Experiences of parents during diagnosis and forward planning for children with Autism Spectrum Disorder.


Published in: Journal of Applied Research in Intellectual Disabilities

Queen's University Belfast - Research Portal: Link to publication record in Queen's University Belfast Research Portal

General rights
Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.
Living with children diagnosed with autistic spectrum disorder: parental and professional views

Karola Dillenburger, Mickey Keenan, Alvin Doherty, Tony Byrne and Stephen Gallagher

The number of children diagnosed with an autistic spectrum disorder (ASD) is rising and is now thought to be as high as 1:100. While the debate about best treatment continues, the effects of having a child diagnosed with ASD on family life remain relatively unexplored. This article, by Karola Dillenburger of Queens University Belfast, Mickey Keenan of the University of Ulster, Alvin Doherty from the Health Service Executive Western Region, Tony Byrne of Parents’ Education as Autism Therapists (PEAT) and Stephen Gallagher of the University of Ulster, sets out to adjust that balance. Drawing upon data from a comprehensive study of parental needs, these authors argue that parental and professional views do not always concur; that families make extraordinary sacrifices; that siblings are affected; and that parents are under tremendous stress. Parents argue that educational and social service supports are not efficient and that they are forced to rely largely on support from within the family or from friends. In particular, some important differences between parental and professional perceptions became apparent in relation to interventions based on Applied Behaviour Analysis (ABA). The authors of this article propose that these differences need to be taken seriously by teachers and other professionals as well as by policy-makers.

Key words: autism, family life, parents, needs, behaviour.

Autistic spectrum disorder (ASD) is diagnosed where a triad of behaviour patterns, including delayed or atypical social interaction and communication (verbal and/or non-verbal) and rigid, ritualistic behaviour is observed over a prolonged period of time (APA, 2000). The number of children diagnosed with ASD is rising and is now estimated to be as high as 1:100 (Knapp, Romeo & Beecham, 2007). Causes are thought to include genetic as well as environmental factors, although the exact aetiology is not yet established (Szpir, 2006).

Although there is evidence of high levels of appropriate and very good parenting among parents of children diagnosed with ASD (Siller & Sigman, 2002), these parents suffer more stress than parents of children with special health care needs or other developmental disorders, and typically developing children (Dunn, Burbine, Bowers & Tantleff-Dunn, 2004; Schieve, Blumberg, Rice, Visser & Boyle, 2007). There seem to be gender differences with regard to the impact of parenting a child diagnosed with ASD, with mothers generally reporting more stress and depressive symptoms than fathers (Hastings, Kovshoff, Ward, degli Espinosa, Brown & Remington, 2005). No ethnic/cultural differences have been found relating to stress levels when caring for a child diagnosed with ASD (Blacher & McIntyre, 2006). With the exception of Montes and Halterman (2007), there is not much research that compares the psychological health of parents of children diagnosed with ASD with the general population. They found that in the 2003 National Survey of Children’s Health, 364 of the 61,772 participating children were identified on the autism spectrum and that mothers of these children were more likely to report poor/fair mental health than the general population, although these mothers also were more likely to report coping well with parent tasks and having close relationships. Interestingly, a number of studies found that professionals and parents do not agree on the causes of stress (Bebko, Konstantareas & Springer, 1987; Lecavalie, Leone & Wiltz, 2006).

There is little information on the impact of living with a child diagnosed with ASD on the whole family (Munteanu & Dillenburger, 2009), although divorce rates of 82% have been estimated among these families (National Center for Autism Research and Education, 2008), and Bromley, Hare, Davison and Emerson (2004) found that one in three families of children diagnosed with ASD were headed by lone parents.

Research on the impact of having a brother or sister diagnosed with ASD (Hastings, 2004) shows that siblings of a child diagnosed with ASD may be more embarrased in the presence of other children and peers than siblings of children with intellectual disabilities, for example, Down syndrome (Roeyers & Mycke, 1995). DeMyer (1979) found that 30% of siblings reported feelings of being neglected and 18% expressed worries and anxieties associated with ASD. These children also frequently worry more about the future than siblings of typically developing children, feel lonely and have more problems with peer relationships (Bågenholm & Gillberg, 2008). In addition, a relatively high incidence of learning difficulties and language-related problems has been reported in siblings of children diagnosed with ASD.
with ASD (Rutter, 2005). There is no evidence, however, of how professionals’ and parents’ perceptions compare with regard to the effect on siblings.

