Preschoolers with autism spectrum disorders: the impact on families and the supports available to them

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Introduction

In recent years, increasing number of children are being identified with autism spectrum disorders (ASD) and this is happening at a younger age (Fombonne, 2005). This creates a new population of preschool children and families for whom support services are likely to be needed. To date, there is limited information available on the characteristics of these children and their family backgrounds.

Instead, the primary focus of much past research and practice initiatives has been on assessment and diagnosis of the child with a continuing debate on the most effective
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approaches to intervention (Francis, 2005; Webster, Feiler, & Webster, 2003). Charman and Clare (2005) noted the dearth of research into the effect on families and provision of services. This is in contrast with the family-centred research that has been undertaken with children who have other developmental disabilities (Guralnick, 2005). Moreover, there is a growing consensus on the form and function of services provided to families who have children with special needs, especially in the preschool years (HM Government, 2004; Department of Health, 2004).

A basic premise is that these services need to be tailored to the individual needs of children and of their families. However, broader service planning requires information to be available on the characteristics and needs of the particular client group which is presently lacking. The studies that have focussed on families with preschoolers who have ASD have used small samples (e.g. Christie & Chandler, 2002; Mansell & Morris, 2004; Whitaker, 2002). Hence, this study aimed to recruit a large representative sample of families whose children had a confirmed diagnosis of ASD and who were less than five years of age. The research objectives were:

● to describe the demographic characteristics of preschoolers and their families;
● to discover parental perceptions of the child’s difficulties;
● to identify the impact the child has on family life;
● to outline the supports available to families and those they would like to have.

Procedure

Sample

All families whose child had been recently diagnosed at two community-based specialist clinics, serving two defined geographical areas (total population of 480,000), were offered the opportunity to participate in the project. Each clinic had a multi-disciplinary team consisting of a community paediatrician, a psychologist and a speech and language therapist. ICD-10 criteria were used in making a diagnosis of ASD.

The recruitment of parents took place over a three-year period. The final sample consisted of 104 self-selected parents with a child aged under five years of age at the time of the interview. The number of refusals was small although no accurate count was kept. However, while this sample was representative of children diagnosed at these two clinics, they may not reflect the families seen by other clinics.

Mothers were the sole informants in 74 families (71%); both parents were present in 26 families (25%) and fathers were informants in four families (4%).

Method

Home-based interviews were conducted with the parents; each lasting around 90 minutes. These were undertaken by University researchers or project personnel with experience of preschool children with ASD funded by Autism NI. They mostly had no involvement with the clinics or ongoing service provision.
A structured interview schedule was used to ensure a standardised approach across all the interviewers. This consisted of a mix of open and closed questions that had been developed in line with the study aims and pilot tested with 10 families. Interviewers noted parental responses verbatim as pilot testing had indicated a reluctance among parents for the interviews to be audio-taped.

In addition three scales were completed with some or all of the parents.

1. **Vineland Adaptive Behaviour Scale** (Sparrow, Balla, & Cicchetti, 1984): This scale contains 297 items grouped into four domains: communication, daily living skills, socialisation and motor skills. Items are presented in developmental order within each domain and parental ratings are used to determine the total subscore within each domain as well as an overall score for adaptive behaviours. These can be converted to standard scores (Mean 100) using age norms provided in the Test Manual. Based on a nationally representative sample in the USA of children aged 2 to 5 ($n = 600$), reliabilities for each of the four domains range from 0.78 to 0.92. (Sparrow et al., 1984).

2. **Gilliam Autism Rating Scale** (Gilliam, 2001): This scale assesses particular features of autism based on parental reports. Behaviours are grouped into four subscales: (i) Stereotyped Behaviours, (ii) Communication, (iii) Social Interaction and (iv) Developmental Disturbances. Coefficients of reliability (internal consistency and test-retest) for the subscales and entire test range from 0.81 to 0.88. Summary scores can be derived in terms of percentiles and an autism quotient which is deemed to be the most reliable of all the scores generated on this scale. A score 90 and above is deemed to be indicative of autism with scores in excess of 111 highly indicative. However, a subsequent validation study by South et al. (2002) suggested that lower quotient scores are indicative of children having ASD.

