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To cite this article: Karola Dillenburger PhD , Mickey Keenan PhD , Alvin Doherty BSc , Tony Byrne PhD & Stephen Gallagher PhD (2012) ABA-Based Programs for Children Diagnosed With Autism Spectrum Disorder: Parental and Professional Experiences at School and at Home, *Child & Family Behavior Therapy*, 34:2, 111-129, DOI: [10.1080/07317107.2012.684645](https://doi.org/10.1080/07317107.2012.684645)

To link to this article: <http://dx.doi.org/10.1080/07317107.2012.684645>



Published online: 07 Jun 2012.



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ABA-Based Programs for Children Diagnosed With Autism Spectrum Disorder: Parental and Professional Experiences at School and at Home

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Having a child diagnosed with Autism Spectrum Disorder (ASD) poses a range of challenges to families, many of which can be addressed through appropriate intervention. A study of parental (n = 95) and professional (n = 67) experiences was carried out in relation to two settings: (a) schools that provided intensive interventions based on the science of Applied Behavior Analysis (ABA), and (b) non-intensive ABA-based home programs. Results show that parents whose children attend ABA-based schools were generally more satisfied with their child's educational provision, monitoring procedures, and level of staff training, than parents who were not offered ABA-based education in schools.

Received 12 June 2010; revised 10 October 2010; accepted 25 October 2010.

This research was funded with a grant from the Royal Irish Academy's Third Sector Research Program under an initiative called "Developing Charity Strategy Through Partnership."

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KEYWORDS applied behavior analysis (ABA), autism spectrum disorder (ASD), home-tuition, parental experiences, school provision

Autism Spectrum Disorder (ASD) is the clinical term for specific complex developmental disorders described in the *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association (*DSM-IV-TR*, 2000) and the *International Classification of Diseases (ICD-10)* (World Health Organization, 2007). Childhood autism is defined by: “(a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behavior. In addition to these specific diagnostic features, a range of other nonspecific problems is common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression” (World Health Organization, 2007). Atypical autism and Asperger’s Syndrome include the same or similar characteristics but differ either in age of onset or intensity of symptoms. ASD is a spectrum disorder insofar as the complexity of atypical behavioral patterns are different for each child and range from those who are high functioning to those who are severely affected (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). Although estimates diverge somewhat, it is thought internationally that as many as 1:100 individuals may be affected by ASD (National Autistic Society [NAS], 2006). The estimated lifetime cost for an individual with ASD is US\$3.2 to US\$4.0 million, including cost for care and lost productivity (Jacobson, Mulick, & Green, 1998; Ganz, 2006).

Over the past 40 years, interventions based on the science of Applied Behavior Analysis (ABA) have been highly effective in mitigating some of the challenges and developing adaptive and social behaviors in many populations (Maurice, Green, & Luce, 1996; Swanson & Sachse-Lee, 2000) and are now internationally recognized as the most effective basis for treatment for children with ASD (Larsson, 2005; Perry & Condillac, 2003). A number of cost-benefit analyses have shown the savings that can be achieved by implementation of effective intensive behavioral interventions based in the science of behavior analysis. For example, in Ontario, Canada, Motiwala, Gupta, Lilly, Ungar, and Coyte (2006) estimated that annually CA\$45 million can be saved if ABA-based Intensive Behavioral Interventions are made available to all children diagnosed with ASD. In Texas, USA, Chasson, Harris, and Neely (2007) showed that a total of US\$208,500 per child could be saved for the education system; while in Pennsylvania, average savings per child were estimated even higher to range from US\$274,700 to US\$282,690. In fact, Jacobson et al. (1998) estimated over 10 years ago that the savings per

individual across their life span range from well over US\$1 million to over US\$2 million.

However, the scientific discipline of ABA has been widely misconstrued by advocates of other approaches and is frequently confused with a limited number of specific intervention modalities (Freeman, 2003); i.e., the acronym (ABA) frequently is wrongly used synonymous with “Lovaas treatment” or Discrete Trail Training (DTT). Other controversies center on treatment modalities and sources of evidence (Keenan & Dillenburger, 2010; Freeman, 2007). In the context of this article, it is important to understand that ABA is not merely a specific method of intervention for children diagnosed with ASD; instead, ABA is the applied branch of the science of behavior analysis that can be valuable regardless of the developmental level or ability of the behaving “organism” (Chiesa, 2005; Dillenburger & Keenan, 2009).