General support for families provided by social, education or health services has a positive impact on parental stress (Weiss, 2002), while limited financial resources, lack of appropriate services and insufficient support are generally held to contribute to poor prognosis (Seifer, Sameroff, Anagnostopolou & Elias, 1992). Gray (1992) observed that for approximately 50% of mothers the child’s diagnosis prevented or restricted employment. Obviously, concerns about adequate financial resources in relation to schooling, therapy and medical services add stress. The total cost of raising a child with a disability is estimated to be approximately three times greater than the cost incurred by raising a typically developing child (Järbrink, Fombonne & Knapp, 2003) and this financial impact is exaggerated by the shortfall that exists between the costs of bringing up a child with severe disabilities and benefits received (Broach, Potter, Heather, Prior & Mustapha, 2003).

Social support on its own is not enough. The expertise of those providing support is an important factor in the alleviation of parental stress, in particular in relation to self-efficacy, behaviour management and provision of home-based care (Sharpley, Bitsika & Efremidis, 1997; Helps, Newsom-Davis & Callias, 1999). There is much debate about the most effective way to support children diagnosed with ASD and a plethora of intervention methods have been developed (Myers & Johnson, 2007). Despite the fact that most of these are not scientifically evaluated (National Autism Center, 2009; Perry, 2000), there is some evidence of parental satisfaction (Hastings et al., 2005).

Applied Behaviour Analysis (ABA) offers the scientific basis for a range of well-known intervention strategies, such as Discrete Trial Training (DTT), Picture Exchange Communication System (PECS), Verbal Behavior Analysis (VBA), Precision Teaching, generalisation and skill maintenance training, Pivotal Response Training (PRT), prompting and prompt fading, imitation, Direct Instruction, Aggression Replacement Training (ART), shaping, Intensive Behavioural Intervention (IBI), chaining, differential reinforcement, incidental teaching, extinction and others (Dillenburger & Keenan, 2009; Hagopian & Boelter, 2009). More than 40 years of research have supplied ample evidence of the effectiveness of ABA-based strategies (see, for example, JABA, 1969–2009).

Parents seem to have embraced the evidence for ABA-based interventions. In an internet-based survey distributed via autism organisations worldwide, 111 treatment options were listed and parents were asked which of the listed treatments they were using (Green, Pituch, Itchon, Choi, O’Reilly & Sigafoos, 2006). After three months, the survey had received 552 responses. Parents reported using an average of seven different therapies for their children. While 52% of the children were on at least one medication and 27% were on special diets, in relation to non-medical treatments ABA-based interventions were among the most frequently used.

Parents who are trained to deliver ABA-based intensive behavioural interventions (Cooper, Heron & Heward, 2007) with the aim of reducing or alleviating the skills differential between children diagnosed with ASD and their typically developing peers (NAPC, 2003) generally report higher levels of satisfaction and reduced stress levels compared to parents who use other kinds of interventions (Dillenburger, Keenan, Gallagher & McElhinney, 2004; Hastings et al., 2005). Parents who avail of ABA-based school provision for their children (that is, their children attend schools that explicitly derive their teaching strategies from the science of applied behaviour analysis) are satisfied that their children’s needs are met (National Development Plan, 2006).

Despite the fact that, increasingly, children diagnosed with ASD are included in mainstream educational settings (Warnock, 1978), teachers and other professionals do not always understand fully the impact that living with a child diagnosed with ASD has on parents and families (Dillenburger et al., 2004) and are generally not trained in the science of ABA (Keenan, Dillenburger, Doherty, Byrne & Gallagher, 2007). While there is much anecdotal evidence (as seen in internet chat rooms and parent discussion groups, for example, ABA-UK@yahoogroups.com), as yet there is no published evidence as to the differences and similarities of professional and parental views regarding a range of issues, including treatment choices.

This article examines similarities and differences of parental and professional views regarding what constitutes difficult child behaviours, the impact of living with a child diagnosed on the autism spectrum on family life, parents and siblings, general support for families and education for the child diagnosed with ASD, as well as the future needs of these families. Findings lead to important implications for teachers, policy makers, and other professionals.

Methodology
Data reported here constitute part of a larger study that assessed the experiences and needs of families who have a child diagnosed with ASD. An exhaustive description of the methodology is available elsewhere (Keenan et al., 2007). Ethical approval for this study was granted by the University of Ulster at Coleraine, Northern Ireland.

Participants
Ninety-five parents and caregivers participated in the study. Eighty-eight percent of the participants were mothers, 9% were fathers, 2% were foster parents and one was a grandparent. Their mean age was 40 years. Eighty-four percent of the respondents belonged to two-parent families, while 16% constituted one-parent families. Twenty-five percent of the parents/carers suffered from one or more chronic health problems. Fifty-six percent of the parents were unemployed due to being full-time caregivers of the child diagnosed with ASD, while 24% of the respondents were in part-time employment. Apart from the target child, 85% of the fami-
lies had an average of two other children (mean age of 10 years), 25% of whom had a formal diagnosis, mainly ASD.

The parents reported on 100 children, mainly boys (80%) with a mean age of eight years (range 1–16 years). All children had been diagnosed with ASD, although 78% of the children had dual diagnoses, such as ASD and intellectual disability (56%) or physical and sensory disability (27%) or both (18%).