3. **Questionnaire on Resources and Stress (QRS-F)** (Friedrich, Greenberg, & Crnic, 1983): This scale was specifically designed to measure the impact of a developmentally delayed or ‘mentally retarded’ child on the family and has been widely used in family research (Scott, Sexton, Thompson, Wood, 1989) and with parents of ASD children (Honey, Hastings, & McConachie, 2005). The questionnaire consists of two main subscales labelled: Parent and family problems arising from the child with the disability (20 items in all) and pessimism (11 items covering the child’s prospects of achieving self-sufficiency). The total score combines both scales.

**Ethical issues**

Formal ethical approval was not sought as the study was deemed to be a service audit that was undertaken in conjunction with the clinics. However, a Steering Group consisting of service representatives and autism specialists drawn from throughout Northern Ireland vetted the procedures used to gain informed consent from parents. The reasons for gathering the information were explained and assurances of confidentiality were given. Parents were made aware that they could refuse to answer any
question or to terminate their participation at any time without affecting the services they or their child received. An information sheet containing contact names was left with the families.

Results

Profile of families

Five families withheld their personal details. The remaining 99 families contained 17 (17%) single parent families in which 16 mothers and 1 father were the primary carers. In the 82 two-parent families (83%); mothers were nominated as the primary carer in 68 households (69%); 9 (9%) reported that it was both parents, 4 families (4%) had fathers as the primary carer and in one family (1%), the grandparent was the main carer.

In 66 of the 82 two-parent families (81%) there was a wage earner but in the 17 single parent families, only 5 (29%) had a wage earner; a statistically significant difference ($\chi^2 = 18.1; df = 1; p < 0.001$). In all, 75 families (76%) owned their own home while 18 (18%) lived in rented accommodation and 6 (6%) lived with their parents. Single parents were less likely to own their own homes ($\chi^2 = 13.4; df = 1; p < 0.001$).

The main carers were mostly aged 30–39 ($n = 60; 61\%$), with 28 (28%) under the age of 30 and 11 (11%) carers between the ages of 40–49. Most carers ($n = 53; 54\%$) were reported to have O Levels/GCSEs, 33 (33%) had attended higher education but 13 (13%) left school at 15. In regard to ethnicity 103 (99%) carers were white, but one carer classed himself as ‘other’.

The child with ASD was most commonly the youngest in the family ($n = 58; 56\%$) with 18 (18%) middle children and 11 (11%) the eldest. In addition, 16 (16%) were only children including a set of female twins. In 17 (17%) families there was only 1 child at home while 48 families (48%) had two children and 46 (46%) three or more children.

However, 23 parents (26% of those with other children) reported that another child in the family had experienced similar problems which included autism, speech and language delays, learning difficulties and epilepsy. Moreover, 33 parents (33%) mentioned that other members of the extended family had similar problems. These included learning difficulties, ‘mental handicap’, epilepsy, speech and language problems, dyslexia as well as autism and Asperger’s. Of the 104 families, 11 (11%) had both another child and a relative with similar problems, but 56 (54%) had neither.

Profile of the children

Of the 104 children with a diagnosis of ASD, 95 (91%) were male and 9 (9%) were female. In all, 32 (31%) were 2 years old at the time of the interview; 46 (44%) were aged 3 and 26 (25%) were 4 years of age. Overall 17 children (16%) were reported to have a sensory impairment, 14 (14%) had epilepsy and 2 (2%) had a physical impairment. However, only one child (1%) had both epilepsy and a sensory impairment.
Table 1 presents the descriptive statistics for children on the Vineland Adaptive Behaviour Scales (Sparrow et al., 1984). All the mean scores were lower than the standard score of 100. However, the children scored significantly higher on the motor skills subscale (although this had the widest range of scores) than they did on socialisation and daily living skills which in turn were significantly higher than scores on the communication domain (paired t-tests; $p < 0.001$).

