secondary school (Mainstream, Regular class) (7)
- Secondary school (Mainstream, Special Education class/programme) (8)
- Special school (9)
- Special developmental school (10)
- Autism specific school (11)
- Specialist school / unit (12)
- Home-schooling (13)
- ABA school (14)
- None of above (15)
- Others (Specify:___________ ) (16)

Q5.9 Do your child’s ABA therapist(s) accompany your child in kindergarten or school as the funded aid?

- Yes (1)
- No (2)

Q5.10 How often do you hold team meetings with your programme supervisor and therapists?

- None (1)
- Once a year or less (2)
- Every 2-6 months (3)
- Every month (4)
- Every two weeks (5)
- Every week (6)
Q5.11 How many hours of programme supervision do you usually receive **per month** (including team meetings, phone, email)?

- Hours_____

Q5.12 How is progress measured in your child’s ABA-programme? (Tick all that apply)

- Continuous frequency/duration/intensity etc of target behaviours, i.e., graphs (1)
- Assessment tests (2)
- Parent interviews/Questionnaires (3)
- Casual chats with therapists (4)
- Don't know
- Others (5)

Q5.13 How is progress measured in your child’s non-ABA-based aspects of his/her programme? (Tick all that apply)

- Continuous frequency/duration/intensity etc of target behaviours, i.e., graphs (1)
- Assessment tests (2)
- Parent interviews/Questionnaires (3)
- Casual chats with therapists (4)
- Don't know
- Others (5)

Q5.14 On average, how long do you travel to access your current child’s ABA programme?

- No travel required (home) (1)
- less than 30 mins (2)
- 30-60mins (3)
- 1-2hours (4)
- 2-3 hours (5)
- 3 hours + (6)

Q5.15 On average, how long do you travel to receive supervision from your programme supervisor?

- No travel required (home) (1)
- less than 30 mins (2)
- 30-60mins (3)
- 1-2hours (4)
- 2-3 hours (5)
- 3 hours + (6)
Q5.16 To what extent is the information about your child’s ABA-programme incorporated into your child’s school/pre-school by the following professionals?

<table>
<thead>
<tr>
<th></th>
<th>Very little</th>
<th>Somewhat</th>
<th>Not sure</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>School/pre-school (eg., Teachers, teacher aides) (1)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Speech Therapists (2)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Occupational Therapists (3)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Psychologists (4)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Q6.1 Compared to before you started ABA programme, what is your daily stress level as a parent now?

- Much Lower (1)
- Slightly Lower (2)
- About the Same (3)
- Higher (4)
- Much Higher (5)

If your stress level has changed, what has been the cause of this change? ………

Q6.2 Compared to before you started ABA programme, how do you rate your child's (children's) quality of life now?

- Much Lower (1)
- Slightly Lower (2)
- About the Same (3)
- Higher (4)
- Much Higher (5)

If his/her quality of life has changed, what has been the cause of this change? ………
Q6.3 To what extent does your child's current ABA programme incorporate the following elements?

<table>
<thead>
<tr>
<th>Element</th>
<th>Not at all (1)</th>
<th>Somewhat (2)</th>
<th>Much (3)</th>
<th>Very Much (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active family involvement (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individualised to each child’s strengths &amp; needs (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individualised to each family needs (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional assessment for intervention planning (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Periodic assessment of progress (5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generalisation and maintenance procedures for new skills (6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multi-disciplinary team working together (7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Including typically developing peers in the programme (8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promoting independent functioning (9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promoting structured environment (e.g., establish routines &amp; predictability) (10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collecting direct observational data of behaviour targets (11)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Appendix: 384
Q6.4 How satisfied is you with your child's current ABA programme?

<table>
<thead>
<tr>
<th>Q6.4</th>
<th>Not satisfied (1)</th>
<th>Somewhat satisfied (2)</th>
<th>Satisfied (3)</th>
<th>Very satisfied (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programme individualised to your child (1)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>Programme individualised to your family (2)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>Opportunities for active family participation (3)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>Therapists' skills (4)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>Supervisor's skills (5)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>Frequency of supervision (6)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>Collaboration among multidisciplinary professionals (7)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>Amount of emphasis placed on generalisation and maintenance of skills (8)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
</tbody>
</table>

Q6.5 To what extent are your child's special interests incorporated in the programme?
- Not At All (1)
- A little (2)
- Somewhat (3)
- Moderately (4)
- Very much (5)
Q6.6 To what extent are your family's concerns incorporated in the programme?
   o Not At All (1)
   o A little (2)
   o Somewhat (3)
   o Moderately (4)
   o Very much (5)

Q6.7 To what extent do you find that the skills addressed in therapy sessions are generalised to the child's daily life?
   o Not At All (1)
   o A little (2)
   o Somewhat (3)
   o Moderately (4)
   o Very much (5)

Q6.8 To what extent were overseas organisation or professionals involved in your child’s ABA programme?
   o Not at all, we use only local providers (1)
   o We use some overseas provision, e.g., training, conference (2)
   o Our ABA consultant is based overseas, i.e., we have regular but infrequent contact (3)
   o Our ABA provider is based overseas, i.e., entire programme comes from overseas (4)
   o Others (Specify:___________ ) (5)

Q6.9 To what extent do you find your ABA programme supervisor & therapists supportive?

<table>
<thead>
<tr>
<th></th>
<th>Not at all (1)</th>
<th>A little (2)</th>
<th>Somewhat supportive (3)</th>
<th>Very supportive (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABA programme supervisor (1)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Therapists (2)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
Q6.10 How often do you get involved in the following aspects of your child’s school/pre-school?

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Not at all (1)</th>
<th>A little (2)</th>
<th>Somewhat involved (3)</th>
<th>Very involved (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participating in team meetings (1)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Planning programmes with the team (2)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Choosing behaviour targets for the child with the team (3)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Setting specific goals for the child with the team (4)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Evaluating outcomes with the team (5)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Joining in with activities during therapy sessions (6)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Using ABA strategies outside therapy sessions (7)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Identifying reinforcers for the target behaviours (8)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Q6.11 What, if any, are the barriers you have experienced while accessing ABA services?
Q7.1 Do you run ABA therapy sessions for your child as a parent-therapist?
   - Yes (1)
   - No (2) (Skip to Q7.2)

Q7.1.1 On average, how many hours of ABA therapy do you do per week? (only count session hours)
   - _____Hours (1)

Q7.1.2 Reasons for becoming a parent-therapist
   - Familiarity with the child (1)
   - To improve skills and knowledge in ABA (2)
   - Financial reasons (3)
   - Difficulty in recruiting therapists (4)
   - Others (Specify:___________ ) (5)

Q7.2 Did you receive any ABA training for parents?
   - Yes, group training (1)
   - Yes, individual training (2)
   - Yes, both group & individual training (3)
   - Yes, online training programme (4)
   - No training (5)

Q7.3 How do you rate your level of skills in ABA?
   - Very Low (1)
   - Low (2)
   - Somewhat High (4)
   - Very High (5)

Q7.4 How did you gain your theoretical knowledge in ABA? (Tick all that apply)
   - Self-taught (e.g. Books, Internet) (1)
   - Training course offered by an ABA-based organisation (e.g., PEAT; PEACH) (2)
   - Training offered by service providers/ supervisors (e.g., Health Trust) (3)
   - University (4)
   - Through ABA therapy work only (5)
   - Others (Specify:___________ ) (6)
Q7.5 How did you gain your practical skills in ABA? (Tick all that apply)

- Self-taught (e.g. Books, Internet) (1)
- Training course offered by an ABA-based organisation (e.g., PEAT; PEACH) (2)
- Training offered by service providers/ supervisors (e.g., Health Trust) (3)
- University (4)
- Through ABA therapy work only (5)
- Others (Specify:___________) (6)

Q7.6 To what extent were overseas organisation or professionals involved in your ABA training?

- Not at all, we use only local providers (1)
- We use some overseas provision, e.g., training, conference (2)
- Our ABA consultant is based overseas, i.e., we have regular but infrequent contact (3)
- Our ABA provider is based overseas, i.e., entire programme comes from overseas (4)
- Don’t know
- Others (Specify:___________) (5)

Q7.7 If you have anything to add regarding training or skill development, leave comments below.

Q8.1 Please leave comments about any of the questions asked, or about the Survey in general.

Q8.2 Do you want to take part in a more detailed telephone interview?

- Yes Could you please leave your convenient contact information here

- No Thanks for your co-operation
家长问卷

自闭症谱系障碍儿童的基于 ABA 干预方法的研究

您好！您被邀请参与由英国贝尔法斯特女王大学教育学院行为分析中心的一项课题研究。该研究的主要目的是探索自闭症谱系障碍（以下简称自闭症）儿童和家庭目前的整体情况并比较中英两国早期 ABA 干预的政策和实践。

第一部分：课题信息

家长/监护人需要符合以下标准：
- 有一个（或以上）被诊断为自闭症儿童
- 家庭里至少有一个参与 ABA 项目

这份问卷将最多花费您 25-30 分钟，问卷调查开放时间为 3 月 25 日-6 月 25 日。

为了感谢您的时间，课题组按照随机抽取的方式赠送纪念品给完成问卷的家长。

第二部分：数据保存

您的名字和任何私人信息将不会对课题组外的任何人公布。在数据使用上，所有信息将会匿名化处理。在研究完成后，所有数据将会存放在学院的数据库系统 5 年后全部销毁。

该研究项目已经过学院研究伦理委员会的同意，并在贝尔法斯特女王大学研究生管理守则下进行。如果您想了解关于该课题更多的信息，请您联系课题负责人，联系方式如下：

廖旖旎
贝尔法斯特女王大学 教育学院 行为分析中心 博士研究生
美国行为分析师认证委员会 注册行为技术员
电话：+44 (0)7927284030（英国） QQ: 598675409
邮箱：yliao05@qub.ac.uk

导师：Karola Dillenburger 教授 邮箱：k.dillenburger@qub.ac.uk
69-71 University Street, Belfast, BT7 1HL

标注：自闭症谱系障碍（ASD）包括自闭症（典型自闭症）、阿斯伯格症和待分类的广泛性发展障碍（PDD-NOS）。

基于应用行为分析干预的项目（以下简称项目）：任何以 ABA 为基础的干预或者使用了 ABA 方法和原则的。这里所指的项目包括综合性的（覆盖多个目标行为区域）或有确定目标的（例如运用 ABA 而进行的单项训练，像社会技巧训练），以家庭、机构或学校为基础的集中（“集中”形容时间的密集度，例如每天 5-8 小时训练）或非集中性的项目。
知情同意书

- 我已经阅读并知晓以上关于研究流程的信息；
- 我明白该同意书是请我参与调查、访谈和日常观察（其中某项或所有）；
- 我明白这次调查数据将会应用于博士论文或作为论文/会议发表；
- 我明白所有信息将会匿名并被严格保密，我的任何信息以及我的孩子/机构/学校/工作单位的任何信息将不会在报告中显示；
- 我明白我的参与是出于自愿，我可以随时在调查或访谈中退出，也可以在之后要求课题组撤销所有我的相关数据。

请在以下 □ 中勾选您是否同意参与：

□是
□否

第一部分：人口学信息

您的选择无对错之分，请在您所选的选项中划“√”或者“O”。

Q1.1 您是目前正在进行 ABA 训练的孩子的
- 母亲（1）
- 父亲（2）
- 爷爷奶奶/外公外婆（3）
- 其他监护人（4）
- 其他（请注明：_____________）（5）

Q1.2 性别
- 男（1）
- 女（2）

Q1.3 您的婚姻状况是？
- 单身（1）
- 已婚（2）
- 法律认可的民事伴侣关系（3）
- 已婚但分居（4）
- 同居（5）
- 离异（6）
- 丧偶（7）

Q1.4 您的年龄是 _______

Q1.5 您来自于哪个省市 _______

Q1.6 您如何界定您常居地的范围？
- 农村（1）
- 城市（2）

Q1.7 您的工作状态是
- 全职照顾家庭（1）


第二部分：家长信息

Q2.1 总体来说，您每周花多长时间照顾您的小孩？
- 1 - 4 小时 (1)
- 5 - 9 小时 (3)
- 10-14 小时 (4)
- 15-19 小时 (5)
- 20-34 小时 (6)
- 35-49 小时 (7)
- 50+小时 (8)

Q2.2 您大概是在哪里了解到 ABA 干预的？（多选）
- 儿科医生 (1)
- 精神病医生 (2)
- 心理医生 (3)
- 语言病理医师 (4)
- 职业治疗师 (5)
- 其他健康方面从业者 (例如，听觉病矫治专家) (6)
- 家人/朋友 (7)
- 自闭症辅导书/指导手册 (8)
- 社会媒体 (9)
- 网站 (10)
- 诊断/评估专家组 (11)
- 社区卫生部门 (12)
- 自闭症组织或团体，例如星星雨 (13)
- 其他 (请注明:___________ ) (14)
Q2.3 ABA 干预/训练是经过别人推荐给您的吗？如果是，请选择经过谁呢？（多选）
○ 儿科医生 (1)
○ 精神病医生 (2)
○ 心理医生 (3)
○ 语言病理医师 (4)
○ 职业治疗师 (5)
○ 其他健康方面从业者 (例如, 听觉病矫治专家) (6)
○ 家人/朋友 (7)
○ 自闭症辅导书/指导手册 (8)
○ 社会媒体 (9)
○ 网站 (10)
○ 诊断/评估专家组 (11)
○ 社区卫生部门 (12)
○ 自闭症组织或团体, 例如星星雨 (13)
○ 其他 (请注明:___________ ) (14)

Q2.4 您有几个孩子？
○ 1     (1)
○ 2     (2)
○ 3     (3)
○ 4     (4)
○ 超过 4 个 (5)

Q2.5 您的孩子已经接受了哪些方面的训练或服务呢？（多选）
○ ABA（例如，图片交换法和语言行为训练）（1）
○ 游戏治疗（2）
○ 职业疗法（3）
○ 感觉统合训练（4）
○ 听觉统合训练（5）
○ 艺术学习（6）
○ 排毒生物疗法（7）
○ 针灸推拿（8）
○ 结构化教学（9）
○ 心智解读（10）
○ 音乐治疗（11）
○ 接触动物训练（例如海豚）（12）
○ 高压氧疗法（13）
○ 其他 (请注明:___________ ) (14)

Q2.6 您目前有几个孩子正在进行 ABA 干预
○ 0     (1)
○ 1     (2)
○ 2     (3)
○ 3     (4)
○ 4     (5)
○ 超过 个 4 个 (6)

Q2.7 您有几个孩子在过去完成了 ABA 项目？
○ 0     (1)
○ 1     (2)
○ 2     (3)
○ 3     (4)
○ 4     (5)
○ 超过 个 4 个(6)
Q2.8 您的家庭年收入大概是？(税前)
- 5 万元及以下 (1)
- 5 - 10 万元（包括 10 万） (2)
- 10 -20 万元（包括 20 万） (3)
- 20 -30 万元（包括 30 万） (4)
- 30-40 万元（包括 40 万） (5)
- 40-50 万元（包括 50 万） (6)
- 50 万元以上 (7)

Q2.9 您目前大概每年花费多少钱在您孩子的 ABA 项目上（包括玩具、资料和相关材料等花费）
- 1 千元及以下 (1)
- 1 千元 - 5 千元（包括 5 千元） (2)
- 5 千元 - 1 万元（包括 1 万元） (3)
- 1 万元 - 1.5 万元（包括 1.5 万元） (4)
- 1.5 万元 - 2 万元（包括 2 万元） (5)
- 2 万元 - 2.5 万元（包括 2.5 万元） (6)
- 2.5 万元 - 3 万元（包括 3 万元） (7)
- 3 万元以上 (8)