Provision of ABA-based education and treatment for children diagnosed with ASD remains inconsistent across the globe (Dillenburger, 2011; Simple Steps, 2012). For example, on the basis of the cost-benefit analyses mentioned above, Ontario, Canada has legislated to make these services available for all children diagnosed with ASD (Perry & Condillac, 2003). In the USA, presently 31 States have legislation to ensure that ABA-based interventions are viewed as medically necessary and paid for either through state funding or medical insurance, while in Europe there is no such legislation and government funded ABA-based service provision is not available in the United Kingdom (UK) or Ireland (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010).

As far as staff training is concerned, there is considerable inconsistency. Although the Minister of Education in Northern Ireland, among others, considers ABA as “one of many commercially available interventions” (Ruane, 2009) and suggested that short courses, sometimes only lasting a day or two, are sufficient training in ABA, the appropriate and internationally recognized qualification is achieved through the Behavior Analysis Certification Board’s (<http://www.bacb.com>) certification process that distinguishes between *Board Certified Behavior Analysts-Doctoral* (BCBA-D), *Board Certified Behavior Analysts* (BCBA; i.e., Masters-level graduate training), and *Board Certified assistant Behavior Analyst* (BCaBA; i.e., Undergraduate-level training). These levels of certification are based on appropriately approved university-based training and extensive supervised professional practice experience (supervised by Board Certified Behavior Analysts) and are not to be confused with certificates from non-regulated bodies.

Despite the fact that eclectic interventions have shown to be less effective than ABA-based interventions (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Zachor, Ben-Itzhak, Rabinovich, & Lahat, 2007), most special education schools in the UK and Ireland provide an eclectic mix of interventions (Report of Task Group on Autism, 2002), including Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH; Schopler, Mesibov, DeVillis, & Short, 1981) and sensory

integration therapy. Little is known about how parents and professional feel about this state of affairs.

This article is part of a larger study of parental and family needs. Findings regarding diagnosis and forward planning and the impact of ASD on family life are reported elsewhere (Keenan et al., 2010; Dillenburger et al., 2010).

The focus of this article is specifically on the experiences of parents and professionals with regard to educational provision for children diagnosed with ASD. At the center are the differences and similarities in experiences, expectations, and future needs between children who attend education institutions that base their teaching methods explicitly on the science of ABA (i.e., ABA-based schools) and those who are attending eclectic mixed-methods schools and receive ABA-based interventions in home programs, due to lack of availability of ABA-based schools in their locality. Despite the fact that subjective parental experiences and views are at times not in line with quantitative evidence of effectiveness (Boothe & Borrego, 2004), they are crucially important not only as an valuable measure of social validity (Dillenburger, Keenan, Gallagher, & McElhinney, 2004) but also because they do not always concur with the views expressed by professionals (Dillenburger et al., 2010). Parental confidence and, therefore, collaboration between parents and professionals can only be increased through exploration of, and effective response to, parental views (Lamb, 2009). This article aims to contribute to improved parental confidence by reporting parental views regarding ABA-based schools and home programs when compared with eclectic education provision. In common with other inductive research, there was no explicit a priori hypothesis on which this research was based, although, all things being equal, the null-hypothesis would propose that regardless of treatment delivery (home or school, eclectic or ABA-based) or relationship to the child (parental or professionals), views would be similar/the same.

METHOD

Ethical Considerations

The School of Psychology Research Ethics Committee (University of Ulster) granted ethical approval. Prior to participation, parents and professionals signed participant information sheets and consent forms.

Participants

Ninety-five parents/primary caregivers with parental responsibility (throughout this article referred to as “parents”) and 67 professionals participated in the study. Most of the parents had one child diagnosed with ASD; however, there were three sibling pairs, and one family had three children diagnosed with ASD. Eight of the parental participants were fathers. Parents were, on average, 40 years of age; most of the parents were married/cohabiting

(86%); nearly half of them were unemployed (48%); few were employed full-time (18%), while others were employed part-time (32%). Most of the parents had secondary level education (84%), while over a third had tertiary level education (39%).

Apart from the target child, 85% of the families had an average of two other children (mean age of 10 years); 14 of the siblings were diagnosed with ASD; and 6 were diagnosed otherwise—e.g., with ADHD, Bardet syndrome, cancer, psychiatric illness, dyspraxia, or language impairment.