Sixty-seven multi-disciplinary professionals took part, including speech and language therapists (n = 13), social workers (n = 10), clinical and educational psychologists (n = 11), ABA tutors (n = 11), occupational therapists (n = 4), autism therapists (n = 3), occupational therapist, children’s ward manager, behaviour support worker, learning disability nurse (n = 2 each), and paediatrician, dietitian, education director, teacher, health visitor, learning disability co-ordinator, behaviour analyst, psychiatrist, and liaison officer (n = 1 each). Eighty-eight percent of the professionals were female and the mean duration of employment in their current post was just over six years (74 months). Nearly half of the professionals (45%) worked exclusively in ASD-related services, while the others worked in multi-service settings.

Research instruments
The Family Autism Needs Questionnaire (FAN-Q) was specifically designed for this study to explore the needs of families with children diagnosed with ASD. The FAN-Q is an extensive 17-page questionnaire that addresses in considerable detail four main areas: child-related information (such as age, gender, diagnoses); parent-related information (such as demographic and employment situation); current provision and future need; and experiences and views. In order to avoid prejudicing responses, the questionnaire offered a range of responses for selection; for example, with regard to interventions participants were free to select one or more of the two most commonly used interventions (ABA and/or TEACCH), and ‘Other (please specify)’. Participants were able to select more than one response (Figure 1).

Thus, the options for responses were kept as open as possible. The full list of response options typically is reflected in the layout of the tables reported in the results section of this article.

The General Health Questionnaire (GHQ-12; Goldberg, 1978) was included as a validated measure of parental general psychological health and stress levels. Focus groups were conducted to obtain qualitative data.

The Professional Autism Needs Questionnaire (PAN-Q) is a six-page questionnaire designed specifically for the study, that includes four sections regarding the views of professionals working with families and children diagnosed with ASD: professional-related information (such as age, gender, demographic, training, and employment situation); experience of working with families and children with ASD; perceived impact of ASD upon families and siblings; perceived future service needs for families living with a child with ASD. The style of the questions was the same as those in the FAN-Q, and response options are reflected in the tables.

Procedure
An invitation to participate in this study was extended to all parents of children diagnosed with ASD who lived in Northern Ireland and the Republic of Ireland and all professionals who work with these families. In order to reach as many participants as possible and in the absence of a central database of children diagnosed with ASD, a research flyer was circulated to all leading ASD charities in Northern Ireland and the Republic of Ireland and also to individual special schools, inviting parents to participate.

Every effort was made to reach parents by surface mail, e-mail or in person. There were no exclusion criteria related to services, age, demographics, ethnic background, sexual orientation, etc. In other words, every parent of a child diagnosed with ASD living in Northern Ireland or the Republic of Ireland who came forward and every organisation that agreed to take part was invited to take part. In total 310 questionnaires were distributed to individual parents or organisations who agreed to distribute them. Again every effort was made to retrieve completed questionnaires that were returned by surface mail or e-mail, or collected in person. Ninety-five questionnaires were returned (a return rate of 31%). Ten parents participated in a focus group that was held in a local hotel and lasted one-and-a-half hours.

In an attempt to include as many professionals as possible, the research flyer also was widely circulated in relevant professional circles, both in Northern Ireland and the Republic of Ireland. In other words, the flyer was sent to all Education and Library Boards, Social Services Boards and Trusts, and Psychological Societies, inviting professionals to take part. Upon request, the PAN-Q was distributed by

---

**Figure 1: Sample questions from FAN-Q**

<table>
<thead>
<tr>
<th>Q20. Is your child receiving any of the following ASD Home Tuition Programmes? (Please tick As appropriate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Applied Behaviour Analysis (ABA)</td>
</tr>
<tr>
<td>TEACCH</td>
</tr>
</tbody>
</table>

© 2010 The Author(s). Journal compilation © 2010 NASEN British Journal of Special Education · Volume 37 · Number 1 · 2010
surface mail, e-mail or in person. Given that professionals and professional bodies were encouraged to distribute the PAN-Q at their own discretion, it is impossible to know exactly how many were distributed; however, 67 PAN-Qs were returned.

Data were analysed using SPSS version 13. This article focuses on a direct comparison of experiences and views reported by parents and professionals related to child behaviours; the impact of ASD on family, parents and siblings; general support for families; education for the target child; as well as future needs for services.

Results and detailed analysis regarding the full range of issues addressed in the FAN-Q and the PAN-Q, including the diagnostic process, educational provision and home tuition, parent training and teacher qualifications, and financial and multi-disciplinary support are reported elsewhere (Keenan et al., 2007).