Q2.10 您是如何支付您孩子的 ABA 的项目？(多选)
a) 政府财政支持 (1)
- 工资 (2)
- 投资 (3)
- 身兼额外工作 (4)
- 请假补助 (5)
- 贷款 (6)
- 向家人/朋友借钱 (7)
- 退休金 (8)
- 遗产 (9)
- 变卖资产 (10)
- 募捐 (11)
- 抵押房子 (12)
- 其他 (请注明:__________) (13)

第三部分：家长关于自闭症的认知和了解
Q3.1 您多大程度上赞同以下关于成因的说法？

<table>
<thead>
<tr>
<th></th>
<th>非常赞同</th>
<th>可能是</th>
<th>不知道</th>
<th>可能不是</th>
<th>十分不赞同</th>
</tr>
</thead>
<tbody>
<tr>
<td>自闭症由 MMR(麻疹、流行性腮腺炎和风疹)的疫苗引起</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>自闭症由环境中的某种物质引起 (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>自闭症由基因有引起 (3)</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Appendix: 394
自闭症由家长不恰当的照料引起 (4)

Q3.2 您多大程度赞同以下关于自闭症治疗的说法？

<table>
<thead>
<tr>
<th></th>
<th>非常赞同</th>
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<th>不知道</th>
<th>可能不是</th>
<th>十分不赞同</th>
</tr>
</thead>
<tbody>
<tr>
<td>有有效的药物疗法帮助自闭症人士 (1)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>有行为干预方法可以有效的帮助自闭症人士，例如ABA (2)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>有其他的非药物疗法能有效的帮助自闭症人士 (3)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>没有什么可以帮助自闭症人士的方法 (4)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>自闭症人士不需要帮助 (5)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Q3.3 您多大程度上的赞同或者不赞同以下关于自闭症人士的几种说法？

<table>
<thead>
<tr>
<th></th>
<th>十分同意</th>
<th>同意</th>
<th>中立</th>
<th>不同意</th>
<th>极不同意</th>
</tr>
</thead>
<tbody>
<tr>
<td>自闭症是一种终身性的残疾，我们无能为力 (1)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>自闭症儿童患者本身的意愿不被重视 (2)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>严重的自闭症人士最好在家里照料 (3)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>对于有自闭症人士的家庭来说，严重自闭症人士最好在家里照料 (4)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Q3.4 以下有几种说法：您觉得自闭症人士有……

<table>
<thead>
<tr>
<th></th>
<th>十分同意</th>
<th>同意</th>
<th>中立</th>
<th>不同意</th>
<th>极不同意</th>
</tr>
</thead>
<tbody>
<tr>
<td>....大脑紊乱 (1)</td>
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<td>□</td>
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<td>□</td>
<td>□</td>
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<tr>
<td>....心理疾病 (2)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>....行为问题 (3)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>....学习障碍 (4)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>.....特殊技能，例如在数学，音乐或者绘画等方面 (5)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Q3.5 您多大程度上赞同以下关于自闭症儿童社会化的说法？自闭症小孩……

<table>
<thead>
<tr>
<th></th>
<th>非常赞同</th>
<th>可能是</th>
<th>不知道</th>
<th>可能不是</th>
<th>十分不赞同</th>
</tr>
</thead>
<tbody>
<tr>
<td>可能没有机会在主流学校就读（1）</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>可能没有机会得到一份工作（2）</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>除了在家里，可能没有办法在户外活动（3）</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>除了父母/监护人以外，可能没有办法被其他人照顾（4）</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>可能无法像其他孩子一样快乐生活（5）</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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</tbody>
</table>

第四部分：自闭症孩子信息
请根据您目前的正在接受 ABA 项目训练的孩子回答问题。
[假如在您的家庭中有一个以上的孩子被诊断为自闭症谱系障碍，除非您特别想以某一个为准，否则请选择那个时间上正在进行最集中 ABA 干预的儿童。]

Q 4.1 您家庭中，被诊断为自闭症孩子的数量是：
- 1 个（1）
- 2 个（2）
- 3 个（3）
- 4 个（4）
- 大于 4 个（5）
Q4.2 性别
- 男 (1) _________
- 女 (2) _________

Q4.3 孩子的年龄是：（例如：7 岁 3 个月 -> 7, 3）
- (1) _________岁 (2) _________月

Q4.4 被发现该孩子可能有自闭症症状/倾向的年龄是：（例如：7 岁 3 个月 -> 7, 3）
- (1) _________岁 (2) _________月

Q4.5 您的孩子目前正式被诊断为自闭症谱系障碍了吗？
- 是 (1)
- 否 (2)

Q4.6 以下哪一种说法符合您的孩子？（多选）
- 自闭症谱系障碍（ASD）(1)
- 自闭症（典型自闭症）(2)
- 阿斯伯格症 (3)
- 待分类的广泛性发展障碍（PDD-NOS）
- 雷特氏症(Rett's disorder) (5)
- 脑性瘫痪 (6)
- 癫痫症 (7)
- 注意缺陷多动障碍 (ADHD) (8)
- 学习障碍症 (9)
- 其他 (请注明:___________) (10)

Q4.7 您的孩子被正式诊断为自闭症谱系障碍儿童的年龄是：
- (1) _________岁 (2) _________月

Q4.8 被谁诊断的呢？
- 儿童医生 (1)
- 精神病医生(2)
- 心理医生(3)
- 语言病理医师(4)
- 自闭症组织或机构 (5)  其他 (请注明:___________) (6)

第五部分：自闭症儿童 ABA 行为干预项目信息
Q 5.1 您的孩子进行 ABA 项目的年龄是
- (1) _________岁 (2) _________月

Q5.2 您等待了多久才开始进行目前的 ABA 项目
- _______年 ________月

Q5.3 目前进行的 ABA 项目是哪一种类型？（多选） [请注明训练的时长]
- 一对一的家庭训练 (1) ________小时
- 一对一的机构训练 (2) ________小时
- 一对一的学校训练 (3) ________小时
- 基于机构的团体训练 (4) ________小时
- 基于学校的团体训练 (5) ________小时
- 多学科训练 (例如 ABA + 语言 +职业治疗) (6) ________小时
- 有 ABA 顾问提供支持的学前班 / 学校 (7) ________小时
- 有 ABA 治疗师提供支持的学前班 / 学校 (8) ________小时
- ABA 游戏小组 (9) ________小时
- ABA 体育项目 (10) ________小时
- 其他 (请注明:___________) (11) ________小时
- 不清楚 (12)
Q5.4 下面哪一种说明更恰当描述了您的孩子目前所进行的 ABA 项目？[“集中”指的是训练时间的密集程度，比如一天进行 5-8 个小时的 ABA 干预训练；“非集中”反之，密集程度少。]
- 集中的和综合性的项目（覆盖多个目标区域） (1) [跳至 Q 5.5]
- 明确于某一项技巧训练的集中项目（例如社交技巧） (2) [跳至 Q 5.5]
- 由以前集中和综合的项目向较小集中的转变 (3)
- 由非集中项目开始的综合性项目 (4)
- 明确于某一项技巧训练的非集中项目 (5)
- 其他（请注明：___________） (6)

Q5.4.1 为您的孩子采用较小集中/非集中训练项目的原因是？（多选）
- 孩子不需要集中训练 (1)
- 资金原因 (2)
- 时间限制 (3)
- 正处于向主流学校转接阶段 (4)
- 项目本身的设置 (5)
- 没有特别的原因 (6)
- 其他（请注明：___________） (7)

Q5.5 您的孩子目前所进行的 ABA 项目着重于哪一方面？（多选）
- 语言交流 (1)
- 社会交往技巧 (2)
- 游戏技巧 (3)
- 学习技能（例如，读和写） (4)
- 一般知识和推理 (5)
- 困难/问题行为 (6)
- 强迫和仪式化行为 (7)
- 感知问题 (8)
- 运动技能 (9)
- 饮食问题 (10)
- 睡眠问题 (11)
- 心理问题（例如，易怒和焦虑） (12)
- 自理能力训练（例如，如厕和穿衣）(13)
- 需要参与集体环境学习的技能 (14)
- 其他（请注明：___________） (15)

Q5.6 您的孩子目前接触了哪些服务？（多选）
- 语言治疗 (1)
- 职业疗法 (2)
- 药物疗法 (3)
- 体育活动（例如游泳和体操） (4)
- 音乐活动（例如音乐疗法） (5)
- 早期干预项目（非行为类的） (6) 请指明：___________
- 无 (7)
- 其他（请注明：___________） (8)
Q5.7 您的孩子目前正在进行以下哪些？（多选）
- 儿童护理 (1)
- 早教/干预项目 (2)
- 幼儿园 (3)
- ABA 学前班 (4)
- 小学 (主流学校的普通班级) (5)
- 小学 (主流学校的特殊教育班级/项目) (6)
- 中学 (主流学校的普通班级) (7)
- 中学 (主流学校的特殊教育班级/项目) (8)
- 特殊教育学校 (9)
- 专门针对发展性障碍学生的特殊学校 (10)
- 专门针对自闭症儿童的学校 (11)
- 有自闭症领域专家的做咨询/指导学校 (12)
- 家庭学校教育 (13)
- ABA 专门学校 (14)
- ABA 机构/组织 (15)
- 无 (16)
- 其他 (请注明:__________) (17)

Q5.8 ABA 专业老师会有偿的陪伴您的孩子参与到他/她所在学校吗？
- 是 (1)
- 否 (2)
- 不存在 (3)

Q5.9 您每个月大概会接受多少个小时的项目咨询服务 (包括小组会议、电话和邮件交流等)？
- ____ 小时

Q5.10 您孩子的 ABA 项目的进度是如何被测量的？（多选）
- 目标行为持续的频次/时长/强度等，例如通过图表反应 (1)
- 评估测试 (2)
- 家长访谈/问卷 (3)
- 通过与治疗师的闲时聊天 (4)
- 不清楚 (5)
- 其他 (请注明:__________) (6)
Q5.11 您孩子的 **非ABA项目** 进度是如何被测量的？（多选）
- 目标行为持续的频次/时长/强度等，例如通过图表反应 (1)
- 评估测试 (2)
- 家长访谈/问卷 (3)
- 通过与治疗师的闲时聊天 (4)
- 不清楚 (5)
- 其他 (请注明：_________ ) (6)

Q5.12 您的孩子是在当地进行 ABA 干预吗？
- 是 (1)
- 否 (2)

Q5.13 您的孩子目前在哪里进行 ABA 干预项目？
- 本县城 (1)
- 本市 (2)
- 本省 (3)
- 外市，请注明_________ (4)
- 外省/自治区/直辖市，请注明_________ (5)
- 港澳台地区 (6)
- 海外，请注明_________ (7)
- 其他 (请注明：_________ ) (8)

Q5.14 您平均花多长时间带您的孩子到目前的机构进行 ABA 干预？
- 不需要花费时间，在家里进行 (1)
- 30 分钟以内 (2)
- 30-60 分钟 (3)
- 1-2 个小时 (4)
- 2-3 个小时 (5)
- 3 个小时及以上 (6)

Q5.15 关于您孩子的 ABA 干预项目，以下从业人员在多大程度上与其学校/学前班相互合作的？

<table>
<thead>
<tr>
<th>从不</th>
<th>很少</th>
<th>不确定</th>
<th>很好</th>
<th>非常好</th>
</tr>
</thead>
<tbody>
<tr>
<td>学校/学前班 (例如，老师或教师助理) (1)</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[X]</td>
<td>[ ]</td>
</tr>
<tr>
<td>语言治疗师 (2)</td>
<td>[X]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>职业治疗师 (3)</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[X]</td>
<td>[ ]</td>
</tr>
<tr>
<td>心理医生 (4)</td>
<td>[X]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

Appendix: 400
Q6.1 相比您的孩子还没有进行 ABA 干预项目之前，您的日常压力变化是_____
  - 极大减小了 (1)
  - 轻微减小了 (2)
  - 差不多一样 (3)
  - 轻微升高了(4)
  - 极大升高了 (5)
  如果您感觉自己的日常压力有所改变，其原因是？_________

Q6.2 相比您的孩子进行 ABA 干预项目之前，您觉得您的孩子的生活质量是_____
  - 极大减小 (1)
  - 轻微减小 (2)
  - 差不多一样 (3)
  - 轻微提高(4)
  - 极大提高 (5)
  如果他/她的生活质量有所改变，其原因是_________

Q6.3 您孩子目前的 ABA 干预项目是如何与以下选项相融合的？

<table>
<thead>
<tr>
<th>从不 (1)</th>
<th>某程度上 (2)</th>
<th>较大 (3)</th>
<th>极大 (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>积极的家庭参与 (1)</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>个体化的针对孩子的优势和需求 (2)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>个体化的针对家庭的需求 (3)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>干预计划的功能性评估 (4)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>项目过程的定期评估 (5)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>对新技能的泛化和保持过程 (6)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>多学科团队共同工作 (7)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>把没有发展障碍的同龄人列入 ABA 项目 (8)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>促进独立运作能力 (9)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>促进结构化环境（例如建立日常活动和可预料的环境） (10)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>直接观察法收集目标行为数据 (11)</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
</tbody>
</table>

Appendix: 401
Q6.4 您对你孩子目前的 ABA 干预项目的满意程度是？

<table>
<thead>
<tr>
<th>项目</th>
<th>不满意 (1)</th>
<th>较满意 (2)</th>
<th>满意 (3)</th>
<th>非常不满意 (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>项目个体化到孩子本身 (1)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>项目个体化到家庭 (2)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>家庭积极参与的机会 (3)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>治疗师的专业技能 (4)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>咨询师的专业技能 (5)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>受咨询的频次 (6)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>与多学科的专家合作 (7)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>在技能的泛化和维持上强调查的多少 (8)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Q6.5 您孩子的兴趣点会在多大程度上与 ABA 的干预项目相结合？
- 一点也不 (1)
- 很少 (2)
- 稍有 (3)
- 适度的 (4)
- 很大 (5)

Q6.6 您及其他家庭成员的观点在多大程度上能老师被融入到 ABA 干预项目中？
- 一点也不 (1)
- 很少 (2)
- 稍有 (3)
- 适度的 (4)
- 很大 (5)

Q6.7 您的孩子在干预期间所学到的技能在多大程度上泛化到孩子的日常中的？
- 一点也不 (1)
- 很少 (2)
- 稍有 (3)
- 适度的 (4)
- 很大 (5)

Q6.8 海外组织或者专业人员在多大程度上参与您孩子的 ABA 项目？
- 一点也不，我们只使用当地的服务 (1)
- 会使用一些海外组织，例如在培训和会议上 (2)
- 我们的 ABA 咨询师是部分基于海外的，例如有一些定期但并非频繁的联系 (3)
○ 我们的 ABA 服务是整体基于海外的，例如，整个项目都来自于海外(4)
○ 不知道（5）
○ 其他（请注明：__________ ）（5）