Parents reported on a total of 100 children. The gender distribution of the children was 4:1 (boys:girls); their mean age was 8 years; 78% of the children had dual diagnoses, which meant that these children were diagnosed with ASD as well as intellectual disability (56%), physical and sensory disability (27%), or other concurrent diagnoses (28%). Most of the children (96%) lived at home with their biological parent(s), two of the children resided with their extended family, and two of the children were in foster care.

Sixty-seven professionals participated in the study. Eighty-eight percent of the professionals were female. Their professional qualifications included speech and language therapists (20%), ABA tutors (17%), social workers (15%), clinical psychologists (14%), occupational therapists (6%), autism therapists (4%), child ward managers, behavior support workers, educational psychologists, learning disability nurses (3% each), education director, teacher, health visitor, learning disability co-ordinator, paediatrician, behavior analyst, psychiatrist, and liaison offer (one each).

Of the professionals, 61% were employed in statutory settings, 9% by voluntary agencies, and 18% were employed by other organizations such as voluntary sector schools, Universities, or independent bodies. The mean duration of employment in their current post was over 6 years.

Research Instruments

Two questionnaires were specifically designed for the study. Both questionnaires are included in the American Psychological Association's PsycTESTS database (PsycINFO, L. Willis, personal communication, September 8, 2010). Questions were based on extensive discussion with parents and other stakeholders as well as literature research that identified the areas/topics to be included. Both questionnaires were pilot tested and found to address relevant and important questions in a socially valid format.

The Family Autism Needs Questionnaire (FAN-Q; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2007) was designed for parents and carers and included 69 questions related to family background and demographics, diagnosis and forward planning, educational provision, staff/parent training, finance, home and respite support, parental views and experiences, impact on family life, and assessment of future needs. Questions offered Likert-type

responses, yes/no responses, lists of responses with tick box choices, and space for additional comments.

The Professional Autism Needs Questionnaire (PAN-Q) was designed for professionals (Keenan et al., 2007) and included 29 questions related to professional background, training and experience, educational provision and ASD services, perception of parental and family situations, and professional assessment of future needs. Questions were designed in the same format as in the FAN-Q.

Focus group discussions were conducted to provide qualitative illustrations of the data.

Procedure

A gatekeeper approach was used to recruit participants; i.e., special educational needs schools, autism charities, and health and social care as well as education departments informed service users of the study. Subsequently, all volunteers for participation who met the inclusion criterion (i.e., being a parent of a child diagnosed with ASD) received a copy of the FAN-Q either by surface mail or email attachment. In total, 310 questionnaires were distributed to families, 95 FAN-Qs were returned (return rate 31%).

Using the same gatekeeper approach, ASD-related voluntary, education, and social services agencies circulated the PAN-Q to professionals who worked with children diagnosed with ASD; 67 completed questionnaires were returned.

Focus group discussions were conducted in a quiet hotel conference room and lasted one and a half hours. A total of 10 parents took part in focus group discussions. Discussions were tape-recorded, transcribed, and used as phenomenological illustrations of quantitative findings.

RESULTS

Schools and Educational Provision

Most of the professionals (82%) noted that parents of children on the autism spectrum experienced significant distress when trying to access appropriate education. Yet, over half of the parents learned about different educational provisions (ABA-based vs. eclectic models) from non-statutory services (53%) such as personal research, other parents of children with ASD, or friends and family, rather than being informed by professionals.

Some families lived close to an ABA-based special school in Ireland (27%), while most parents did not have ABA-based schools available in their locality (73%). Nearly half of the parents had considered moving house in order to avail themselves of ABA-based schooling (49%) and some parents actually had moved house to be closer to this kind of school provision (8%).

Most of the children attended primary or secondary school, with 25% of the children attending ABA-based schools, the remainder attending either eclectic special schools or mainstream schools. 2% of the children were in third level education and (2%) did not have any day service (Table 1).

While hours spent in class seemed to be very similar in eclectic, mainstream, and ABA-based schools, teacher:pupil ratio was more favorable in ABA-based schools. There were no ABA-based secondary schools due to the fact that children were expected to attend mainstream secondary schools. Table 2 shows the level of school attendance and teacher:pupil ratios in these schools.

Of parents whose children attended mainstream or eclectic special schools, 45% felt that their child's education was always appropriate; 48% of these parents felt that their child's education was only sometimes appropriate; 6% felt their child's education was never appropriate; and one parent was unsure of the appropriateness of their child's educational provision.