Results

**Difficult child behaviours**
The majority of the parents felt that deficits in their child’s social and communication skills, lack of self-help skills and sleeplessness caused most difficulties. The majority of the professionals felt that parents would have most difficulties with their children’s sleep patterns and challenging behaviours, although most felt that social and communication deficits would also cause distress to parents (Table 1).

**Table 1: Parental and professional assessment of difficult child behaviours**

<table>
<thead>
<tr>
<th>Types of behaviours</th>
<th>Parental response</th>
<th>Professional response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of interaction and play with others</td>
<td>94%</td>
<td>86%</td>
</tr>
<tr>
<td>Deficits in social skills</td>
<td>93%</td>
<td>79%</td>
</tr>
<tr>
<td>Language and communication deficits</td>
<td>92%</td>
<td>83%</td>
</tr>
<tr>
<td>Behaviours that challenge</td>
<td>90%</td>
<td>91%</td>
</tr>
<tr>
<td>Deficits in self help skills</td>
<td>88%</td>
<td>64%</td>
</tr>
<tr>
<td>Erratic sleep patterns</td>
<td>80%</td>
<td>91%</td>
</tr>
<tr>
<td>Excessive ritualistic behaviour</td>
<td>60%</td>
<td>80%</td>
</tr>
<tr>
<td>Lack of interaction with parents</td>
<td>60%</td>
<td>77%</td>
</tr>
<tr>
<td>Routine behaviour</td>
<td>49%</td>
<td>76%</td>
</tr>
<tr>
<td>Weight control</td>
<td>36%</td>
<td>40%</td>
</tr>
<tr>
<td>Attention deficit and hyperactivity</td>
<td>22%</td>
<td>66%</td>
</tr>
<tr>
<td>Sexual behaviour</td>
<td>21%</td>
<td>48%</td>
</tr>
<tr>
<td>Other*</td>
<td>19%</td>
<td>10%</td>
</tr>
</tbody>
</table>

* Includes aggression, diet restriction, epilepsy, no sense of danger, Obsessive Compulsive Disorders (OCD), depression, low self-esteem, hyperactivity, sensory disabilities, and toilet training.

**Impact of ASD on families**
Most parents and professionals agreed that having a child on the autism spectrum restricted the family’s ability to plan and pursue recreational and leisure interests, social and community interests, and/or go on holidays or family excursions. Professionals were slightly more worried about these restrictions on family life than were parents (Table 2).

**Table 2: Parental and professional views of restrictions on family activities**

<table>
<thead>
<tr>
<th>Restricted activity</th>
<th>Parental response</th>
<th>Professional response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social and Community</td>
<td>86%</td>
<td>95%</td>
</tr>
<tr>
<td>Recreation and leisure</td>
<td>82%</td>
<td>97%</td>
</tr>
<tr>
<td>Holidays and excursions</td>
<td>81%</td>
<td>98%</td>
</tr>
</tbody>
</table>

Parents clearly worried about the impact of having a child diagnosed with ASD on the family as a whole, as the following parents’ comments show:

’Had to stay away from friends and family who are very negative towards my autistic daughter, less likely for us to visit friend’s house.’

’Very very stressful. The family seems to disappear. You tend to become isolated and wonder what you ever did to deserve this.’

’Whole family life evolves around the child, both parents unable to work, feel that friends and family don’t understand the devastation and worry that we have.’

**Impact of ASD on parents**
Eighty percent of the parents had been in employment in the past. However, most of the parents stated that their commitment to their child affected their availability for full-time employment and 56% of the parents presently were unemployed. Most parents and professionals agreed that having a child diagnosed with ASD has a strong restrictive impact on parental activities, although professionals were slightly more concerned with these issues than were parents. The only issues parents were more concerned about than professionals were occupation and employment and education (Table 3).

**Table 3: Parental and professional views of restrictions on parental activities**

<table>
<thead>
<tr>
<th>Restricted activity</th>
<th>Parental response</th>
<th>Professional response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social and community</td>
<td>86%</td>
<td>94%</td>
</tr>
<tr>
<td>Recreational and leisure</td>
<td>85%</td>
<td>95%</td>
</tr>
<tr>
<td>Occupation and employment</td>
<td>84%</td>
<td>79%</td>
</tr>
<tr>
<td>Education</td>
<td>78%</td>
<td>77%</td>
</tr>
</tbody>
</table>
Most parents and professionals thought that having a child on the autism spectrum restricted parental time spent with their partner, their other children and/or their extended family and friends, although professionals seemed to be somewhat more concerned about these issues than were parents (Table 4).