Q6.9 您觉得您的 ABA 干预项目老师给予了多大程度上的支持？
○ 一点也不（1）
○ 很少（2）
○ 稍有（3）
○ 适度的（4）
○ 很大（5）

Q6.10 您的孩子学校/学前班与以下选项列出内容的参与度是？

<table>
<thead>
<tr>
<th>参与内容</th>
<th>从不 (1)</th>
<th>较少 (2)</th>
<th>较为参与 (3)</th>
<th>非常参与 (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>参与团队会议(1)</td>
<td>☐</td>
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<td>☑</td>
</tr>
<tr>
<td>与团队计划 ABA 项目 (2)</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>跟团队一起确定孩子的目标行为(3)</td>
<td>☐</td>
<td>☐</td>
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<td>☑</td>
</tr>
<tr>
<td>跟团队一起共同制定目标 (4)</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>跟团队一起评估结果 (5)</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>在治疗期间加入活动 (6)</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>在治疗期间以外使用 ABA 方法 (7)</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
<tr>
<td>为孩子的目标行为辨认强化物 (8)</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☑</td>
</tr>
</tbody>
</table>

Q6.11 在您接触 ABA 服务的经历中，你遇到了哪些障碍？

Q7.1 您自己会作为 ABA 老师/治疗师为孩子进行个体化训练吗？
○ 是（1）
○ 否（2）（跳至 Q7.2）
Q7.1.1 大体而言，您每周会为您的孩子进行多少个小时的 ABA 治疗？（只计算您跟孩子一对一 ABA 干预时间，日常交流及其他不包括在内）
○ _______ 个小时 (1)

Q7.1.2 您成为行为治疗师的原因是 _______ (多选)
○ 熟悉自己的孩子 (1)
○ 提高自身 ABA 的技巧和知识 (2)
○ 经济原因 (3)
○ 聘请 ABA 治疗师困难 (4)
○ 其他 (请注明：__________ ) (5)

Q7.2 您自己有接受 ABA 知识和实践的训练吗？
○ 有，团体训练 (1)
○ 有，个体训练 (2)
○ 有，团体和个体训练相结合 (3)
○ 有，网络训练课程 (4)
○ 有，正在/曾经在机构参加培训，例如星星雨 （5）
○ 没有 (6)

Q7.3 你是如何评价你的 ABA 知识和技能的呢？
○ 非常低 (1)
○ 低 (2)
○ 适中 (3)
○ 比较高 (4)
○ 非常高 (5)

Q7.4 您是如何获取 ABA 理论知识的呢？（多选）
○ 自学 (例如，书籍、网络) (1)
○ ABA 机构提供的课程训练 （例如星星雨） (2)
○ 通过 ABA 老师或者其他服务提供者 (例如残联) 培训 (3)
○ 学院/大学教育 (4)
○ 通过 ABA 治疗师/老师 (5)
○ 其他 (请注明：__________ ) (6)

Q7.5 您是如何获取 ABA 实践技巧的呢？（多选）
○ 自学 (例如，书籍、网络) (1)
○ ABA 机构提供的课程训练 （例如星星雨） (2)
○ 通过 ABA 老师或者其他服务提供者 (例如残联) 培训 (3)
○ 学院/大学教育 (4)
○ 通过 ABA 治疗师/老师 (5)
○ 其他 (请注明：__________ ) (6)
Q7.6 如果您有任何关于 ABA 培训或发展个人技能的意见和建议，请在以下说明___________________________________________________

Q8.1 关于本次调查，您还有什么想补充说明的吗？

Q8.2 您是否愿意参与随机抽取纪念品？
   ○ 是 请留下您的联系方式（例如，QQ、微信、手机号码或者邮箱等）
   __________________________________________
   ○ 否  谢谢您的参与

问卷到此结束，感谢您的参与！
Appendix 9 UK therapists’ questionnaire

Questionnaire for therapists working with children with ASD

ABA-based intervention for children diagnosed with autism spectrum disorder

I. Participant information

You are invited to take part in this Doctoral research project by the Centre for Behaviour Analysis of the School of Education at Queen’s University Belfast. If you would like further information regarding any aspect of this project, you are encouraged to contact the researcher via the phone number or email address listed below.

The aim of the study is to find out more about the current situation of children diagnosed with ASD and compare the application of early ABA-based interventions in practices and policies between the UK and China.

Therapists should meet the following criteria:

- Work with one or more children diagnosed with ASD.
- Run ABA-based interventions programmes that are managed/supervised by others.

The survey should take approximately 20-25 minutes.

II. Storage of data

After the study is completed, data will be kept securely at the School of Education data storage facility for 5 years, before being destroyed. Your name or identity will not be disclosed to anyone other the researcher and her supervisor. For all other purposes, you will be given a substitute code and the key to this code will be kept in a separate file and destroyed immediately after the study is completed.

This study was approved by the School of Education Research Ethics Committee and is conducted under QUB research governance guidelines.

If you have further questions, feel free to contact me at

Yini Liao (PhD candidate)
Tel: +44 (0)7927284030
Email: yliao05@qub.ac.uk
Or my supervisor Prof. Karola Dillenburger
Email k.dillenburger@qub.ac.uk
School of Education
Queen’s University Belfast
69-71 University Street, Belfast BT7 1HL
Appendix:

**Note:**

*Autism Spectrum Disorder (ASD):* includes Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder-Not otherwise specified (PDD-NOS).

*Applied Behaviour Analysis (ABA)-based interventions programs:* any programmes that involve ABA-based interventions or the use of Applied Behaviour Analysis strategies or principles. The programme may be comprehensive (covering many targeted areas) or target-specific (e.g. Social Skills training using ABA), intensive or non-intensive, home-, clinic- or school-based.

### III. Consent form

I have read the attached information letter which explains the research process.

I understand that the letter is asking me to participate in an online survey.

I understand that all the information gathered will be kept strictly confidential and that my name and the name of my child / the organisation/school where I work will not be included in any reports.

I understand that participation is voluntary and that I am free to withdraw my consent at any time during the interview or until submission of the anonymous survey.

I understand that this research will be published in the form of a Doctoral dissertation and journal articles.

Please tick one of the following boxes to indicate whether or not you agree to take part:

- ☐ Yes
- ☐ No

### Section 1: Demographic information:

**Q1.1 Gender**
- Male
- Female

**Q1.2 In which age group are you in?**
- 0-17 (1)
- 18-24 (2)
- 25-44 (3)
- 45-64 (4)
- 65-74 (5)
- 75+ (6)

**Q1.3 How would you describe your national identity?**
- English (1)
- Welsh (2)
- Scottish (3)
Section 2: Information on current job
Q2.1 For my ABA work, I am:
   o employed by a service provider (1)
   o a sole trader, i.e., directly employed by the family I work with (2)
   o employed by a school (3)
   o Other(Specify: ______________) (4)

Q2.2 What is your current role?
   ABA lead therapist (1)
   ABA therapist (2)
   Psychologist (3)
   Speech Therapist (4)
   Occupational Therapist (5)
   Administrator (6)
   Teacher (7)
   Teacher aide (8)
   o Other(Specify: ______________) (9)

Q2.3 In which country do you work currently?
   o England (1)
   o Wales (2)
   o Scotland (3)
   o Northern Ireland (4)
   o UK, Britain (more than one country) (5)
   o Republic of Ireland (6)
   o Other(Specify: ______________) (7)

Q2.4 How many boys with ASD do you currently work with? (*ASD- includes Autism, Asperger’s Syndrome, PDD, PDD-NOS) ______

Q2.5 How many girls with ASD do you currently work with? ______

10. Are there any children on a wait-list for your ABA programme? How many children with ASD are on the wait-list? Please specify:
Section 3: Early ABA-based interventions

Q3.1 Type of current ABA programme you deliver (Tick all that apply)
- Home-based 1:1 programme (1)
- Centre-based 1:1 programme (2)
- School-based 1:1 programme (3)
- Centre-based group programme (4)
- School-based group programme (5)
- Multi-disciplinary programme (ABA + Speech +OT) (6)
- Kindergarten / School ABA consultation (7)
- Kindergarten / School support (8)
- ABA playgroup (9)
- ABA Sports programme (10)
- Not sure
- Other(Specify:_____________) (11)

Q3.2 Do you deliver an Early Intensive Behaviour Intervention (EIBI) programme* for families?*Early, intensive, individualised and comprehensive [targeting a range of skill areas] programme using Applied Behaviour Analysis strategies or principles
- Yes (1)
- No (2) (Skip to Q 3.3)

Q 3.2.1 For your EIBI programme, what minimum and maximum age started, number of hours and duration do you recommend to a family?

<table>
<thead>
<tr>
<th></th>
<th>minimum</th>
<th>maximum</th>
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</thead>
<tbody>
<tr>
<td>Starting age recommend</td>
<td>_____yrs. _____mos.</td>
<td>_____yrs. _____mos.</td>
</tr>
<tr>
<td>Duration recommend</td>
<td>_____yrs. _____mos.</td>
<td>_____yrs. _____mos.</td>
</tr>
<tr>
<td>Number of hours recommend</td>
<td>_____hrs.</td>
<td>_____hrs.</td>
</tr>
</tbody>
</table>
Q3.2.2 For the children with ASD received in your EIBI programme, what is the minimum and maximum starting age, number of hours and duration do you undertake?

<table>
<thead>
<tr>
<th></th>
<th>minimum</th>
<th>maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Starting age undertake</td>
<td>_____yrs. _____mos.</td>
<td>_____yrs. _____mos.</td>
</tr>
<tr>
<td>Number of hours undertake</td>
<td>_____yrs. _____mos.</td>
<td>_____yrs. _____mos.</td>
</tr>
<tr>
<td>Duration undertake</td>
<td>_____hrs.</td>
<td>_____hrs.</td>
</tr>
</tbody>
</table>

Q3.2.3 Define what targets your EIBI programmes typically include (Tick all that apply)
- Communication skills
- Social skills
- Play skills
- Academic skills (e.g., reading, writing)
- General knowledge & Reasoning
- Difficult/ problematic behaviours
- Obsessions and rituals
- Sensory issues
- Motor skills
- Dietary issues
- Sleeping issues
- Emotional issues (e.g., anger, anxiety)
- Independent daily life skills (e.g., toileting, dressing)
- Skills needed for group learning environment
- Other (Specify: _______________)

Q3.2.4 Which ABA techniques do you utilise in your EIBI programme? (Tick all that apply)
- Discrete Trial Teaching
- Natural Environmental Training
- Specific Differential reinforcement procedures, i.e., DRO, DRL etc.
- Specific Prompting procedures
- Functional analysis
- Pivotal Response Training
- Incidental teaching
- Activity-embedded trials
- Task analysis
- PECS
- Video Modelling
- Social Stories
- No particular technique
- Chaining procedures, i.e., backward; forward etc.
- Specific Shaping procedures, e.g., changing criterion
- Reciprocal Imitation Training
- Self-management training
- Verbal Behaviour

Appendix: 410
Appendix:

Q3.2.5 Which feature will you address in your EIBI programme? (Tick all that apply)

- Comprehensive treatments (1)
- Targeted at all skill domains (2)
- Individualised intervention (3)
- Gradual transition from small-group to large-group formats (4)
- Focused on increasing behaviours (5)
- Building new repertoires (7)
- Focused on decreasing behaviours (8)
- Parental involvement (9)
- Starting at home (10)
- Generalised to other settings, such as community (11)
- Normal developmental sequences guided by long-term and short-term goals (13)
- Transition to preschools, kindergarten or elementary school after gained required skills (14)
- Don’t know
- Other(Specify:_____________) (15)

Q3.2.6 Which data recording methods do you mainly utilise in your EIBI programme? (Tick all that apply)

- Continuous data collection, frequency (1)
- Continuous data collection, duration (2)
- Continuous data collection, latency (3)
- Time sampling (4)
- Interval recording (5)
- Don’t know
- Other(Specify:_____________) (6)

Q3.2.7 Which data reporting methods do you mainly utilise in your EIBI programme? (Tick all that apply)

- AB design (1)
- ABAB reversal design (2)
- Multiple baselines across behaviours (3)
- Multiple baselines across settings (4)
- Multiple baselines across participants (5)
- Changing criterion Design (6)
- Alternating treatment designs (7)
- Other(Specify:_____________) (8)

Q3.2.8 What is the average cost per year for a family doing your EIBI programme?

- £0-£500 (1)
- £501-£1,000 (2)
- £1,001-£3,000 (3)
- £3001-£5,000 (4)
- £5,001-£10,000 (5)
- £10,001-£20,000 (6)
- £20,001+ (7)
Q3.2.9 Do you think EIBI is effective for children diagnosed with ASD
  o Not at all (1)
  o Somewhat effective (2)
  o Effective (3)
  o Very effective (4)
  o Not sure (5)

Q3.3 Do you offer a target-specific programme* to families?*Programme that focuses on one specific skill area using Applied Behaviour Analysis strategies or principles (eg., Social Skills Training programme, Functional Communication Training programme)
  o Yes (1)
  o No (2)
Q4.1 On average, how many hours of ABA therapy do you deliver per week?
   ○ _____hrs
Q4.2 How many hours of programme supervision do you receive from your ABA programme supervisor per month (eg., team meetings, training)?
   ○ _____hrs

Q5.1 To what extent does your current ABA practice incorporate the following elements?

<table>
<thead>
<tr>
<th>Element</th>
<th>Not at all (1)</th>
<th>Somewhat (2)</th>
<th>Much (3)</th>
<th>Very Much (4)</th>
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<td>Active family involvement (1)</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Individualised to each child’s strengths &amp; needs (2)</td>
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<tr>
<td>Individualised to each family needs (3)</td>
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<td>Functional assessment for intervention planning (4)</td>
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<td>Periodic assessment of progress (5)</td>
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<td>Generalisation and maintenance procedures for new skills (6)</td>
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<td>Multi-disciplinary team working together (7)</td>
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<td>Including typically developing peers in the programme (8)</td>
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<td>Promoting independent functioning (9)</td>
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<td>Promoting structured environment (eg., establish routines &amp; predictability) (10)</td>
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<tr>
<td>Collecting direct observational data of behaviour targets (11)</td>
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Appendix: 413
Q5.2 To what extent are those elements important for your ideal ABA practice? (Tick between 1 for ‘not important at all’ to 10 for ‘extremely important’)

<table>
<thead>
<tr>
<th>Element</th>
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<td>Generalisation of skills (6)</td>
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Section 4: Therapist’s profile

Q6.1 Roughly, how many years have you been working in the area of ABA?

- Number of years (1)________
- Number of months (2)________
Q6.2 What is your highest education level? (Tick all that apply) *If your qualifications gained outside the UK, tick the ‘Foreign qualifications’ box and the nearest UK equivalents (if known)*

- Lower secondary school qualification (e.g., Standard Grade, Intermediates, O Grade GCSE) (1)
- Upper secondary school qualification (e.g., Highers, A levels) (2)
- University or college qualification below a degree (e.g., HND, HNC, City and Guild advanced certificate, nursing diploma, primary school teaching diploma) (3)
- Undergraduate (4)
- Masters (5)
- PhD (6)
- Overseas qualifications (7)
- Other (Specify: ____________) (6)

Q6.3 Do you have or are currently undergoing any of the qualifications below? (Tick all that apply)

- Generally registered psychologist (1)
- Educational/Developmental psychologist (2)
- Clinical psychologist (3)
- Counsellor (4)
- Speech Therapist (5)
- Occupational Therapist (6)
- Social worker (7)
- BCBA (Board Certified Behaviour Analyst) (8)
- BCaBA (Board Certified Assistant Behaviour Analyst) (9)
- BCBA-D (Board Certified Behaviour Analyst- Doctoral level) (10)
- Teacher (11)
- Special education teacher (12)
- Registered Behavioural Technician (13)
- Teacher aide (14)
- Other (Specify: ____________) (15)

Q6.4 How do you rate your level of skills relating to children with ASD?