Of the parents whose child attended ABA-based schools, 67% felt their child's education was always appropriate; while 30% felt their child's education was sometimes appropriate. None of these parents felt their child's

TABLE 1 School Provision

	Pre-school		Primary		Secondary		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Eclectic special school	7	8	29	32	5	5	41	44
Mainstream school	3	3	19	20	5	5	27	29
ABA-based school*	8	9	17	18	—	—	25	27
Total	18	20	65	70	10	10	93	100

Note. ABA = Applied Behavior Analysis. Based on data for 93 children.

*Director qualified behavior analyst—trained to BCBA/PhD level.

TABLE 2 School Attendance

	Attendance (hours)	Teacher:pupil ratio
Eclectic special school and mainstream schools		
Preschool	17 (<i>SD</i> = 6.99)	1:2
Primary	26 (<i>SD</i> = 0.6.20)	1:2
Secondary	29 (<i>SD</i> = 5.57)	1:4
ABA-based schools*		
Preschool	19 (<i>SD</i> = 9.32)	1:1
Primary	26 (<i>SD</i> = 8.80)	1:1

Note. ABA = Applied Behavior Analysis. Based on data for 93 children.

*Director qualified behavior analyst—trained to BCBA/PhD level.

educational provisions were not appropriate, and one parent was unsure of the appropriateness of her child's education provision.

Monitoring Systems

In eclectic special and mainstream schools, educational provision was monitored in 80% of cases, the main monitoring method was qualitative, such as staff notes and commentaries (76%), while quantitative measures; i.e., graphs and observational charts, were used in only 14% of cases.

In ABA-based schools educational provision was monitored in 82% of cases and the main monitoring method was supervision by BCBA/PhD level qualified behavior analysts (60%) and using quantitative measures; i.e., graphs and observational charts (54%). Staff notes and commentaries were also used in 46% of cases.

Teacher Qualifications

Nearly half of the parents (47%) did not know the current qualifications of their child's teachers; 57% in mainstream and eclectic special schools and 22% in ABA-based schools. Most of the other parents thought that teachers were educated to degree level. There were no teachers who were qualified in ABA in mainstream and eclectic special schools; in ABA-based schools two teachers were Board Certified Behavior Analysts (<http://www.bacb.com>) nearly half of the parents (45%) expected teachers in the future to have some form of ABA training.

In the focus group, parents described the areas in which greater support is needed.

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

Schools need ABA provisions both in mainstream and special needs.
Training for teachers and classroom assistances in ABA.

Home Tuition Programs

Just over half of the participating children (53%) were in home tuition. The majority of the home tuition programs were based on ABA (Table 3).

The average age at which children commenced ABA-based home tuition programs was 4.5 years of age. The average length of ABA-based home tuition programs was 25 months.

The majority of parents had learned about ABA-based home tuition programs through personal research (33%); from other parents of children with ASD (30%); or from friends and family, charities, school seminars (24%). Few

TABLE 3 Home Tuition Program Approach, Based on 53 Responses

	n	%
ABA	48	91
ABA & TEACCH	4	8
TEACCH	1	1
Total	53	100

Note. ABA = Applied Behavior Analysis; TEACCH = Treatment and Education of Autistic and related Communication Handicapped Children (Schopler, Mesibov, DeVillis, & Short, 1981).

had heard about ABA-based home tuition programs from statutory bodies or professionals (13%).

The majority of the parents delivered ABA-based home tuition programs with the support of a trained behavior analyst (BCBA/PhD level) or an ABA-based home tutor (52%); only few of the parents were supported by school staff, extended family, or friends (4%). Some parents who carried out the program by themselves used support from a behavior analyst or a home tutor for occasional support but this was not their main way of delivering the program (29%).

Of the 25 ABA-based home programs that were supervised by behavior analysts, most involved only 2 hours supervision per month (96%), while small numbers involved 8 hours supervision by behavior analysts per week (4%). Most ABA-based home programs were non-intensive, lasting less than 10–20 hours per week and were carried out by ABA therapists (31%), by parents alone (31%), parents and home tutors together (17%), or other (6%), while some of the more intensive programs were conducted by both parents on a 24/7 basis (15%).

In the focus group discussions, parents expressed their experiences of delivering ABA-based home tuition programs and the effect it had on their child and their families.