Eighty-eight percent of the parents perceived their own levels of stress as high, and stated that these stress levels had been continuous for an average of five years. In terms of general psychological health as measured by the General Health Questionnaire (GHQ-12), there was a significant correlation (Pearson correlation analysis) between GHQ-12 scores and personal assessment of stress ($r = -0.41; p < 0.01$). Forty-eight percent of the parents scored above the GHQ-12 threshold of four, indicating ‘caseness’ in need of further psychological assessment. This compares to 17% in the general population (ARK, 2006). The average GHQ-12 score of parents was 4.35 (SD = 3.99), within a range of 0–12 points.

GHQ-12 scores were not statistically significant with regard to the child’s age, diagnostic process, dual diagnoses, siblings with a diagnosis, employment, demographic location, home tuition, education, home, family or respite support. However, higher levels of multi-disciplinary support were significantly associated with higher GHQ-12 scores ($r = 0.28; p < 0.01$) and higher levels of family support were significantly correlated with lower GHQ-12 scores ($t = -2.06; df = 90; p < 0.05$).

Some of the parents considered the impact of having a child diagnosed with ASD more as a challenge than a restriction:

‘I always considered myself very good with children with special needs and now I have a child like this. I hope I am able to cope with anything put in my way.’

‘Learning to be tolerant, and although we don’t like our daughter’s behaviour we have learned to love her despite this.’

Impact of ASD on siblings

Eighty-five percent of the families had more than one child. While there was some agreement between parents and professionals regarding siblings’ feelings of being neglected, treated unfairly and worried, professionals viewed siblings as more sensitive and resentful, feeling guilt and fear, while parents seemed to be somewhat more concerned with siblings’ feelings of engagement (Table 5).

Parents’ views with regard to impact on siblings varied:

‘Positive, I think it brought siblings closer together.’

‘The strain it puts on siblings and the guilt you feel on a daily basis that you could be doing more.’

‘Marriage break-up, teacher career put on hold (financial problems). In terms of family life, siblings resent the needs of child with autism on a daily basis.’

General support for families

Sixty-six percent of the professionals had noted that parents experienced significant distress when seeking funding to support their children’s treatment and education, yet 44% of the parents had not been informed by statutory services about available financial support.

None of the parents were in receipt of full-time home tuition fees for their child. Other kinds of payment, such as disability and mobility allowance or direct payments for respite care and incapacity benefit, amounted on average to less than £3,000 annually.

The experiences of parents seeking financial support for their child were stressful, as the following parents’ comments demonstrate:

‘I have just finished re-applying for Disability Living Allowance (DLA). The forms took me 6 week to complete, why does it have to be such a long winded process, when your child has been diagnosed with having a life long illness?’

‘He had his DLA reduced, don’t know why, as he’s worse since the first application and comparing applications confirms this. Being a single parent in

<table>
<thead>
<tr>
<th>Restriction on time with</th>
<th>Parental response</th>
<th>Professional response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner</td>
<td>78%</td>
<td>96%</td>
</tr>
<tr>
<td>Extended family and friends</td>
<td>76%</td>
<td>94%</td>
</tr>
<tr>
<td>Other children</td>
<td>73%</td>
<td>98%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sibling feels</th>
<th>Parental response</th>
<th>Professional response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neglected</td>
<td>80%</td>
<td>73%</td>
</tr>
<tr>
<td>Engaged</td>
<td>73%</td>
<td>64%</td>
</tr>
<tr>
<td>Treated unfairly</td>
<td>67%</td>
<td>67%</td>
</tr>
<tr>
<td>Worried</td>
<td>67%</td>
<td>72%</td>
</tr>
<tr>
<td>Sensitive to sibling</td>
<td>65%</td>
<td>71%</td>
</tr>
<tr>
<td>Sensitive to others</td>
<td>58%</td>
<td>58%</td>
</tr>
<tr>
<td>Resentment</td>
<td>53%</td>
<td>66%</td>
</tr>
<tr>
<td>Isolation from peers</td>
<td>32%</td>
<td>44%</td>
</tr>
<tr>
<td>Willing to help</td>
<td>24%</td>
<td>44%</td>
</tr>
<tr>
<td>Guilt or fear</td>
<td>14%</td>
<td>32%</td>
</tr>
</tbody>
</table>
full-time work, I didn’t feel I had the time, strength and support to fight the decision.’

‘Had to re-mortgage my home, to raise funds to support my child’s home programme.’

Despite the fact that over two-thirds of the professionals had noticed that parents experienced distress when trying to access multi-disciplinary support services, 42% of the parents were not informed by statutory services about multi-disciplinary support available to their family. Fifty-six percent of the parents stated that they would avail of this support if they had the right information.

Professionals thought that nine different support services would be the appropriate number required, yet most of the children (71%) received multi-disciplinary support from an average of only three different professionals, including speech and language therapists, occupational therapists and social workers. ABA home programme support services were provided mainly by a non-statutory parent-led charity. Twenty-nine percent of the children did not receive any multi-disciplinary support services.