- Very Low (1)
- Low (2)
- Fair (3)
- Somewhat High (4)
- Very High (5)

Q6.5 How do you rate your level in applying ABA techniques as an individual practitioner?

- Very Low (1)
- Low (2)
- Fair (3)
- Somewhat High (4)
- Very High (5)
Q6.6 How did you gain your theoretical knowledge in ABA? (Tick all that apply)
   o Self-taught (e.g. Books, Internet) (1)
   o Training course offered by an ABA-based organisation (eg., PEAT; PEACH) (2)
   o Training offered by service providers/ supervisors (e.g., Health Trust) (3)
   o University (4)
   o Through ABA therapy work only (5)
   o Other(Specify:_____________) (6)

Q6.7 How did you gain your practical skills in ABA? (Tick all that apply)
   o Self-taught (e.g. Books, Internet) (1)
   o Training course offered by an ABA-based organisation (eg., PEAT; PEACH) (2)
   o Training offered by service providers/ supervisors (e.g., Health Trust) (3)
   o University (4)
   o Through ABA therapy work only (5)
   o Other(Specify:_____________) (6)

Q6.8 To what extent were overseas organisation or professionals involved in your ABA training?
   o Not At All (1)
   o A little (2)
   o Somewhat (3) If so, please name the organisation__________
   o Very much (4) If so, please name the organisation__________

Q6.9 To what extent do you believe is the amount of initial training opportunities available for new ABA therapists adequate the UK?
   o Not At All (1)
   o A little (2)
   o Somewhat (3)
   o Very much (4)

Q6.10 To what extent do you believe the amount of ongoing professional development opportunities is adequate in your area?
   o Not At All (1)
   o A little (2)
   o Somewhat (3)
   o Very much (4)

Q6.11 How familiar are you with recent research evidence on effectiveness of ABA programmes (published within the last 5 years)?
   o Not At All (1)
   o A little (2)
   o Somewhat (3)
   o Very much (4)
Q6.12 How often do you access research evidence on ABA?
   o Never (1)
   o Once a year or less (2)
   o A few times a year (3)
   o Once a month (4)
   o Once a week or more (5)

Q7.1 Please leave any comments about this questionnaire, or things you would like to add to any of the questions above.
Q7.2 Do you want to be telephone interviewed?
   o Yes    Could you please leave your convenient telephone number here__________
   o No     Thanks for your co-operation
Appendix 10  UK supervisors’ questionnaire

Questionnaire for supervisors working with children with ASD

ABA-based intervention for children diagnosed with autism spectrum disorder

IV. Participant information
You are invited to take part in this Doctoral research project by the Centre for Behaviour Analysis of the School of Education at Queen’s University Belfast. If you would like further information regarding any aspect of this project, you are encouraged to contact the researcher via the phone number or email address listed below.

The aim of the study is to find out more about the current situation of children diagnosed with ASD and compare the application of early ABA-based interventions in practices and policies between the UK and China.

Supervisors should meet the following criteria:

- Work with one or more children diagnosed with ASD.
- Currently manage and/or supervise ABA programmes

The survey should take approximately 20-25 minutes.

V. Storage of data
After the study is completed, data will be kept securely at the School of Education data storage facility for 5 years, before being destroyed. Your name or identity will not be disclosed to anyone other the researcher and her supervisor. For all other purposes, you will be given a substitute code and the key to this code will be kept in a separate file and destroyed immediately after the study is completed.

This study was approved by the School of Education Research Ethics Committee and is conducted under QUB research governance guidelines.

If you have further questions, feel free to contact me at

Yini Liao (PhD candidate)
Tel: +44 (0)7927284030
Email: yliao05@qub.ac.uk

Or my supervisor Prof. Karola Dillenburger
Email k.dillenburger@qub.ac.uk
School of Education
Queen’s University Belfast
69-71 University Street, Belfast BT7 1HL

Note:
Applied Behaviour Analysis (ABA)-based interventions programs: any programmes that involve ABA-based interventions or the use of Applied Behaviour Analysis strategies or principles. The programme may be comprehensive (covering many targeted areas) or target-specific (e.g. Social Skills training using ABA), intensive or non-intensive, home-, clinic- or school-based.

VI. Consent form
I have read the attached information letter which explains the research process.

I understand that the letter is asking me to participate in an online survey.

I understand that all the information gathered will be kept strictly confidential and that my name and the name of my child / the organisation/school where I work will not be included in any reports.

I understand that participation is voluntary and that I am free to withdraw my consent at any time during the interview or until submission of the anonymous survey.

I understand that this research will be published in the form of a Doctoral dissertation and journal articles.

Please tick one of the following boxes to indicate whether or not you agree to take part:

☐ Yes
☐ No

Section 1: Demographic information:

Q1.1 Gender
    ○ Male
    ○ Female

Q1.2 In which age group are you?
    ○ 0-17 (1)
    ○ 18-24(2)
    ○ 25-44 (3)
    ○ 45-64(4)
    ○ 65-74 (5)
    ○ 75+ (6)

Q1.3 How would you describe your national identity?
    ○ English (1)
    ○ Welsh (2)
    ○ Scottish (3)
    ○ Northern Irish (4)
    ○ British (5)
Section 2: Information on current job

Q2.1 For my ABA work, I am:
  o employed by a service provider (1)
  o a sole trader, i.e., directly employed by the family I work with (2)
  o employed by a school (3)
  o Other(Specify:_____________) (4)

Q2.2 What is your role? (Tick all that apply)
  o Site director (1)
  o Manager (2)
  o ABA programme supervisor (3)
  o ABA therapist (4)
  o Psychologist (5)
  o Speech Therapist (6)
  o Occupational Therapist (7)
  o Administrator (8)
  o Teacher (9)
  o Teacher aide (10)
  o Other(Specify:_____________) (11)

Q2.3 In which country do you work currently?
  o England (1)
  o Wales (2)
  o Scotland (3)
  o Northern Ireland (4)
  o UK, Britain (more than one country) (5)
  o Republic of Ireland (6)
  o Other(Specify:_____________) (7)

Q2.4 How many boys with ASD do you currently supervise/manage ABA programme for? (*ASD includes Autism, Asperger’s Syndrome, PDD, PDD-NOS) ______

Q2.5 How many girls with ASD do you currently supervise/manage ABA programme for? ______

Q2.6 Are there any children on a wait-list for your ABA programme?
  o Yes (1)
  o No (2) (Skip to Section 3)

  Q2.6.1 How many children with ASD are on the wait-list? Please specify ______
Section 3: Early ABA-based interventions

Q3.1 Type of current ABA programme you offer (Tick all that apply)
- Home-based 1:1 programme (1)
- Centre-based 1:1 programme (2)
- School-based 1:1 programme (3)
- Centre-based group programme (4)
- School-based group programme (5)
- Multi-disciplinary programme (ABA + Speech +OT) (6)
- Kindergarten / School ABA consultation (7)
- Kindergarten / School support from ABA therapists (8)
- ABA playgroup (9)
- ABA Sports programme (10)
- Other(Specify:_____________) (11)

Q3.2 Do you offer an Early Intensive Behaviour Intervention (EIBI) programme* to families?**Early, intensive, individualised and comprehensive [targeting a range of skill areas] programme using Applied Behaviour Analysis strategies or principles
- Yes (1)
- No (2) (Skip to Q 3.3)

Q 3.2.1 For your EIBI programme, what minimum and maximum age started, number of hours and duration do you recommend to a family?

<table>
<thead>
<tr>
<th></th>
<th>minimum</th>
<th>maximum</th>
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<tbody>
<tr>
<td>Starting age</td>
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</tr>
<tr>
<td>Duration</td>
<td>_____yrs. _____mos.</td>
<td>_____yrs. _____mos.</td>
</tr>
<tr>
<td>Number of hours</td>
<td>_____hrs.</td>
<td>_____hrs.</td>
</tr>
</tbody>
</table>
Q3.2.2 For the children with ASD accepted in your EIBI programme, what is the minimum and maximum starting age, number of hours and duration do you undertake?

<table>
<thead>
<tr>
<th></th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Starting age undertake</td>
<td>_____yrs. _____mos.</td>
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<td>Number of hours undertake</td>
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<tr>
<td>Duration undertake</td>
<td>_____hrs.</td>
<td>_____hrs.</td>
</tr>
</tbody>
</table>

Q3.2.3 Define what targets your EIBI programmes typically include (Tick all that apply)
- Communication skills (1)
- Social skills (2)
- Play skills (3)
- Academic skills (e.g., reading, writing) (4)
- General knowledge & Reasoning (5)
- Difficult/ problematic behaviours (6)
- Obsessions and rituals (7)
- Sensory issues (8)
- Motor skills (9)
- Dietary issues (10)
- Sleeping issues (11)
- Emotional issues (e.g., anger, anxiety) (12)
- Independent daily life skills (e.g., toileting, dressing) (13)
- Skills needed for group learning environment (14)
- Other(Specify:_____________) (15)

Q3.2.4 Which ABA techniques do you utilise in your EIBI programme? (Tick all that apply)
- Discrete Trial Teaching (1)
- Natural Environmental Training (2)
- Specific Differential reinforcement procedures, i.e., DRO, DRL etc. (3)
- Specific Prompting procedures (4)
- Functional analysis (5)
- Pivotal Response Training (6)
- Incidental teaching (7)
- Activity-embedded trials (8)
- Task analysis (9)
- PECS (10)
- Video Modelling (11)
- Social Stories
- No particular technique (13)
- Chaining procedures, i.e., backward; forward etc. (14)
- Specific Shaping procedures, e.g., changing criterion (15)
- Reciprocal Imitation Training (16)
- Self-management training (17)
- Verbal Behaviour (18)
- Other(Specify:_____________) (19)
Q3.2.5 Which feature do you include in your EIBI programme? (Tick all that apply)
- Comprehensive treatments (1)
- Targeted at all skill domains (2)
- Individualised intervention (3)
- Gradual transition from small-group to large-group formats (4)
- Focused on increasing behaviours (5)
- Building new repertoires (7)
- Focused on decreasing behaviours (8)
- Parental involvement (9)
- Starting at home (10)
- Generalised to other settings, such as community (11)
- Normal developmental sequences guided by long-term and short-term goals (13)
- Transition to preschools, kindergarten or elementary school after gained required skills (14)
- Other(Specify:_________________) (15)

Q3.2.6 Which data recording methods do you mainly utilise in your EIBI programme? (Tick all that apply)
- Continuous data collection, frequency (1)
- Continuous data collection, duration (2)
- Continuous data collection, latency (3)
- Time sampling (4)
- Interval recording (5)
- Other(Specify:_________________) (6)

Q3.2.7 Which data reporting methods do you mainly utilise in your EIBI programme? (Tick all that apply)
- AB design (1)
- ABAB reversal design (2)
- Multiple baselines across behaviours (3)
- Multiple baselines across settings (4)
- Multiple baselines across participants (5)
- Changing criterion Design (6)
- Alternating treatment designs (7)
- Other(Specify:_________________) (8)

Q3.2.8 What is the average cost per year for a family doing your EIBI programme?
- £0-£500 (1)
- £501-£1,000 (2)
- £1,001-£3,000 (3)
- £3001-£5,000 (6)
- £5,001-£10,000 (7)
- £10,001-£20,000
- £20,001+ (8)
Q3.2.9 Do you think EIBI is effective for children diagnosed with ASD
   o Not at all (1)
   o Somewhat Effective (2)
   o Effective (3)
   o Very effective (4)
   o Not sure (5)

Q3.3 Do you offer a target-specific programme* to families?* Programme that focuses on one specific skill area using Applied Behaviour Analysis strategies or principles (eg., Social Skills Training programme, Functional Communication Training programme)
   o Yes (1)
   o No (2)

Q3.4 What other services do you provide? (Tick all that apply)
   o Family-based therapy (1)
   o Speech therapy (2)
   o Occupational therapy (3)
   o Assessment/ Diagnosis (4)
   o ABA Information sessions (5)
   o ABA training (6)
   o ASD training (7)
   o Initial consultation with family (8)
   o Ongoing consultation with family (9)
   o School ABA consultation (10)
   o School or Kindergarten support (11)
   o Family support programme (12)
   o Siblings support programme (13)
   o Counselling (14)
   o ABA only (15)
   o Other(Specify:____________) (16)
Q3.5 Which specific approaches do you draw on in your mode of delivery? (Tick all that apply)

- UCLA model (Lovaas, 1987) (1)
- Autism Partnership model (McEachin & Leaf, 1999) (2)
- Verbal behaviour model (Sunberg & Partington, 1998) (3)
- Eden model (Holmes, 1997) (4)
- ESDM (Early Start Denver Model) (Rogers & Dawson, 2009) (5)
- Natural Language Paradigm (Koegel, O’Dell, & Koegel, 1987) (7)
- Douglas Developmental Disabilities Centre programme (Handleman & Harris, 2005) (8)
- May Institute (1955) (9)
- Autism Preschool Programme (Handleman & Harris, 1994) (10)
- Princeton Child Development Institute Programme (McClannahan & Krantz, 1997) (11)
- Manual specifically made for your agency (13)
- None (14)
- Unsure (15)
- Other (Specify:__________________) (16)

Q3.6 If any, what guidelines/training manuals does your ABA programme follow? (Tick all that apply)

- UCLA model training manual (Lovaas, 1987) (1)
- Autism Partnership model manual (Leaf, McEachin & Harsh, 1999) - A Work in Progress (2)
- The Eden Model manual (Holmes, 1997) - Autism Through the Lifespan (3)
- PECS & the Pyramid Model (Bondy & Frost, 1994) (4)
- Verbal Behaviour Model manual (Sundberg & Partington, 1998) (5)
- Prior et al., (2012) Guidelines for Good Practice (7)
- Professional ethical guidance, e.g., British Psychological Society, Health Care Professions Council (10)
- Manual specifically made for your agency (11)
- None (12)
- Unsure (13)
- Other (Specify:__________________) (14)
Q4.1 What duration does your typical ABA programme go for?
- < 3 months (1)
- 3-6 months (2)
- 6-12 months (3)
- 12-24 months (4)
- 24-36 months (5)
- 36 months + (6)

Q4.2 Which data recording methods do you mainly utilise in your EIBI programme? (Tick all that apply)
- Continuous data collection, frequency (1)
- Continuous data collection, duration (2)
- Continuous data collection, latency (3)
- Time sampling (4)
- Interval recording (5)
- Other (Specify:_____________) (6)

Q4.3 Which data reporting methods do you mainly utilise in your EIBI programme? (Tick all that apply)
- AB design (1)
- ABAB reversal design (2)
- Multiple baselines across behaviours (3)
- Multiple baselines across settings (4)
- Multiple baselines across participants (5)
- Changing criterion Design (6)
- Alternating treatment designs (7)
- Other (Specify:_____________) (8)

Q4.4 What is the average cost per year for a family doing your ABA programme?
- £0-£500 (1)
- £501-£1,000 (2)
- £1,001-£3,000 (3)
- £3001-£5,000 (6)
- £5,001-£10,000 (7)
- £10,001-£20,000 (8)
- £20,001+ (9)
Q4.5 How many hours of programme supervision do you usually provide for one child per month? (including team meetings, phone, email)
   - Other(Specify:_____________)  

Q4.6 How often do you provide supervision for one child?
   - Every week (1)
   - Every two weeks (2)
   - Every month (3)
   - Every 2-6 months (4)
   - Once a year or less (5)
   - None (6)
   - Other(Specify:_____________) (7)  

Q5.1 What assessments do you use to plan an ABA programme for a child? (Tick all that apply)
   - Functional Behavioural Assessment/Analysis (1)
   - ABBLS (The Assessment of Basic Language and Learning Skills) (2)
   - VB-MAPP (The Verbal Behaviour Milestones Assessment and Placement Programme) (3)
   - Standardised cognitive tests (4)
   - Standardised measures of social, adaptive, communicative domains (5)
   - Data from direct observation (6)
   - None (7)
   - Other(Specify:_____________) (8)

Q5.2 What assessments do you use to monitor progress? (Tick all that apply)
   - Functional Behavioural Assessment/Analysis (1)
   - ABBLS (The Assessment of Basic Language and Learning Skills) (2)
   - VB-MAPP (The Verbal Behaviour Milestones Assessment and Placement Programme) (3)
   - Standardised cognitive tests (4)
   - Standardised measures of social, adaptive, communicative domains (5)
   - Data from direct observation (6)
   - None (7)
   - Other(Specify:_____________) (8)
Q5.3 What assessments do you use to evaluate outcome? (Tick all that apply)
- Functional Behavioural Assessment/Analysis (1)
- ABLLS (The Assessment of Basic Language and Learning Skills) (2)
- VB-MAPP (The Verbal Behaviour Milestones Assessment and Placement Programme) (3)
- Standardised cognitive tests (4)
- Standardised measures of social, adaptive, communicative domains (5)
- Data from direct observation (6)
- None (7)
- Other(Specify:_____________) (8)

Q5.4 How often do you review the individual treatment plan for the child/family?
- Never
- Every month
- Every 2 months
- Every 3 months
- Every 4 months
- Every 5 months
- Every 6 months
- Every 7 months
- Every 8 months
- Every 9 months
- Every 10 months
- Every 11 months
- Every 12 months
- Not sure

Q6.1 To what extent does your current ABA practice incorporate the following elements?