Our child has become much more social, a real transition, ABA has had a wonderful impact on our lives – child is responding really well with the different strategies they put in place. Feel child's school should embrace ABA and apply it where it is needed/required.

ABA has made a huge change to our family life. We can now understand that our child is not just being badly behaved, we can make changes to a child's life to enable her to lead a more functional life.

The majority of the ABA-based home programs used one or more quantitative monitoring procedures such as graphs/observational charts (81%), tables (40%), notes/commentaries (69%), and/or supervision by a behavior analyst (81%). Some of the programs did not use any monitoring procures

(6%). Treatment integrity during home tuition was monitored mainly through competency-based assessment (74%), multiple-choice test (2%), or direct observation during program delivery (2%), or not monitored (12%).

Yet, only 16% of the parents reported that quantitative data; i.e., graphs or charts from home programs were always included in eclectic education or care plans, while 29% of the parents reported that these data were sometimes included. Forty-two percent of the parents reported that home program data were never included in eclectic education plans; 10% of parents did not know.

The majority of these parents felt that ABA programs were always specific and appropriate to their child's needs (89%), while some felt the ABA-based program was sometimes appropriate to their child's needs (9%), or were unsure (2%).

In the focus group discussions, parents talked about professional responses to parental delivery of ABA home tuition programs.

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.

Extremely awful, feel I am on trial when they visit the home.

Many of the participating parents had received some sort of training in ASD, ABA and/or other (63%). Most of these parents had experienced more than one training event, such as workshops and/or conferences and ABA training was more frequently used than generic ASD training (ratio 2:1). In the focus group discussions, parents discussed professional reactions to positive outcomes from ABA-based programs and the knowledge differential between parents and professionals.

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

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.

Professional Involvement in Home Tuition Programs

Nearly half of the professionals stated that they had been involved in home tuition programs (45%). Many of the professionals reported that they had received ASD related training (40%), while others stated that they had received training in ABA (39%); although most of this training was not accredited by professional bodies and took place in short courses, workshops, or conferences. Some of the professionals involved in home tuition programs

had not received any training (23%), others had received training in monitoring methods such as single-case designs, use of tables or figures, or notes or commentaries (27%).

Treatment integrity and skills of nearly half of the professionals who were involved in home programs were monitored and assessed using multiple methods—including written examination, multiple choice test, competency-based training, and viva (47%); however, many were not monitored or assessed (37%), data missing (16%).

The vast majority of the professionals stated that they required future training in ABA (91%), with nearly one quarter considering Master's level BACB accredited training most appropriate. In addition, over three quarters of the professionals stated that they also required further ASD training.

In the focus group discussions, parents expressed their experiences of seeking support from professionals to deliver ABA-based programs.

School informed me that I should carry on with ABA program at home, but they were not interested in bringing it into the school.

Asked health professionals and they said that was educational responsibility. So asked education and was told it was the responsibility of health.

Future Need for ABA-Based Educational Provision

Most of the parents who delivered ABA-based home programs felt that their children would require a home tuition program in the future (83%); some were undecided about requirements (11%); and some thought that their children did not require a home tuition program in the future (4%); data missing (2%). Parents also stated that they would welcome support from their child's school. Nearly all of the parents who require future home programs for their child stated that they had future training needs (98%).

Parents expressed that the overall need for future provision of services from qualified behavior analysts ($n = 46$) outweighed the present provision ($n = 16$) by nearly 3:1. The expressed future need of school support for home programs ($n = 14$) rose from present provision ($n = 1$) at a ratio of 14:1. Consequently, if more ABA-based school places were available, the needs of parents working alone with their child would reduce from 26 to 2 (ratio 13:1) and the need of both parents working with the child would reduce from 12 to 2 (ratio 6:1).

Application of ABA to Areas Other Than ASD

Parents felt that ABA was applicable to an average of seven different areas apart from ASD—including social skills, learning disabilities, school education, parenting skills, conduct disorders, sleep problems, self control,

aggression replacement treatment, stress, attention deficit hyperactivity, obsessional compulsive disorder, anxiety/phobias, anti-social behavior, mental health, sexual behaviors, weight control, addictions, paediatrics, marital therapy, and bereavement ($n = 670$ responses) and requested further information in an average of nine of these different areas ($n = 817$ responses).

Professionals felt that ABA was applicable to an average of six other areas ($n = 418$ responses) and requested further information for an average of three of these ($n = 204$ responses). Nearly, one quarter of the professionals thought more information would not be beneficial in any of the areas.