Parents’ comments indicated distressing experiences when seeking multi-disciplinary support services:

‘Services are very fragmented with little or no coherence. Went 2 years without a social worker, didn’t know I was entitled to one until another parent told me and then I had to chase up.’

‘We wouldn’t need multi-disciplinary support if our child was getting ABA in school.’

‘Professionals talk to me as through I have no sense, very patronising.’

Even though nearly 80% of professionals had noted that parents experienced significant distress or difficulties when trying to access home, residential or respite support, 48% of the parents had not been informed by statutory services about support available to their family. Only 38% of the parents actually were in receipt of home or respite support, while 24% of the families were in receipt of support through direct payments. Sixty-eight percent of the parents felt the home and family support sometimes met the needs of their child and the remainder felt that it did not. Thirty-three percent of the children were in receipt of respite support, and most parents (84%) felt that respite support sometimes met the needs of their child. However, parents expressed the view that they often felt inferior when asking for support:

‘If we don’t know the questions to ask, then we don’t get any answers. Social services should be called secret services.’

‘When I asked for respite, Social worker refused as my child’s IQ was below average (i.e., too high). I highlighted that my child’s IQ was deteriorating.

In addition to statutory supports, 75% of the parents were seeking additional non-statutory support from their extended family and friends.

Education for the child diagnosed with ASD

Thirty-eight percent of the children attended special educational needs schools or classrooms and 22% attended mainstream schools. Forty-five percent of the parents of these children were satisfied that these schools met their child’s needs, while 48% of the parents felt that provision was only sometimes appropriate, and 6% felt that their child’s educational provision was never appropriate.

Twenty-three percent of the children attended schools that based their teaching explicitly on the science of ABA. Sixty-seven percent of the parents of these children were satisfied that their child’s educational provision was always appropriate, while 30% felt that that provision was sometimes appropriate. None of these parents were dissatisfied with provision.

Forty-eight percent of the children were in ABA-based home tuition programmes and 50% of the parents were personally involved in the delivery of these programmes. Sixty-three percent of the parents had received some form of training in ASD, ABA and/or other topics. Parents reported that the response of professionals to home programmes was not encouraging:

‘They don’t want to know, I think that as long as you want to do it yourself and you don’t want any assistance from them they are happy to let you do it.’

‘As ABA is not seen as a viable therapy with the educational boards and our health boards, I know my understanding is greater than their’s.’

‘I’ve discovered not to rely on professionals knowing what’s best for my child. In many areas, ABA being one of them, my knowledge by far outweighs theirs.’

Future needs

For the most part, parents and professionals agreed that increased support, information and training should be made available to parents of children diagnosed with ASD, although there were some subtle differences with regard to intervention methods and supports. Parents, more so than professionals, saw the need for advocacy and ABA-based training and schooling (Table 6).

Parents worried about present unmet needs and planning for the future:

‘Greater general and public awareness . . . Support in learning about your child’s condition.’
Table 6: Parental and professional views of future needs

<table>
<thead>
<tr>
<th>Future needs</th>
<th>Parental response</th>
<th>Professional response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information sharing</td>
<td>100%</td>
<td>98%</td>
</tr>
<tr>
<td>Professional advice</td>
<td>100%</td>
<td>96%</td>
</tr>
<tr>
<td>Parent training in ABA</td>
<td>100%</td>
<td>70%</td>
</tr>
<tr>
<td>ABA-based schools</td>
<td>99%</td>
<td>57%</td>
</tr>
<tr>
<td>Parent training in ASD</td>
<td>98%</td>
<td>95%</td>
</tr>
<tr>
<td>Multi-disciplinary support</td>
<td>98%</td>
<td>100%</td>
</tr>
<tr>
<td>Family advocate</td>
<td>97%</td>
<td>73%</td>
</tr>
<tr>
<td>Home &amp; respite support</td>
<td>93%</td>
<td>97%</td>
</tr>
<tr>
<td>Parental choice</td>
<td>90%</td>
<td>87%</td>
</tr>
</tbody>
</table>

‘Greater interaction, speech therapy, classroom assistants, should be more readily available with more money put in place for ABA schools.’

‘Professionals to communicate to me in the same manner and respect as they would interact in their dealings with other professionals.’

‘I worry who is going to look after her when I die. I worried about her deterioration in IQ levels, and I worry how all this affects her brothers’ behaviour.’

‘What happens to my child when we are no longer here to look after her?’

Discussion

Effective communication and collaboration between parents and teachers and other professionals is increasingly viewed as an important factor in the education and treatment of children diagnosed with ASD (Avdi, Griffin & Brough, 2000). However, little is known about similarities and differences of the views of parents and professionals with regard to the impact of living with a child diagnosed with ASD on parents and families (Stone & Rosenbaum, 2005). In the research reported here, 95 parents representing 100 children diagnosed with ASD and 67 multi-disciplinary professionals expressed their views regarding child behaviours; impact on family, parents and siblings; general supports and interventions; as well as future needs. A mixed-methods approach was used; detailed questionnaires supplied quantitative data and focus group discussions contributed qualitative data.