<table>
<thead>
<tr>
<th>Element</th>
<th>Not at all (1)</th>
<th>Somewhat (2)</th>
<th>Don’t know (3)</th>
<th>Much (4)</th>
<th>Very Much (5)</th>
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<tr>
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<td>Generalisation and maintenance procedures for new skills (6)</td>
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<td>Including typically developing peers in the programme (8)</td>
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<td>Promoting independent functioning (9)</td>
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<td>Promoting structured environment (eg., establish routines &amp; predictability) (10)</td>
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<td>Collecting direct observational data of behaviour targets (11)</td>
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</table>
Q6.2 To what extent are those elements important for your ideal ABA practice? (Tick between 1 for ‘not important at all’ to 10 for ‘extremely important’)

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**Section 4: Supervisor’s profile**

Q7.1 Roughly how long have you been working in the area of ABA?
- Number of years (1)_______
- Number of months (2)_______

Appendix: 430
Q7.2 What is your highest education level? (Tick all that apply) *If your qualifications gained outside the UK, tick the ‘Overseas qualifications’ box and the nearest UK equivalents (if known)*

- Lower secondary school qualification (e.g., Standard Grade, Intermediates, O Grade GCSE) (1)
- Upper secondary school qualification (e.g., Highers, A levels) (2)
- University or college qualification below a degree (e.g., HND, HNC, City and Guild advanced certificate, nursing diploma, primary school teaching diploma) (3)
- Undergraduate (4)
- Masters (5)
- PhD (6)
- Overseas qualifications (7)
- Other (Specify: ____________) (6)

Q7.3 Do you have or are currently undergoing any of the qualifications below? (Tick all that apply)

- Generally registered psychologist (1)
- Educational/Developmental psychologist (2)
- Clinical psychologist (3)
- Counsellor (4)
- Speech Therapist (5)
- Occupational Therapist (6)
- Social worker (7)
- BCBA (Board Certified Behaviour Analyst) (8)
- BCaBA (Board Certified Assistant Behaviour Analyst) (9)
- BCBA-D (Board Certified Behaviour Analyst- Doctoral level) (10)
- Teacher (11)
- Special education teacher (12)
- Registered Behavioural Technician (13)
- Teacher aide (14)
- Other (Specify: ____________) (15)

Q7.4 How do you rate your level of skills relating to children with ASD?

- Very Low (1)
- Low (2)
- Fair (3)
- Somewhat High (4)
- Very High (5)

Q7.5 How do you rate your level in applying ABA techniques as an individual practitioner?

- Very Low (1)
- Low (2)
- Fair (3)
- Somewhat High (4)
- Very High (5)
Q7.6 How did you gain your theoretical knowledge in ABA? (Tick all that apply)
- Self-taught (e.g. Books, Internet) (1)
- Training course offered by an ABA-based organisation (e.g., PEAT; PEACH) (2)
- Training offered by service providers/supervisors (e.g., Health Trust) (3)
- University (4)
- Through ABA therapy work only (5)
- Other (Specify: __________) (6)

Q7.7 How did you gain your practical skills in ABA? (Tick all that apply)
- Self-taught (e.g. Books, Internet) (1)
- Training course offered by an ABA-based organisation (e.g., PEAT; PEACH) (2)
- Training offered by service providers/supervisors (e.g., Health Trust) (3)
- University (4)
- Through ABA therapy work only (5)
- Other (Specify: __________) (6)

Q7.8 To what extent were overseas organisations or professionals involved in your ABA training?
- Not at all, we use only local providers (1)
- We use some overseas provision, e.g., training, conference (2)
- Our ABA consultant is based overseas, i.e., we have regular but infrequent contact (3)
- Our ABA provider is based overseas, i.e., entire programme comes from overseas (4)
- Others (Specify: __________) (5)

Q7.9 How many hours of professional development related to ABA have you completed in the last 12 months?

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Q7.10 To what extent do you believe that initial training opportunities available for new ABA supervisors are adequate in your area?
- Not At All (1)
- A little (2)
- Somewhat (3)
- Very much (4)
Q7.10 To what extent do you believe that initial training opportunities available for new ABA supervisors are adequate in your area?
  o  Not At All (1)
  o  A little (2)
  o  Somewhat (3)
  o  Very much (4)

Q7.11 To what extent do you believe that initial training opportunities available for new ABA therapists are adequate in your area?
  o  Not At All (1)
  o  A little (2)
  o  Somewhat (3)
  o  Very much (4)

Q7.12 To what extent do you believe that ongoing professional development opportunities in ABA are adequate in the UK?
  o  Not At All (1)
  o  A little (2)
  o  Somewhat (3)
  o  Very much (4)

Q7.13 How familiar are you with recent research evidence on effectiveness of ABA programmes (published within the last 5 years)?
  o  Not At All (1)
  o  A little (2)
  o  Somewhat (3)
  o  Very much (4)

Q7.14 How often do you access research evidence on ABA?
  o  Never (1)
  o  Once a year or less (2)
  o  A few times a year (3)
  o  Once a month (4)
  o  Once a week or more (5)

Q8.1 Do you want to be telephone interviewed?
  o  Yes  Could you please leave your convenient telephone number here____________
  o  No  Thanks for your co-operation

Q8.2 Thanks for your participation! Please leave comments about any of the questions, or about the Census in general.
Appendix 11 Chinese professionals’ questionnaire

ABA从业者问卷
自闭症谱系障碍儿童的基于 ABA 干预方法的研究
您好！您被邀请参与由英国贝尔法斯特女王大学教育学院行为分析中心的一项课题研究。该研究的主要目的是探索自闭症谱系障碍（以下简称自闭症）儿童和家庭目前的整体情况并比较中英两国早期 ABA 干预的政策和实践。

第一部分：课题信息
ABA从业者（以下简称从业者）需要符合以下标准：
跟一个（或多个以上）被诊断为自闭症谱系障碍的儿童工作
目前正在进行/管理 ABA 项目
这份问卷将最多花费您 20-25 分钟，问卷调查开放时间为 3月25日-6月25日。
为了感谢您的时间，课题组将按照随机抽取的方式赠送纪念品给完成问卷的老师。最后，课题最终结果将会与您分享。

第二部分：数据保存
您的名字和任何私人信息将不会对课题组外的任何人公布。在数据使用上，所有信息将会匿名化处理。在研究完成后，所以数据将会存放在学院的数据库系统五年后全部销毁。
该研究项目已经过学院研究伦理委员会的同意，并在贝尔法斯特女王大学研究生管理守则下进行。如果您想了解关于该课题更多的信息，请您联系课题负责人，联系方式如下：

廖旖旎
贝尔法斯特女王大学 教育学院 行为分析中心 博士研究生
美国行为分析师认证委员会 注册行为技术员
电话：+44 (0)7927284030（英国） QQ: 598675409
邮箱：yliao05@qub.ac.uk
导师：Karola Dillenburger 教授 邮箱：k.dillenburger@qub.ac.uk
69-71 University Street, Belfast, BT7 1HL

标注：自闭症谱系障碍（ASD）包括自闭症（典型自闭症）、阿斯伯格症和待分类的广泛性发展障碍（PDD-NOS）。
基于应用行为分析干预的项目（以下简称项目）：任何以ABA为基础的干预或者使用了ABA方法和原则的。这里所指的项目包括综合性的（覆盖多个目标行为区域）或有确定目标的（例如运用ABA而进行的单项训练，像社会技巧训练），以家庭、机构或学校为基础的集中（“集中”形容时间的密集度，例如每天5-8小时训练，“非集中”反之）或非集中性的项目。

知情同意书

我已经阅读并知晓以上关于研究流程的信息；
我明白该同意书是请我参与调查、访谈和日常观察（其中某项或所有）；
我明白这次调查数据将会应用于博士论文或作为论文/会议发表
我明白所有信息将会匿名并被严格保密，我的任何信息以及我的孩子/机构/学校/工作单位的任何信息将不会在报告中显示；
我明白我的参与是出于自愿，我可以随时在调查或访谈中退出，也可以在之后要求课题组撤销所有我的相关数据。

请在以下☐中勾选您是否同意参与：
☐是
☐否

第一部分：人口学信息

您的选择无对错之分，请在您所选的选项中划“√”或者“O”。

Q1.1 性别
男（1）
女（2）
Q1.2 您的年龄是_______
Q1.3 您的最高学历是？
○ 小学（1） ○初中（2）
○中专（3） ○高中（4）
○大专（5） ○本科（6）
○硕士研究生（7） ○博士研究生（8）
○双学位（9） ○海外文凭（10）
○其他（请注明：_________）（11）

Q1.4 您的专业是_______
Q1.5 您来自于哪个省市_______

Appendix: 435
第二部分：工作信息
Q2.1 关于您目前这份与 ABA 有关的工作，您是______
   ○ 机构创始人 (1)
   ○ 受雇于服务提供单位，例如民营机构 (2)
   ○ 自雇，例如直接受雇于工作的家庭 (3)
   ○ 受雇于学校 (4)
   ○ 其他 (请注明: __________ ) (5)

Q2.2 您的角色是? (多选)
   ○ 组织/机构创始人 (1)
   ○ 管理者 (2)
   ○ ABA 督导 (3)
   ○ ABA 治疗师 (4)
   ○ 心理医生 (5)
   ○ 语言治疗师 (6)
   ○ 职业治疗师 (7)
   ○ 行政管理者 (8)
   ○ ABA 老师 (9)
   ○ ABA 老师助手 (10)
   ○ ABA 实习老师 (11)
   ○ 其他 (请注明: __________ ) (12)

Q2.3 您目前在哪个城市工作? ______

Q2.4 有多少男孩正在进行您的 ABA 项目? [在该研究中，自闭症谱系障碍包括自闭症（典型自闭症）、阿斯伯格症和待分类的广泛性发展障碍（PDD-NOS）]
   _______

Q2.5 有多少女孩正在进行您的 ABA 项目? ______

Q2.6 还有其他的孩子在等待进行 ABA 项目吗?
   是 (1)
   否 (2) (跳至第三部分)

Q2.6.1 有多少孩子正在等待，请标明: __________

Q2.7 您的机构目前为自闭症儿童和家庭提供哪些方面的服务呢？（多选）
   ○ ABA （例如，回合法、图片交换法和语言行为训练等） (1)
   ○ 游戏治疗 (2)
   ○ 职业疗法 (3)
   ○ 感觉统合训练 (4)
   ○ 听觉统合训练 (5)
   ○ 艺术学习 (6)
   ○ 排毒生物疗法 (7)
   ○ 针灸推拿 (8)
○ 结构化教学 (9)
○ 心智解读 (10)
○ 音乐治疗 (11)
○ 接触动物训练（例如海豚） (12)
○ 高压氧疗法 (13)
○ 其他 (请注明: __________ ) (14)

第三部分: 基于 ABA 的早期行为干预

Q3.1 您目前提供的 ABA 项目是 (多选)
○ 一对一的家庭训练 (1)
○ 一对一的机构训练 (2)
○ 一对一的学校训练 (3)
○ 机构里进行的团体训练 (4)
○ 学校里进行的团体训练 (5)
○ 家长 ABA 知识和技能培训组织 (6)
○ 多学科训练 (例如 ABA + 语言 + 职业治疗) (7)
○ 有 ABA 顾问提供支持的学前班 / 学校 (8)
○ 有 ABA 治疗师提供支持的学前班/学校 (9)
○ ABA 游戏小组 (10)
○ ABA 体育项目 (11)
○ 其他 (请注明: __________ ) (12)

Q3.2 您为自闭症儿童提供早期集中行为干预吗？
【早期的，强化的，个体化和综合性的（针对一系列技巧）基于 ABA 策略和原则，主要使用回合式教学 (DTT) 和自然环境训练 (NET)】
○ 是 (1)    否 (2)

Q3.3 请界定您的 ABA 项目主要包括以下哪些方面？ (多选)
○ 语言交流 (1)
○ 社交交往技巧 (2)
○ 游戏技巧(3)
○ 学习技能 (例如，读和写) (4)
○ 一般知识和推理 (5)
○ 困难/问题行为 (6)
○ 强迫和仪式化行为 (7)
○ 感知困难 (8)
○ 行动能力 (9)
○ 饮食问题 (10)
○ 睡眠问题 (11)
○ 心理问题 (例如，易怒和焦虑) (12)
○ 自理能力训练 (例如，如厕和穿衣服) (13)
○ 需要参与集体环境学习的技能 (14)
○ 其他 (请注明: __________ ) (15)
Q3.4 您的 ABA 项目中使用哪些 ABA 的方法和技巧？(多选)

- 回合式教学（DTT） (1)
- 自然环境教学（NET） (2)
- 区别强化，例如其他行为的区別性增强(DRO)和低频率反应的选择性强化(DRL)等 (3)
- 辅助 (4)
- 功能性分析 (5)
- 关键反应训练（PRT） (6)
- 随即教学法（IT） (7)
- 活动嵌入方法 (8)
- 任务分析法 (9)
- 图片交换沟通系统（PECS） (10)
- 视频模仿法 (11)
- 社交故事方法 (12)
- 连环法教学，例如反向和正向 (13)
- 塑造法，例如渐进式目标 (14)
- 相互模仿训练（RIT） (15)
- 自我管理训练 (16)
- 言语行为（VB） (17)
- 早期集中行为干预（EIBI） (18)
- 没有特别的方法 (19)
- 其他 (请注明:___________ ) (20)
Q3. 5 您包括了以下哪些特点在 ABA 项目中呢? (多选)
综合治疗 (1)
- 针对所有技能领域 (2)
- 个体化干预 (3)
- 逐渐从小团体过渡到大团体模式 (4)
- 关注增加技能性行为 (5)
- 建立新的回合系统 (6)
- 关注减少问题行为 (7)
- 家长参与 (8)
- 首先从家里开始 ABA 干预 (9)
- 泛化到其他环境中，例如社区 (10)
- 由长期目标和短期目标指导的普通发展模式 (11)
- 获得所需技能后被转接到幼儿园、学前班或小学 (12)
- 没有 (13)
- 不知道 (14)
- 其他 (请注明:___________ ) (15)