Future Requirements

Overall, parents stated that 65% of their children required different day services within the next 5 years. For most of these children, this included a change of school; however, it also included 26% of children who will no longer required schooling. Future needs for 9% of children were undecided.

Table 4 shows that collectively over the next 3–4 years, 89% of all future day service requirements for the children in this sample will be for schooling, while 11% of children and young people will require some form of adult day service provision. Given that the children in this study were already of school age, there was no need for pre-school places for them. This does not mean that there is no need in the general population. The need for ABA-based schools accounted for 52% of all future education requirements.

The following quotations from the focus group discussions reflect the experiences and challenges of the parents seeking education provisions for their child.

You need to be prepared to fight for everything. Not enough speech and language. Not enough integration, if your child is in a classroom with other ASD children, how are they meant to learn from peers?

TABLE 4 Future Needs for Education and Day Service of the Sample, Based on 65 Responses

	Pre-school		Primary		Secondary		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
ABA* school	2		23	35	9	14	34	52
Mainstream class	–	–	2	3	6	9	9	14
Special needs school	–	–	11	17	4	6	15	23
Adult services	–	–	–	–	–	–	7	11
Total	2	3	36	55	19	29	65	100

Note. ABA = Applied Behavior Analysis.

*Provided by qualified behavior analyst—trained to BCBA/PhD level.

Nightmare, don't know where to begin with this one, he's bright and at mainstream school but there aren't the provisions there for him. He is just expected to fit in and he can't. He's too bright for special school. Dreading transition to secondary school as there is nothing out there tailored to his needs, very concerned about how his mental health will suffer in secondary school.

Future Schooling and Educational Needs

Nearly all of the parents (99%) but only just over half of the professionals (57%) agreed that increased opportunities for ABA-specific schooling should be in place in the future for families of children with ASD. Ninety-nine percent of the parents and 68% of the professionals agreed that increased opportunities for general ABA training should be in place in the future for families of children with ASD. Most of the parents (94%) and again just over half of the professionals (57%) agreed that increased opportunities for general siblings training in ABA should be in place in the future.

The focus group discussions reflected the future needs identified by parents.

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

Training for teachers and classroom assistants in ABA.

DISCUSSION

In line with recommendations of the Mental Health and Learning Disability Review (Bamford & McClelland, 2006), a review of services and future needs of children on the autism spectrum was carried out. In total, 95 parents representing 100 children with ASD and 67 multi-disciplinary professionals took part. A mixed-methods approach was used; detailed questionnaires supplied quantitative data and a relatively small number of focus group discussions contributed qualitative data simply to illustrate the quantitative points made. Results indicate a severe lack of ABA-based educational provision and accredited staff training, that lead to a vacuum of appropriate statutory provision and forces parents to take the initiative to set up and deliver their own ABA-based home-programs.

This study did not report on treatment fidelity or intensity or explore the outcomes for the children; for interested readers, Larsson (2005) provides extensive references across 40 years of research regarding treatment outcomes. Those interested in meta-analyses of outcome data of ABA-based interventions are referred to Eldevik, Jahr, Eikeseth, Hastings, and Hughes (2010), Hart and Banda (2009), Swanson and Sachse-Lee (2000), or Virués-Ortega (2010); those interested in comparative studies between

ABA-based and eclectic approaches are referred to Dillenburger (2011), Howard et al. (2005), and Zachor et al. (2007).

This study explored more generally parental and professional involvement and experiences of ABA-based interventions at school and at home. Given the contentious nature of some of the discussions around autism interventions, it is important to note that the sample in this study was not selected by the researchers; rather, invitations to participate in this study were widely circulated to all relevant statutory, educational, and voluntary gate-keeper bodies and no one who wanted to take part was excluded. In common with any research based on informed consent, participation is self-select and a certain level of sample bias therefore cannot be excluded.

A number of issues arose from this research. It was apparent that most of the parents were informed about internationally recognized evidence-based interventions based on the science of ABA and aimed to ensure educational opportunities for their children accordingly (Dillenburger, 2012). This study also showed that professionals oftentimes were less well-informed than parents and were less open to new learning; i.e., parents were interested in new information about applications for ABA 3 times as much as professionals. This finding confirms, for example, the view of Charlene Green, Deputy Superintendent for the Clark County School District in Las Vegas, Nevada, who acknowledged: "We were doing what we thought was best at the time, but I learned that parents were more advanced than we were about knowing what was good for children with autism" (Winerman, 2008, para. 2).