Previous research found that a reciprocal relationship existed between levels of parenting stress and child behaviour problems (Baker, McIntyre, Blacher, Crnic, Edelbrock & Low, 2003; Davis & Carter, 2008). This is worrying in light of Stone and Rosenbaum’s (2005) findings that discrepant views between teachers and parents can have implications for collaborative working and thus add further stress to parents. Our findings showed some similarities but some important discrepancies between parental and professional views. We found that professionals were more concerned with externalising behaviours, such as erratic sleep patterns, challenging or routine behaviours, and hyperactivity, while parents were more worried about behaviours more commonly associated with ASD, such as deficits in interaction, play, social skills and communication. Since any effective intervention has to begin with an agreed definition of the target behaviours (Cooper et al., 2007), these findings draw attention to the importance of professionals listening more carefully to parental concerns before deciding on educational strategies.

Furthermore, results indicate some discrepancy in views regarding the impact of a child diagnosed with ASD on family life. Professionals were somewhat more worried than parents regarding potential restrictions of the families’ social and community life, recreation and leisure, as well as holidays and excursions. Although the difference was relatively small, it may indicate that parents are more prepared to sacrifice social and leisure activities for their child’s education than many professionals give them credit for, an observation commonly made by parent educators (Keenan, 2006).

In fact, there were marked differences with regard to the view of impact of ASD on parents themselves. While professionals and parents largely agreed the parental activities that were affected, parents felt somewhat more strongly that employment and education were restricted, issues that relate to debates in other caregiver literature regarding opportunity cost (Fennell, 2005). With regard to social life, professionals worried more about restrictions on time with partner, family and other children. Parents were somewhat less concerned that these issues caused a problem.

According to GHQ-12 scores, the general psychological health of nearly half of the parents in this study (48%) caused concern and would require further psychological assessment. Using the GHQ-12 in this study allowed for direct comparisons with large-scale data from general population studies in the same locality, in which 17% had scored over the threshold in the GHQ-12 (ARK, 2006). As such, parents of children diagnosed with ASD are nearly three times as vulnerable to psychological ill health than the general population. The exact causes for these poor results are difficult to identify. However, it is possible that discrepancies between parental and professional views played a part. For example, while professionals realised that parents were stressed by lack of information, parents felt that professionals did not supply sufficient information to alleviate this stress. Regardless of whether or not this conclusion has any merit, the extent of the stress means that teachers, other professionals, and policymakers should consider these points carefully.

Parents and professional agreed by and large on the impact of having a sibling diagnosed with ASD. Siblings were thought to experience feelings of being neglected, treated unfairly and isolated from their peers. With regard to their sibling diagnosed with ASD, parents and professionals agreed that brother and sisters felt worry, anxiety and general sensitivity, but also at times resentment. Support and inclusion of siblings is important and parents were clear about the need for explicit training for siblings.
Findings reported here show a large discrepancy between present multi-disciplinary support (n = 3) and future requirements (n = 9). The significant correlation between the number of multi-disciplinary support workers and high GHQ-12 scores was intriguing. There is no doubt that the expertise from these professionals is invaluable, yet parents who received more multi-disciplinary support were more stressed than parents who received less multi-disciplinary support.

While it is possible that parents who were more stressed sought out more multi-disciplinary support, it is also possible that the diversity of multi-disciplinary support caused additional stress and that the key issue is the question of consistency and coherence of multi-disciplinary support. We now know that eclectic approaches are not as effective as behaviour analytic interventions (Howard, Sparkman, Cohen, Green & Stanislaw, 2005; Zachor, Ben-Itzchak, Rabinovich & Lahat, 2007). Therefore it would make sense, in terms of evidence-based practice, if all multi-disciplinary support professionals were trained in the science of behaviour analysis (Eikeseth, 2008) and therefore able to apply this knowledge to their own area of expertise, as is the case, for example, in the New England Centre for Children, Boston, USA (www.necc.org) and the Morningside Academy, Seattle, USA (http://www.morningsideacademy.org).

Parents and professionals agreed that there were times when families require general support such as family or respite services and that by and large these services were not sufficiently available. However, it is not only availability of services that was the issue here. Alongside the importance of a coherent approach by the multi-disciplinary team, it is important that family workers or respite support workers carry out interventions consistently. In other words, staff involved in family and respite support need to be trained to use a coherent scientific approach.