Q3. 6 您主要使用以下哪一种 数据收集方法 在 ABA 项目中? (多选)
- 连续性的数据收集，频次 (1)
- 连续性的数据收集，持续时间 (2)
- 连续性的数据收集，等待时间 (3)
- 时间采样 (4)
- 间隔记录法 (5)
- 没有 (6)
- 不清楚 (7)
- 其他 (请注明:___________ ) (8)

Q3. 7 您主要使用哪一种 数据记录方法 在 ABA 项目中? (多选)
- AB 设计 (1)
- ABAB 逆向设计 (2)
- 跨越整个目标行为的多重基线设计 (3)
- 跨越不同环境的多重基线设计 (4)
- 跨越不同参与者的多重基线设计 (5)
- 渐进式目标设计 (6)
- 其他训练方法设计 (7)
- 没有 (8)
- 不清楚 (9)
- 其他 (请注明:___________ ) (10)

Q3. 8 您估计参加 ABA 项目训练的家庭一年平均费用要多少?
- 1 千元 及以下 (1)
- 1 千元 - 5 千元（包括 5 千元） (2)
- 5 千元 - 1 万元（包括 1 万元） (3)
- 1 万元 - 1.5 万元（包括 1.5 万元） (4)
- 1.5 万元 - 2 万元（包括 2 万元） (5)
- 2 万元 - 2.5 万元（包括 2.5 万元） (6)
- 2.5 万元 - 3 万元（包括 3 万元） (7)
Q3.9 您觉得 ABA 对自闭症谱系障碍儿童有效吗？
- 一点都不 (1)
- 较有效 (2)
- 有效 (3)
- 非常有效 (4)
- 不确定 (5)

Q3.10 您会为家庭提供针对目标行为的项目吗？项目包括使 ABA 策略和原则来制定，围绕单一技能领域的项目（例如社会技能训练项目等）。
- 是 (1)
- 否 (2)

Q4.1 您每周平均为自闭症儿童进行多少个小时的 ABA 干预训练呢？
______ 小时

Q4.2 您每个月会从 ABA 专家/咨询师获得多少个小时的 ABA 项目训练/培训？（例如，团队会议或者培训）
______ 小时

Q5.1 您目前的 ABA 项目是如何与以下选项相融合的？

<table>
<thead>
<tr>
<th>选项</th>
<th>从不 (1)</th>
<th>某程度上融合 (2)</th>
<th>较大的 (3)</th>
<th>极其大的 (4)</th>
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<tr>
<td>积极的家庭参与</td>
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<tr>
<td>针对孩子优势和需求来的个体化项目</td>
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<td>针对家庭需求来的个体化项目</td>
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<td>干预计划的功能性评估</td>
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<td>项目过程的定期评估</td>
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<td>对新技能的泛化和巩固过程</td>
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<td>多学科团队共同工作</td>
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<td>把没有发展障碍的同龄人列入 ABA 项目</td>
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<td>促进独立技能</td>
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<td>促进有规律的环境（例如建立日常规律和活动可预料性）</td>
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<tr>
<td>直接观察法收集目标行为数据</td>
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Appendix: 440
Q5.2 在您心目中的理想 ABA 项目中，请评估以下因素的重要性？（勾选 1 代表‘一点都不重要’，10 代表‘非常重要’。）

<table>
<thead>
<tr>
<th>因素描述</th>
<th>1</th>
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<tr>
<td>积极的家庭参与 (1)</td>
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<td>针对孩子的优势和需求来的个体化项目 (2)</td>
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<td>针对家庭的需求来的个体化项目 (3)</td>
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<td>干预计划的功能性评估 (4)</td>
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<td>项目过程的定期评估 (5)</td>
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<td>针对新技能的泛化和巩固过程 (6)</td>
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<td>多学科团队共同工作 (7)</td>
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<td>把没有发展障碍的同龄人列入 ABA 项目 (8)</td>
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<td>促进独立技能 (9)</td>
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<td>直接观察法收集目标行为数据 (11)</td>
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第四部分: 治疗师信息

Q6.1 粗略估计，您在 ABA 领域已经工作了多长时间？
(1)________年 (2)_______月
Q6.2 您目前有或正在进行哪些资格证的培训呢？（多选）
- 注册心理师 (1)
- 教育/发展心理学医师 (2)
- 心理治疗师 (3)
- 督导 (4)
- 语言治疗师 (5)
- 职业治疗师 (6)
- 社会工作者 (7)
- 美国应用行为分析协会行为分析师-博士水平 (BCBA-D) (8)
- 美国应用行为分析协会行为分析师 (BCBA) (9)
- 美国应用行为分析协会助理行为分析师 (BCaBA) (10)
- 美国应用行为分析协会注册行为师 (RBT) (11)
- 普通教育老师 (12)
- 特殊教育老师 (13)
- 老师助理 (14)
- 都没有 (15)
- 其他 (请注明: __________ ) (16)

Q6.3 您如何评价自己与自闭症儿童的工作水平？
- 非常低 (1)
- 低 (2)
- 较高 (3)
- 非常高 (4)

Q6.4 您如何评价自己 ABA 知识和技能的运用？
- 非常低 (1)
- 低 (2)
- 较高 (4)
- 非常高 (5)

Q6.5 您是如何获取 ABA 理论知识的呢？（多选）
- 自学 (例如，书籍、网络) (1)
- ABA 机构提供的课程训练 （例如星星雨）(2)
- 通过 ABBA 咨询师或者其他服务提供者 (例如残联) (3)
- 学院/大学教育 (4)
- 通过 ABA 治疗师 ABA 专业老师 (5)
- 其他 (请注明: __________ ) (6)

Q6.6 您是如何获取 ABA 实践技巧的呢？（多选）
- 自学 (例如，书籍、网络) (1)
- ABA 机构提供的课程训练 （例如星星雨）(2)
- 通过 ABA 服务提供者/督导 (例如残联) (3)
- 学院/大学教育 (4)
- 通过 ABA 治疗师 (例如 ABA 老师) (5)
- 其他 (请注明: __________ ) (6)
Q6.7 海外组织或者专业人员在多大程度上参与您的 ABA 训练？

- 一点也不参与，我们只使用当地的服务 (1)
- 会使用一些海外组织，例如在培训和会议上 (2)
- 我们的 ABA 咨询师是部分基于海外的，例如有一些定期但并非频繁的联系。请注明该组织的名字 _______ (3)
- 我们的 ABA 服务是整体基于海外的，例如，整个项目都来自于海外。请注明该组织的名字 _______ (4)
- 其他 (请注明: ________) (5)

Q6.8 在我国，您觉得新的 ABA 老师获得培训的机会多吗？

- 非常少 (1)
- 很少 (2)
- 较多 (3)
- 非常多 (4)

Q6.9 在您的领域中，您觉得从业者目前获得职业发展的机会多吗？

- 非常少 (1)
- 很少 (2)
- 较多 (3)
- 非常多 (4)

Q6.10 您觉得自己熟悉 ABA 领域里的最新研究文献吗？（近五年发表的相关论文）

- 一点都不了解 (1)
- 一点点 (2)
- 较了解 (3)
- 十分了解 (4)

Q6.11 您多久查阅跟 ABA 有关的研究呢？

- 从不 (1)
- 一年一次或更少 (2)
- 一年几次而已 (3)
- 每月一次 (4)
- 一周一次或更多 (5)

Q7.1 关于本次调查，您还有什么想补充说明的吗？

________________________________________

Q7.2 您是否愿意参与随机抽取纪念品？

是  请留下您的联系方式（例如，QQ、微信、手机号码或者邮箱等）

________________________________________

否  谢谢您的参与

问卷到此结束，感谢您的参与！

Appendix: 443
CALL FOR PARTICIPANTS

Applied Behaviour Analysis -based intervention for children diagnosed with autism spectrum disorder

To find out more about the current situation of children diagnosed with autism spectrum disorder (ASD) and compare the application of Applied Behaviour Analysis (ABA) -based intervention, specifically Early Intensive Behavioural Intervention (EIBI) practices and policies in the UK and China.

Would you like to tell me about your experiences and be part of the study please?

If you are parents:
☑ Is your child involved in EIBI or any other ABA-based intervention programme?

If you are ABA therapists/supervisors:
☑ Are you currently running/managing and/or supervising ABA programmes?

If YES, could I ask you an hour (maximally) for an interview please?
Lunch will be provided

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Please email me, I will send you the interview outline and consent form before our interview.

You can also visit my project website:
http://eibiproject.weebly.com/

Appendix: 444
Appendix 13 UK parents’ interview schedule

Interview outline for parents
Introduction: Thanks for agreeing to be interviewed
Show interviewees a package of informed consent form, ethical approval, introducing letter etc.

[Interview note – if more than one child has been diagnosed with ASD in the family, ask them separately and complete details on different forms. Unless the parent wishes to do otherwise start with the one who is doing the most intensive.]

Section 1: Demographic information:
Q1.1 Relationship to the child (children) doing ABA
Q1.2 Gender
Q1.3 Would you mind telling me your marital status?
Q1.4 Would you mind telling me your age?
Q1.5 In which country do you live currently?
Q1.6 How would you describe your national identity?
Q1.7 What is your current working status?
Q1.8 What is your highest education level?

Section 2: Parents’ information:
Q2.1 When you think of somebody with autism what, if any, do you think are the main challenges and what are the main strengths?
Q2.2 In total, how many hours do you spend each day providing help or care for your child (children) diagnosed with ASD
Q2.3 Where did you find out about ABA-based interventions/therapy in general?
Q2.4 Was ABA-based interventions/therapy recommended to you? If so, by whom?
Q2.5 How many of your child/children are currently doing ABA-based programmes?
Q2.6 How many of your children have completed ABA-based programmes in the past?
Q2.7 Do you mind telling me, what is your family income per annum (Pre-tax)
Q 2.8 Approximately how much do you currently spend on your child/children’s ABA-based programmes per year? (Per child, including cost of materials etc.)
Q2.9 What forms of financial support do you receive for your child/children's ABA programmes? Include prior payments if applicable.

Section 3: Child’s profile
Q3.1 The age of child now_____ the gender of child_____  
Q3.1.1 Is he or she the only child in your family?  
Q3.1.2 If not, what age and gender are the siblings?  
Q3.1.3 How did you manage day care for your other child/children?  
Q3.2 When did you notice that this child's behaviour was different?  
   Q 3.2.1 How old was your child at that time?  
   Q3.2.2 What kind of difference did you notice?  
   Q3.2.3 Who did you ask for help first?  
   Q3.2.4 Looking back, how did you feel at that time?  
Q3.3 How old was your child when he or she was finally diagnosed with ASD?  
   Q3.3.1 Can you describe you feeling at that time?  
   Q3.3.2 What did you decide to do when your child got the final diagnosis?  
Q3.4 Does your child have  
   (1) Special needs education, (2) a specialist service for children, (3) a specialist intervention?  
   (1)Yes/No (2) Yes/No (3) Yes/No  
Q 3.5 How was the decision about services made and by whom?  

Section 4: Early ABA-based behaviour interventions  
Q4.1 Do you use EIBI (Early Intensive Behaviour Intervention) for your child?  
   If so…..  
   Q4.1.1 Where and when did you learn about EIBI?  
   Q4.1.2 When did your child start to receive EIBI?  
   Q4.1.3 Where does the EIBI take place?  
   Q4.1.4 In what way is EIBI carried out?  
   Q4.1.5 Does the EIBI include methods other than Discrete Trial Training? If so, what other methods are used?  
      If not, what are the reasons for not using the EIBI for your child?  
Q4.2 Do you use any other ABA-based interventions for your child?  
   If so, which interventions are included in his/her programme?  
   If not, what are the reasons for not using other ABA-based methods for your child?
Q4.3 Has your child been transited to preschools, kindergarten, elementary school classrooms after this programme? After how long?
   
   Q4.3.1 Is it a special needs school? If so, why?
   Q4.3.2 Is it a mainstream school? If so, to what extent is your child included with the other children, e.g., full inclusion, special classroom, pull-out individual or group sessions?

Q4.4 Do you use any non-behaviour interventions for your child?

Q4.5 Do you co-operate with ABA professionals when they are working with your child?
   
   Q4.5.1 How did you co-operate with professionals?

Q4.6 How has your child’s behaviour changed during and after ABA-base intervention, e.g., EIBI?
   
   Q4.6.1 When did you notice this change?

Q4.7 Do you use the same intervention (way of working with your child) at home as well as that used by professionals in your centre, school or specialist centre?

Section 5: policy and culture

Q4.8 How have you changed the intervention you use as your child has grown older?

Q4.9 What do you expect for your child’s future? What kind of intervention methods are you expecting to use for your child in their adult life?

Q4.10 How do you assess the current service used?

Q5.1 Are there any other supports you would like to use for your child?
   
   Q5.1.1 If not, what is preventing you from using them?

Q5.2 What do you think are the main challenges children with autism face?

Q5.3 Do you have any other comments want to add?
Appendix 14  UK professionals’ interview schedule

Interview outline for professionals
Introduction: Thanks for agreeing to be interviewed
Show interviewees a package of informed consent form, ethical approval, introducing letter etc.

Section 1: Demographic information:
Q1.1 Gender
Q1.2 Would you mind telling me your age? 
Q1.3 How would you describe your national identity? 
Q1.4 What is your highest education qualification?

Section 2: Information on current job
Q2.1 During your ABA work, you are___________ (e.g., employed by a service provider, a sole trader or employed by a school) 
Q2.2 What is your role? (may hold two or more posts concurrently) 
Q2.3 In which country do you work currently? 
Q2.4 How long have you worked in your present organisation? (part-time or full-time)

Section 3: Early Intensive Behavioural Intervention (EIBI)
Q3.1 What type of ABA-based programmes do you offer at present? 
Q3.2 Have you heard about Early Intensive Behaviour Intervention (EIBI) for children diagnosed with ASD? (Early, intensive, individualised and comprehensive [targeting a range of skill areas] programme using Applied Behaviour Analysis strategies or principles, mainly using Discrete trial Training and Natural environment training)

Yes  No (go to Q4.1)

Q3.2.1 Where and when did you learn about EIBI? 
Q3.2.2 If you know EIBI programmes, what is the minimum age do you recommend to the child? 
Q3.2.3 What is the maximum age to finish do you recommend to the child? 
Q3.2.4 How many hours do you recommend? 
Q3.2.5 How long (duration) do you recommend? Prompt: ask why 

Q3.3 Do you offer an Early Intensive Behaviour Intervention (EIBI) programme* to families? 

Yes  No (go to Q4.1)
Q3.3.1 If you are offering EIBI programmes, what is the minimum starting age of a child did you work with?

Q3.3.2 What is the maximum age for EIBI programmes in your experience?

Q3.2.3 How many hours do you use each week? (Your most recent client)

Q3.2.4 How long (duration) do you use EIBI for? (Your most recent client)

Prompt: ask why

Q3.4 Define what targets your EIBI programme typically includes? (e.g., communication skills, social skills, play skills, academic skills etc.)