As far as intervention delivery was concerned, a difference was apparent between parents who were able to avail of ABA-based schools due to the fact that they lived near such schools (Smyth, de Salvo, & Ardif, 2005) and parents who did not live in proximity to such schools. Despite the fact that children in the latter group attended either mainstream or eclectic special schools, parents chose to provide ABA-based programs for the majority of these children at home (Byrne & Byrne, 2005). Clearly, parents were choosing ABA-based methods over eclectic approaches, even where these services were not available free to them in schools.

The difference in uptake of ABA-based schooling and home tuition programs raises ethical as well as practical concerns, especially for children whose parents are unable to offer appropriate home tuition programs. Most parents whose children were in mainstream or eclectic special schools were not fully satisfied with the statutory education system (Mayerson, 2004). These findings confirm earlier studies (Dillenburger et al., 2004; Lamb, 2009). Solity (1991) identified that behavioral techniques oftentimes are merely grafted onto classroom management without the full understanding of the psychological principles that underpin these techniques. Not surprisingly, Lamb (2009) found a lack of parental confidence in eclectic special educational needs provision. In light of this, parents are forced to offer ABA-based interventions at home and pay for them themselves, which is obviously not possible in more deprived areas.

Not all the issues are resolved in ABA-based schools. In Ireland, for example, these schools were not fully integrated into statutory provision (in fact they were considered “projects” rather than schools) and only approximately 300 places were available for an estimated population of 10,910 children and young people with ASD (Irish Autism Action, 2005). Most recently, parents had applied to set up 11 new ABA-based schools for the over 350 children on the waiting lists, but these applications were not granted and now, in order to be recognized as special school and secure permanent funding, the majority of these schools in Ireland have become eclectic, mixed-model schools having to give up ABA as their guiding principle (O Fátharta, 2010). In addition, the sector requires all staff to hold a teacher qualification; since most qualified behavior analysts are not teachers and most teachers are not qualified in behavior analysis, ABA therapists are offered jobs as special needs assistants and have lost all teaching responsibilities.

One third of professionals stated that they had some training in ABA. The depth and level of this study was uncertain. However, it is likely that much of this training was delivered in non-accredited short courses, workshops, or conferences, since at the time of the study, there were no accredited ABA courses at local universities (<http://www.bacb.com>) and typically psychology, social work, education, etc., students receive at most one very general lecture about “behavioral approaches.”

Nearly all of the professional participants acknowledged that they required further ABA training. Indeed, professionals were less knowledgeable than parents about the range of applications of ABA and seemed to be much less interested in receiving information; parents were 3 times more interested in new information. This finding reflects a substantial problem in much of the autism literature (Humphrey & Parkinson, 2006), which leads many professionals to view ABA wrongly as only one specific treatment for autism rather than a science of behavior (Dillenburger & Keenan, 2009).

While parents were unanimous about the need for ABA-based interventions for their children, findings reported here substantiate that statutory bodies were not offering such training, “. . . when parents seek support for such a service the boards are dependent on external providers and have not taken steps as yet to become self-sufficient in this respect.” (Report of the Task Group on Autism, 2002, p. 37). In addition, many of the parents reported that detailed data regarding their children’s progress in home tuition programs were not included consistently in the eclectic educational plans of their children, despite the acknowledged need for improvements (O’Connor, Hartop, & McConkey, 2006).

CONCLUSION

While there were some differences, by-and-large there was general agreement between professionals and parents about the need for future

improvements in regard to education services for children diagnosed with ASD. As Charlene Green said, “If we can’t offer what’s best for a child, then what we’re offering isn’t enough” (Winerman, 2008, “Bridging the Research-to-Practice Gap,” para. 7). Based on this research, a balanced and inclusive approach to treatment selection should be grounded in parental participation and choice because ultimately parents are responsible for lifetime care of their children with ASD (Dillenburger & McKerr, 2009). In the past, the relationship between parents and government may have been passive; however, this is changing in a world that embraces new technologies (including behavioral technologies). “Instead of people saying, ‘Well, it’s the government’s job to fix that’ . . . are taking ownership and saying, ‘Hey, wait a minute. Government is us. We are government. So let’s take a responsibility and start changing things ourselves’” (C. Johnson, as cited in Sutter, 2009, para. 11).

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