This is an interesting point when considered in conjunction with differences between parents’ and professionals’ preferred treatment choices. Parents clearly favoured ABA-based interventions and called for increased ABA-based training for themselves, professionals and siblings and there was a discrepancy between parents’ views and the views of professionals. It would be easy to conclude that this means that the sample of parents was biased from the start and therefore that these data are not reliable. However, in order to accurately interpret these findings, it is important to remember that the invitation to participate was open to all parents who have a child diagnosed with ASD in Northern Ireland and the Republic of Ireland and equally to all professionals who work in the area of ASD, and that no one who volunteered to take part and met these simple inclusion criteria was excluded.

Furthermore, one could think that these parents did not know ‘better’, that is, they did not know about other approaches. However, the dominant treatment approach used in pre-schools, schools and daycentres all over Northern Ireland and the Republic of Ireland is Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH; Schopler, Mesibov & Hearersey, 1995) and as part of the adjustment process, parents tend to do their own thorough research, for example, on the internet (Fleischmann, 2004, 2005). In fact as it turned out, due to lack of provision, the majority of children actually did not attend ABA-based schools/classrooms (77%) or have ABA-based home programmes (52%). It is, therefore, safe to say that parents were familiar with a range of different approaches and their benefits and shortfalls.

Of course, it is possible to argue that the questions were skewed towards leading parents to respond in a certain direction; however, as mentioned in the methods section, questions for parent and professionals were virtually the same and they included a range of selection choices as well as an ‘Other, please specify’ response option. Ultimately, the findings reported here have to be accepted as non-partisan; put simply, parents favoured ABA-based treatment approaches and their views are supported by an ever-growing body of effectiveness research, reported in meta-analysis (Eldevik, Hastings, Hughes, Jahr, Eikeseth & Cross, 2009), systematic reviews (Howlin, Magiati & Charman, 2009; Eikeseth, 2008; Perry, 2000), most recently by the National Standards Project of the National Autism Center (2009) and even the official journal of the American Academy of Pediatrics:

‘The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings.’

(Myers & Johnson, 2007, p. 1164)

What is much more disconcerting is that while, of course, there are many interventions that are used for children with ASD, it has been argued that many professionals may have allegiances to particular approaches and therefore that they may find it hard to believe that parents are so resolutely in favour of ABA-based interventions. It is likely though, that professionals’ treatment loyalties may be caused by unfamiliarity with or misinformation about ABA-based approaches rather than evidence that the approach they favour is in fact the most effective one in achieving desired outcomes for service users. This issue has been debated for quite some time (Freeman, 2003; Keenan, 2004; see, for example, The Scottish Government, 2009, for most recent example of misrepresentation of ABA; and UNBIAS, 2009, for parent initiative to get it corrected). Of course, this may be mainly due to lack of appropriate training opportunities; for example, to date in Ireland, most training in ABA is focused on parents’ skills and carried out in the voluntary sector, while approved training in the science of behaviour analysis for special educational needs teachers and other multi-disciplinary professionals remains relatively hard to find (BACB, 2009).

Given that ABA offers a scientific basis for education and treatment of socially relevant behaviours (Baer, Wolf & Risley, 1968) and is offered to families with children
diagnosed with ASD routinely in many parts of the world (Parry, 2002), findings reported here indicate the need for improvements in formal ABA-based training for professionals in Ireland. Of course, it is important that this training adheres to international standards (Shook, Johnston & Mellichamp, 2004).

In sum, there was agreement between professionals and parents on many issues, such as the need for future improvements with regard to interventions and social supports. There was also agreement about the need for better opportunities for inclusion, advocacy, and information flow between parents and professionals, especially with regard to services and financial planning. However, there was some discrepancy regarding perceptions of family needs, and while there was clear evidence of support from parents for the use of the scientific method as a basis for interventions, this was not shared indubitably by professionals.

Finally, Figure 2 is an artist’s expression that illustrates the ‘bumpy’ road for children diagnosed with ASD. It demonstrates that where comprehensive, integrated, evidence-based support systems are in place, the challenges inherent in a diagnosis of ASD can be overcome and children can be enabled to achieve their full potential.

Acknowledgements
This research was funded with a grant from the Royal Irish Academy’s Third Sector Research Programme under an initiative called ‘Developing Charity Strategy Through Partnership’. Reprint request to Dr Karola Dillenburger, School of Education, Queen’s University of Belfast, 69 University Street, Belfast, BT7 1HL, email: k.dillenburger@qub.ac.uk

References


*Journal of Applied Behavior Analysis (JABA)* (1969–2009) [online at: http://seab.envmed.rochester.edu/jaba/].


UNderstanding Behavioural Interventions for Autism in Scotland (UNBIAS) (2009) [online at http://sites.google.com/site/unbias2009/].


Address for correspondence:
Karola Dillenburger
Queen’s University Belfast
School of Education
69/71 University Street
Belfast BT7 1HL
Email: k.dillenburger@qub.ac.uk

Article submitted: October 2008
Accepted for publication: December 2009