Q3.5 Which techniques do you utilize in your EIBI programme? (e.g., Discrete Trial Teaching and Natural Environmental Training etc.)

Q3.6 What are the most important target behaviours to address behavioural deficits?

Q3.7 What are the most important target behaviours to build on behavioural strengths?

Q3.8 Where do you typically begin your EIBI programme? At home, centre or school?

Q3.9 How do you include parents in this process (i.e., EIBI programme)?

Q3.10 What obstacles do you experience in a highly structured programme? (e.g., task from simple ones to complicated ones)

Q3.11 How do you generalise child’s learnt skills to other settings, such as school and community. (Based on most children you have worked with)

Q3.12 How many of your clients have been transited to preschools? After how long?

To kindergarten? After how long?

To elementary school classrooms after your programme? After how long?

How many of them have been transited to special needs school?

Q3.13 As with those who have been transited to mainstream school, how are these children included with typical children? (e.g., full inclusion, special classrooms, pull-out sessions)

Q3.14 How do you assess EIBI in general? Prompt: ask why or why not

Q3.15 Does your ABA-based programme follow a particular guideline/training procedure? (e.g., UCLA model Early Start Denver Model (ESDM); Verbal Behaviour (VB); PECS)

Q3.16 What is the average cost per year for a family doing your EIBI programme?

Q3.17 As far as you known, do parents receive any support for the cost of EIBI, such as funding or voluntary help.

Section 4: Early ABA-based behaviour interventions

Q4.1 In what case do you recommend not using the EIBI?
Q4.2 Are there any other ABA-based techniques that are used in your centre?
Q4.3 What kind of qualification related to ABA do you hold?
Q4.4 How do you measure behavioural changes before, during and after intervention?
Q4.5 What do you think of the service delivery (hours, duration, cost, frequency of supervision) regarding the ABA-based programmes delivered by your organisation?
Q4.6 What do you think of the assessments or treatment plans delivered by your organisation?
Q4.7 Are there any barriers preventing you from delivering you ideal ABA-based practice?
Q4.8 What, if any, do you consider needs to change in ABA-based service in the UK/China?
Q4.9 What do you think are the minimum training requirements for staff working in ABA-based interventions?
Q4.10 As far as you know, are the same interventions used by parents at home as well as by professionals in your centre?

Section 5 Autism, policy and culture

Q5.1 What kind of interventions are used among people diagnosed with ASD in their adult life (over 16 year-old) in the UK/China?
Q5.2 How do you assess the current service used for people diagnosed with ASD in your country?
Q5.3 How do you assess the current special needs education used for people diagnosed with ASD in your country?
Q5.4 How do you assess the current interventions used for people diagnosed with ASD in your country?
Q5.5 Do you know of any other medical or non-behaviourally based therapy parents are using?
Q5.6 Do you know of any other social policy to support children diagnosed with ASD?
Q5.7 What do you think are the main cultural or social challenges faced by children with autism? Do you think these have changed over the past few years and if so, why do you think they have changed?
Q5.8 Do you have any other comments want to add?
Appendix 15  Chinese parents` interview schedule

家长访谈提纲

介绍：感谢您接受访谈

首先向受访者介绍知情同意书和伦理委员会授权信

（如果家里有一个多个孩子被诊断为自闭症谱系障碍，请家长选择正在进行早期集中性 ABA 训练的小孩）

第一部分：人口学信息

Q1.1 与正在做 ABA 干预的孩子的关系 Relationship to the child (children) doing ABA

Q1.2 性别

Q1.3 您介意告诉我您的婚姻状况吗

Q1.4 您介意告诉我您的年龄吗

Q1.5 您目前居住在哪里

Q1.6 您目前的工作状态是

Q1.7 您的最高学历

第二部分: 家长信息

Q2.1 您看待被诊断为自闭症谱系障碍（以下简称自闭症）的人，您觉得主要的是挑战还是长处

Q2.2 总体而言，您每天花多少钟头照顾被诊断为自闭症的孩子

Q2.3 您是在哪里找到关于 ABA 干预/治疗方法的

Q2.4 ABA 干预/治疗是被建议给您的吗？如果是，通过谁呢

Q2.5 目前，您有几个孩子正在进行 ABA 干预项目
Q2.6 到目前为止，有几个孩子完成了该项目

Q2.7 您介意告诉我您的家庭年收入吗（税前）

Q2.8 粗略估计，您每年会花费多少在孩子的 ABA 干预项目中（每个小孩，包括玩具和其他材料等）

Q2.9 您当前正在进行 ABA 项目的孩子得到了哪种经济支持？包括预先付款，如果有的话

第三部分：孩子信息

Q3.1 孩子目前年龄 性别

  Q3.1.1 她/他是您家里唯一的小孩吗

  Q3.1.2 如果不是，其他兄弟/姐妹的年龄和性别是？

  Q3.1.3 您是如何照顾其他兄弟/姐妹的

Q3.2 您是什么时候发现孩子的行为跟其他孩子不一样的

  Q3.2.1 当时的年龄是

  Q3.2.2 有哪些不一样的特征

  Q3.2.3 您第一个请求帮忙的人是？

  Q3.2.4 回顾过去，您的感受是

Q3.3 您的孩子被正式诊断为自闭症的年龄是

  Q3.3.1 您能描述下您的心理感受吗

  Q3.3.2 在得到最终诊断后，您的决定是？

Q3.4 您的小孩有接受

  (1) 特殊教育 (2) 特殊服务或待遇 (3) 特殊干预

  (1) 是/否 (2) 是/否 (3) 是/否

Appendix: 452
Q 3.5 当时是如何做决定的？由谁？

第四部分：早期 ABA 行为干预

Q4.1 您的小孩是否正在进行 EIBI 干预

假如是：

Q4.1.1 何时何地了解到 EIBI

Q4.1.2 您的孩子何时开始接受 EIBI

Q4.1.3 在何地进行

Q4.1.4 用何种方式进行的（治疗师/家长人员安排，学校/家庭治疗安排）

Q4.1.5 您的孩子所进行的 EIBI 包括行为分解训练（DTT）吗，还有其他方法吗？

如果没有进行 EIBI，出于何种原因呢？

Q4.2 您还使用其他 ABA 干预方法吗

如果是，哪一种干预方法

如果不是，没有使用其他 ABA 干预方法的原因是？

Q4.3 您的小孩被转接到幼儿园/小学/中学了吗？经历了多久？

Q4.3.1 这是一所特殊学校吗？如果是，原因是？

Q4.3.2 这是一所普通学校吗？如果是，您的孩子和其他小孩融入的程度是？例如，

完全融合，特殊课堂，课外活动或者小组活动 pull-out individual or group sessions？

Q4.4 您的小孩还在进行非行为干预的治疗吗

Q4.5 当 ABA 老师与您的孩子工作时，您会努力配合吗？

Q4.5.1 是如何共同合作的

Q4.6 孩子的行为在 ABA（例如 EIBI）干预前和干预后，是如何改变？

Q4.6.1 您是何时发现这种改变的
Q4.7 您在家里会使用与中心/机构/特殊学校里从业人员一样的干预方法吗

Q4.8 随着孩子年龄的长大，您是如何改变干预技巧的？

Q4.9 您对您孩子未来的期待是？在他/她成年后（大于 18 岁），哪一种干预方法您预估会使用

Q4.10 您如何评价目前所接收的公共服务

Q5.1 您期待还能得到哪些方面的支持和帮助

    Q5.1.1 如果没有受到应有的支持和帮助，是什么阻止了您的获得？

Q5.2 您觉得自闭症孩童目前受到的主要挑战是

Q5.3 您还有其他想要补充的吗？
Appendix 16  Chinese professionals’ interview schedule

从业人员访谈提纲

介绍：感谢您介绍访谈

向受访者介绍知情同意书和伦理委员会授权信

第一部分：人口学信息

Q1.1 性别

Q1.2 您介意告诉我您的年龄吗

Q1.3 您的居住地是

Q1.4 您的最高学历是

第二部分：工作信息

Q2.1 您目前的工作，您是受雇于机构/学校还是独立工作者

Q2.2 您的主要职责是（可能负责多个工作职能）

Q2.3 您在目前的单位工作了多久（全职还是兼职）

第三部分：早期集中行为干预（以下简称 EIBI）

Q3.1 您目前提供哪方面的 ABA 干预项目

Q3.2 您是否有听说过 EIBI（早期的，强化的，个体化和综合性的 [针对一系列技巧] 基于 ABA 策略和原则，主要使用 DTT 和 NET Natural environment training）

是  否 (go to Q4.1)

Q3.2.1 您是何时何地了解到 EIBI 的？Where and when did you learn about EIBI？
Q3.2.2 如果您知道 EIBI，您建议最小开始的年龄是？

Q3.2.3 您建议最大的年龄段是？

Q3.2.4 您建议每个星期多少小时？

Q3.2.5 您建议持续多久？ 进一步问：原因

Q3.3 您为家庭提供 EIBI 吗

是 否 (go to Q4.1)

Q3.3.1 如果您提供 EIBI，您开始的最小开始的年龄是？

Q3.3.2 在您的工作经历中，最大的年龄是？

Q3.2.3 每周多少个小时 (如果有几个学生，请选择您认为在进行最强化训练的那一 位)

Q3.2.4 持续多久呢？ (如果有几个学生，请选择您认为在进行最强化训练的那一 位) 进一步问：原因

Q3.4 界定您的 EIBI 项目典型的包括？ Define what targets your EIBI programme typically includes? (例如交流技能，社会交往技能，游戏技巧，学习技能等.)

Q3.5 您在 EIBI 中主要应用哪种方法 (e.g., DTT 或者 NET)

Q3.6 您认为如何强调目标行为中的不适当行为

Q3.7 您认为在建立适当目标行为时最重要的是什么 What are the most important target behaviours to build on behavioural strengths?

Q3.8 您一般是在哪里进行 EIBI，家里，机构还是学校？

Q3.9 您在过程中是如何融入家长参与的 (i.e., EIBI 项目)

Q3.10 在高度结构化的项目中您经历了哪些困难？ (e.g., 从简单到负责的任务)

Q3.11 您是如何把小孩学习到的技巧泛化到其他环境中的，例如学校和社区. (以您所接触的大部分孩子为例)
Q3.12 有多少学生被转接到小学学校中? 经过了多久?
到幼儿园中? 多久后?
中学中? 多久?
有多少学生被转接到特殊学校中?

Q3.13 对于那些被转接到普通学校的，您的学生是如何与其他典型小孩融合的？(e.g., 完全融合, 特殊教室, pull-out sessions)

Q3.14 总体而言，你是如何评价 EIBI 的 进一步问:原因

Q3.15 您的 ABA 项目会参考某一具体的指导/训练步骤吗？(e.g., UCLA model Early Start Denver Model (ESDM); Verbal Behaviour (eg. VB-MAPP); PECS)

Q3.16 您所服务的家庭中，您预计一个家庭每年要花费多少在 EIBI 项目上

Q3.17 据您所知，家长有接受哪些支持吗？例如资金支持或者志愿者服务的帮助？

第四部分：早期 ABA 干预

Q4.1 您不适用 EIBI 的原因是

Q4.2 您的机构还是用其他基于 ABA 的方法吗？

Q4.3 您目前获得了 ABA 方面的哪些资格证

Q4.4 您是如何用数据测量行为在干预前，中和后的变化？

Q4.5 您如何评价贵机构目前的 ABA 服务模式的 What do you think of the service delivery (小时的数量，时常，花费，被监督 (supervision)

Q4.7 您是如何评价贵机构目前的评估和治疗计划的 assessments or treatment plans

Q4.8 有没有/有哪些阻止您进行更为理想化的 ABA 实践的？

Q4.9 如果有的话，您觉得目我国的 ABA 服务有哪些需要改进的地方？

Q4.10 您觉得 ABA 从业者的最小训练标准是？ the minimum training requirements for staff working in ABA-based interventions?
Q4.11 据您所知，家长在家里用的方法与机构所使用的是一样的吗？

第五部分：自闭症、政策和文化

Q5.1 自闭症儿童成年后（大于 16 岁）会用什么样的干预方法？

Q5.2 您如何评价我国目前针对自闭症人士的服务系统？

Q5.3 您是如何评价我国目前针对自闭症人士的特殊教育系统的？

Q5.4 您是如何评价我国目前的干预系统？

Q5.5 据您所知，人们会使用药物治疗或者非行为干预的治疗方法吗？

Q5.6 您知道我国有哪些专门针对自闭症儿童的社会政策吗

Q5.7 您觉得目前自闭症儿童所面临的主要文化或者社会挑战是什么？相比以前，有改变吗？如果有，具体是哪些？为什么会有这些改变呢？

Q5.8 您还有其他想要补充说明的吗

Appendix: 458
### Appendix 17  Excerpts of quotations from Chinese interviewees

<table>
<thead>
<tr>
<th>Chinese</th>
<th>Translation</th>
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<tbody>
<tr>
<td>我之前在带他在 H 市看过，说是不像自闭症，但发育迟缓肯定有的，让我再等等，先送早教班。我回来之后说再等等半个月，如果还是不说话，那我就再带他看一下。其实那时候在早教就好了，但过了半个月，他自己就开口叫妈妈了，非常清楚，我以为就是像别人说的贵人讲话迟啊之类的，就没去看，再等等吧。（Chang）</td>
<td>I took him to H city for a check. The doctor said he did not look like a child with autism, but definitely have developmental delay and he made me wait for a while. I waited for half a month. If he still did not speak, I would take him to check again. How I wish I could take him for a check earlier! As half month passed, he started to call Mummy, very clearly. I thought he might be like other people said, great mind speak late, so I did not take him for a further check. Let’s see and wait. (Chinese mother, Chang)</td>
</tr>
<tr>
<td>(检验自闭症) 他就是排除，把这些都排除掉，什么都没有，那就只剩下这一条路了，就只能是这里了，然后我们又去查自闭症。当时自闭症就说，那个北医六院比较权威嘛，我们就去那里了，去那里[专家]就说是疑似…...他爸到现在还在怀疑，他到底是什么情况，到底是不是属于自闭症的范畴还是发育迟缓。（Meimei）</td>
<td>What they were using (methods of diagnosis) was exclusive methods. Exclude other conditions, nothing else, then, only left one possibility (autism). Then we took the child to Beijing Six hospital, an authoritative hospital in China. The expert said it looks like autism. Until now, his Dad was thinking whether or not our boy was on the autism spectrum or just had developmental delay. (Chinese mother, Meimei)</td>
</tr>
<tr>
<td>那么现在家长就是说, 东一下、西一下，走了很多很多路，这个圈里面，我想就是，一般是这么总结，就是花上两三年的时间去找这孩子到底是什么问题. 是花四五年的时间试遍所有方法，最后把孩子最佳干预期给耽误了，最后放弃了. 最可</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>还有一种观点：如果我孩子智商不高，家庭也不富裕，那我为什么还要训练他呢，反正训练之后也是一个傻子。还有家长希望我努力了，那么有一天孩子能被治好。 (Meiyin)</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Translation</td>
<td>The parents had another point of view: If my children’s IQ is not high and my family were not rich enough, then why would I train him?! No matter how much he was trained, he would still be a stupid person (shazi 傻子). While there were some parents hoped if taking the child to train with lots of efforts, the child would recover. (Beijing AC School, Meiyin)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chinese</th>
<th>他原来是那种无目的的跑，就是来回跑，然后还有就是上马路以后，他只管一个人吭吭的往前跑，没有危险意识。他现在最起码出去以后，拉着妈妈的手，跟妈妈一起走。或者是我手中拿东西，我让他拽住我的衣服，跟我走就可以了，他就不乱跑了，最起码你在他的后面走，他在前面，他会回头看你在不在他的后面，或者说你在前面，他会追着你。上ABA这个，就是自己有这个意识以后，也教，然后后来才，原来上马路之后，我不敢撒手，现在可以撒手，就是跟着我，一步一步走，只要我给他下个指令，来，跟着妈妈一步一步走，就可以了。 (Wuling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Translation</td>
<td>He was running without a purpose, back and forth and running around on the street. He had no situation awareness at all. Now, he at least knew taking Mummy’s hand and walking with Mum. If I had something full at hands, I would let him grab my clothes and walk together. Sometime, he was walking in front of me, he would look back to check if I was there; if I was walking in front, he...</td>
</tr>
</tbody>
</table>
was chasing after me. After the ABA training, I could let him walk independently, [as] he was able to following me if I gave him an instruction: come on, walk with Mummy step by step. That’s it. (Chinese mother, Wuling)

<table>
<thead>
<tr>
<th>Chinese</th>
<th>Translation</th>
</tr>
</thead>
<tbody>
<tr>
<td>(某些培训老师)他对 ABA 也只是有一点了解，并没有深入研究，比如说 D T T，他都写成 D T D等等，反正很多错的，而且你给他指出错误的时候，他还会攻击[我们学校]，你们好多东西都是错的。最后我们会变的很紧张，导致以后再去政府机构，我们就都闭嘴，不说，或者说他们好呗。政府的培训有一部分是大学老师，但是他们有的根本不懂，大学里又没有 ABA。现在只要国内有关于 ABA 的培训，讲的是国外人士讲授，或者你是在国外学习的，我都会去听，但是如果是国内的讲授，都不会去。我们不是说不那个（配合）。以为我们觉得，至少我们的 ABA 比国内同样的机构要早十年，二十年，我们相对更专业一些。许多培训的东西都是错的，还必须去学，所以我们一般不会去参加这样的培训。 (Meiyin)</td>
<td>Some of the trainers only understood a little bit of ABA, had not done thorough research. For example, I came across a trainer who spelled DTT to DTD. When you pointed out their errors, they would even attack us. Some of the trainings were provided by government and were university teachers, but I felt they did not understand ABA. There were no university teaching ABA in China... If only the trainers were from abroad or study abroad, I would go. It is not that we are not co-operative [with government organizers], but we believed we were at least 10 and 20 years ahead of other organisations. We are more professional’ (Beijing AC School, Meiyin)</td>
</tr>
</tbody>
</table>
Appendix 18  Excerpts of one UK interviewee transcription

Interview outline of Lucy

Section 1: Demographic information:

<table>
<thead>
<tr>
<th>Relationship to the child</th>
<th>Mother (Anonymised to Lucy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>F, Married, 39</td>
</tr>
<tr>
<td>country do you live currently</td>
<td>NI, Belfast</td>
</tr>
<tr>
<td>national identity</td>
<td>British</td>
</tr>
<tr>
<td>current working status</td>
<td>Employed</td>
</tr>
<tr>
<td>Highest education level?</td>
<td>Ungraduated degree</td>
</tr>
<tr>
<td>family income per annum (Pre-tax)</td>
<td>For both of us (family income) it is probably about £55000</td>
</tr>
</tbody>
</table>

Section 2: Children and diagnosis

| Age of child’s behaviour was different and symptoms | At birth, Female [child] was different when she was born. She was just different to my other children because she cried all the time. She was very difficult to comfort. I didn’t know what it was. It was very hard to figure out what it was. Because I had two other children I know it wasn’t normal behaviour that you couldn’t take her out anywhere and that she just cried all day long, for seemingly no reason. So I was constantly at the doctors. And that’s how we discovered she had **allergy**. That was diagnosed really early, like 3 months. She was also referred for very severe eczema. So at that time we thought it was these issues. And it might have been. I’m not sure. But as time went on, even though she was treated for both of these things, she was still crying. So to me it was possible she had sensory issues…the noise…but definitely it was from birth. |

Appendix: 462
Section 3: programme approaches

| Any other non-behaviour interventions | Speech therapy. She hasn’t actually had speech therapy as in practicing pronunciation. From the start the speech therapy was about getting her to sit in the seat. And it was very different. It was more like play therapy and teaching her to do something and then you can get her to do something else. Just to get her to comply. **About 6 months** of the speech therapy was getting her to sit in her seat and doing what they were asking her to do. Because she was not interested in doing anything and anyone wanted her to do. |

Section 4: Early ABA-based behaviour interventions

| Where did you find out ABA | Before she was diagnosed, as soon as we knew there was a problem and it was plausibly being autism. We looked on the internet. And this is where I found out about ABA. [Ask: Find out about it yourself?] yeah |
| Cost on ABA | Not as much as other people spend. The problem is, when [child] was born, we had just put an extension to the house, which sent our mortgage through the roof. **So I’d prefer to spend more to get her more ABA but then we’d have to move house.** So it’s a balance. So at the minute its £50/wk for [the therapist] and buying material… we buy her extra toys and materials and it’s probably another £50/mth, couple of games and materials. So let’s say it about £250/mth. But the recommendation is 40hr/wk. |
| ABA programme | She’s only getting **4 hr a week**. But she is usually able to sit and do her work. When any child, she was 3, when they’re expected to sit for 2 hr and do activities that they might not want to do. So I think she’s getting on well. But the areas I’ve expressed concern is **her social skills**. And it’s hard to practice that in the environment. You need to be out with other children to practice that and it’s one of her biggest deficits. Unless there was an ABA group where a few children can go and work together. Only the playday [of NIU charity]. But it’d be better if there were smaller groups. I think they do it for older children, teenagers. But don’t have anything for younger children. When I ask for the health
trust, the paediatrician, she just laughed. You can’t do that in a false environment, she just need to learn social skills at nursery and her day to day life. I think a smaller one where people are aiming [to work on social interaction] would help.

**Section 5: EIBI**

| Use EIBI or not        | No, haven’t really heard about it. I just that it was ABA. But I’ve heard of ABA intensive for 40 hr a week. Even of it didn’t work, I think it really helps that you’re doing something. Even if you did 40 hrs a week and nothing happened you’d still feel better because you’ve tried. |

**Section 6: ABA, school and policy**

| Financial support received | From the Cordwell funding… that’s what we received. We didn’t initially because we were over the income threshold. So we didn’t apply. But then I heard someone else had got it, because they look at how much have come in and how much is going out and see how much you got left so I **applied anyway and they actually gave it to me last year.** **But it’s only done on an annual basis** and we’ll have to apply again this year and it may not be as favourable. |

**Section 7: effectiveness of ABA**

<p>| Life changes by ABA | She’s better now. I think now that she can ask for what she wants or say I don’t like it or I’m frightened or I’m scared…She’s happier now. |
| Parent therapist | [Learn ABA] a limited amount. I would do more before [therapist] came but it was really difficult because I’m not there all the time and because [child] goes to bed at 7pm, because on the weekend other children needs to go to other things. So it’s a brilliant help having [therapist] come in. But it has meant that I have left it more to her. I think I |</p>
<table>
<thead>
<tr>
<th>Section 8: Future expectation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expectations to the future</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section 9: Cultural perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Think of somebody with autism what, if any, do you think are the main challenges and what are the main strengths</td>
</tr>
</tbody>
</table>
## Appendix 19 Data recording sheet of direct observations

<table>
<thead>
<tr>
<th>Date: ________________</th>
<th>Time: ________________</th>
<th>Event: ________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>21</td>
<td></td>
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<tr>
<td>2</td>
<td>22</td>
<td></td>
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<tr>
<td>3</td>
<td>23</td>
<td></td>
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<tr>
<td>4</td>
<td>24</td>
<td></td>
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<td>5</td>
<td>25</td>
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<td>6</td>
<td>26</td>
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<td>27</td>
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<td>8</td>
<td>28</td>
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<td>9</td>
<td>29</td>
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<td>10</td>
<td>30</td>
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<td>11</td>
<td>31</td>
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<td>12</td>
<td>32</td>
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<td>14</td>
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<td>17</td>
<td>36</td>
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<td>18</td>
<td>37</td>
<td></td>
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<td>19</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>39</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 20  Invitation letter from a Chinese sample site

Beijing Stars & Rain Education Institute for Autism
Stars & Rain
Education Institute for Autism
18 Hanyuan, Shuang Qiao Dong Lu,
Chaoyang District 100121, Beijing China
Tel: 0086-10-85373236
Fax: 0086-10-85373236
pspe@autismchina.org
www.autismchina.org

Beijing, Dec 30, 2014

Invitation

The invitation hereby to invite and explain of Ms. Yini Liao will do volunteer work in Stars and Rain Education Institute for Autism from March 9th 2014 to April 30th 2014.

Stars and Rain was founded in 1993 by a parent and is China’s first non-governmental educational organization to serve children with autism. But we still face the problem with poor professional resources on special education of autistic children at present. So it is very important to get support from international experts and researchers on autism education, which could improve the skills of our teachers.

Ms. Yini Liao, is doing her PhD at center for Behavior Analysis, School of Education, Queen’s University Belfast, will work in our preschool department as volunteer to help and assistant our teacher and give the parents and teachers speech on Early Intensive Behavior Intervention and ABA practical work from March 9th 2014 to April 30th 2014.

Through the volunteer work experience it is hoped that Ms. Yini Liao will be part of a collaborative effort with Stars and Rain’s staff and other volunteers. Getting more knowledge of Stars and Rain and know more information about Chinese special education on autism.

During the work time, Ms. Yini Liao will be staying at Dongxu Xin Can located Chaoyang district Beijing, China.

Beijing Stars and Rain
Education Institute for Autism
Beijing, Dec 30, 2014

STARS & RAIN
www.autismchina.org
Tel: 0086-10-85373236
Fax: 0086-10-85373486
### Appendix 21  Reasons for the change of child’s quality of life

<table>
<thead>
<tr>
<th>Themes</th>
<th>Codes</th>
<th>Countries</th>
<th>Example responses</th>
<th>Assessor 1</th>
<th>Assessor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's changes</td>
<td>a</td>
<td>UK</td>
<td>‘He is able to communicate more now’; ‘He is happy child now enjoying playing with brothers, doing well at school, enjoys going out, enjoys doing things just like other kids do eg., Watching TV, DVDs playing video games’</td>
<td>7(77.78%)</td>
<td>8(88.89%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘ABA teaching makes child have a goal to learn and live the life’; ‘He can use an appropriate way to express his thoughts and his needs’</td>
<td>22(62.86%)</td>
<td>20(57.14%)</td>
</tr>
<tr>
<td>Professional support</td>
<td>b</td>
<td>UK</td>
<td>‘1:1 teaching’</td>
<td>2(2.57%)</td>
<td>1(1.29%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘find the right methods’; ‘Education and training’; ‘the intervention helps’</td>
<td>4(11.43%)</td>
<td>4(11.43%)</td>
</tr>
<tr>
<td>Parental skills improved</td>
<td>d</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘parents no longer follow his(child’s) minds to do things but insisted principles’; ‘When met something he cannot make it, we can teach him how to do it based on our learning’; ‘Parents persists in learning and do interventions on child and make the child learn something’</td>
<td>6 (17.14%)</td>
<td>6 (17.14%)</td>
</tr>
<tr>
<td>Positive attitudes of the family</td>
<td>e</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘The attitudes of adults to the child have changed in some aspects’</td>
<td>1 (2.86%)</td>
<td>1(2.86%)</td>
</tr>
<tr>
<td>Unspecified reasons</td>
<td>h</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘Have no time for leisure activities. Basically centred around him’; ‘my daily living is not convenient’</td>
<td>2(5.71%)</td>
<td>4(11.43%)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td>42(100%)</td>
<td>42(100%)</td>
</tr>
</tbody>
</table>
## Appendix 22  Barriers experienced while accessing ABA services

<table>
<thead>
<tr>
<th>Themes</th>
<th>Codes</th>
<th>Countries</th>
<th>Example responses</th>
<th>Assessor 1</th>
<th>Assessor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Misunderstanding towards behaviour intervention</td>
<td>a</td>
<td>UK</td>
<td>‘Myths and misunderstandings about what it is’; ‘Local education authority opposed’.</td>
<td>4(30.77%)</td>
<td>3(23.08%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘Family members have different opinions towards the ABA services.’; ‘Some aspects of the ABA services is in conflict with my personal opinions’.</td>
<td>2(3.33%)</td>
<td>2(3.33%)</td>
</tr>
<tr>
<td>Lack of public resources (include policy)</td>
<td>b</td>
<td>UK</td>
<td>‘There is no services with regards to aba within the health service, if u have money then u have’; ‘No involvement by school with ABA’</td>
<td>3(23.08%)</td>
<td>4(30.77%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘ABA cannot be combined in mainstream Kindergarten’; ‘None of the government departments support ABA’; ‘There are no autism organisations at my living place.’</td>
<td>6(10.00%)</td>
<td>6(10.00%)</td>
</tr>
<tr>
<td>Financial constraints</td>
<td>c</td>
<td>UK</td>
<td>‘It is expensive.’; ‘Funding a home based programme is incredibly expensive.’</td>
<td>5(38.46%)</td>
<td>5(38.46%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘Financial pressure’; ‘It is expensive’</td>
<td>6(10.00%)</td>
<td>6(10.00%)</td>
</tr>
<tr>
<td>Lack of professional support</td>
<td>d</td>
<td>UK</td>
<td></td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘Many teachers are not professionals. They have no plan’; ‘(Therapists were) not professional and (therapists) focused on every aspects of the child’; ‘a lack of BCBA and BCaBA. a great shortage of professionals’; ‘…Teacher cannot understand where the child’s interest lies in’</td>
<td>10(16.67%)</td>
<td>11(18.33%)</td>
</tr>
<tr>
<td>Time constraints</td>
<td>e</td>
<td>UK</td>
<td>‘…lack time to do ABA with child myself.’</td>
<td>1(7.69%)</td>
<td>1(7.69%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>China</td>
<td>‘Some problem behaviours cannot be found out and be solved in a short-term’; ‘The time of ABA training is too short.’</td>
<td>4(6.67%)</td>
<td>4(6.67%)</td>
</tr>
<tr>
<td>Perceived effectiveness of the intervention</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>China</td>
<td>‘child still did not do as parents asked’; ‘I feel it(ABA services) was not flexible when first using it, but later felt it was good and could be combined very well with other teaching methods’; ‘generalisation’.</td>
</tr>
<tr>
<td>Parents lack of guidance on ABA</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>China</td>
<td>‘I did not have too much experience and I felt difficulty in conducting interventions for my child’; ‘I felt it was easy to learn but hard to undertake’; ‘Parents personal ability to deal with the issues and cannot manage appropriately’; ‘The difficulty of making the learnt theory to practice on the child’.</td>
</tr>
<tr>
<td>Parents' psychological pressure</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>China</td>
<td>‘Family faced psychological pressures. How to provide psychological support for parents’; ‘I felt a low motivation’; ‘Parents felt tired’.</td>
</tr>
<tr>
<td>Unspecified responses</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>China</td>
<td>‘many’</td>
</tr>
<tr>
<td>Distance constraints</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>China</td>
<td>‘location problem’; ‘There are no autism organisations at my living place. My working place could not accept a temperate leave for taking the child outside for training.’</td>
</tr>
<tr>
<td>family member conflicts</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>China</td>
<td>‘There are conflicts among us’; ‘family problem’.</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>