A subgroup of 61 children (59%) were also rated by mothers on the Gilliam Autism Rating Scale (1995). A score 90 and above is deemed to be indicative of autism with scores in excess of 111 highly indicative. A subsequent validation study by South et al. (2002) suggested that lower quotient scores were indicative of children having ASD and indeed the mean quotient for the present sample was 87.3 (SD: 11.6; range 57–115). The correlations between these scores and the subscales of the Vineland were low ($r = 0.239–0.361$) which suggests that they were measuring different facets of the child’s behaviour. Again the wide range of scores is noteworthy.

**Parental perceptions of child’s difficulties**

A listing of nine features of ASD was drawn up from the Guidelines for Parents produced by the National Autistic Society (updated 2006). As Table 2 summarises, parents were asked to indicate those that were a problem from their child; those that had been a problem but were getting better and those that never had been a problem. (The latter have been omitted from the Table but the percentages can be imputed from the data provided.)

The most commonly mentioned problems—language, play and relating to others—broadly reflect the classic triad of impairments that is associated with these conditions. Equally, it should be noted that not all the children showed even the most commonly defined features of ASD.

However, mothers reported combinations of problems, with an average of 5.1 (SD: 2.3) problems per child. A Discriminant Analysis was used to discover the characteristics of those parents reporting a greater number of problems. This analysis included all the relevant child and family characteristics noted but only two significant predictors were found (Wilk’s $\lambda = 0.805; \chi^2 = 21.1; df = 2; p < 0.001$). They were children who had had significantly lower scores on the communications subscale of the Vineland (mean 59.8 compared to mean 65.7 for children with fewer problems). Also, parents who had lower educational attainments were significantly more likely to

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<td>62.9</td>
<td>9.97</td>
<td>43–95</td>
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<tr>
<td>Daily living</td>
<td>65.8</td>
<td>10.03</td>
<td>43–108</td>
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<tr>
<td>Socialisation</td>
<td>65.1</td>
<td>9.61</td>
<td>47–97</td>
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<tr>
<td>Motor skills</td>
<td>76.5</td>
<td>16.7</td>
<td>50–115</td>
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<tr>
<td>Overall adaptive behaviour</td>
<td>62.5</td>
<td>9.94</td>
<td>33–97</td>
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report five or more problems (61%) than those with ‘A’ levels or higher education (29% of whom reported five or more problems).

When parents were asked to indicate the problems they found most difficulty in dealing with, 55 (53%) mentioned speech and communication. The next most frequently mentioned were temper tantrums \( (n = 22; 21\%) \) and aggressive behaviours \( (n = 21; 20\%) \) along with the child’s non-compliance \( (n = 10; 10\%) \). In all, 12 parents \( (12\%) \) mentioned the child’s need for routine and the fears and anxiety that new experiences generated and 8 \( (8\%) \) commented on the lack of social interaction. Among the other difficulties mentioned by two to six parents were sleep problems, no sense of danger—and the need for constant supervision, screaming, difficulties with eating, toilet training, attention-seeking; short attention span and self-injurious behaviour.

These quotes from parents illustrate the range of difficulties, they are faced with:

‘When he wants something and he can’t tell you what it is. If given things he doesn’t like—throws object and goes into an inconsolable tantrum. There’s tantrums too if he’s expecting to go out in the morning and he doesn’t go. He’s obsessive with video and has problems with making choices’ (59).

When we are out and about—he runs away in shops and does not come back when he’s called. He doesn’t like things finishing—throws tantrum when leaving the playgroup. He’s developed little routines of his own (49).

He’s not communicating. He’s frustrated by no one understanding. Other children treat him like a baby (23).

His lack of understanding and communication. The fact that things have to be done in a certain way—his rigidity. Sleeping’s a problem too (88).

Not being able to understand him and his needs. What causes his fear and anguish? What caused him to deteriorate? (101).

Only small proportions of children were seen to be improving as Table 2 indicates. Indeed nearly 50\% \( (n = 49) \) of parents reported no improvements on any of the problems listed. As before, a ‘discriminant analysis’ was again used to identify the
distinguishing characteristics of parents who reported no improvements and three significant predictors were found (Wilk’s $\lambda = 0.781; \chi^2 = 22.1; df = 3; p < 0.001$). These tended to be parents of two year olds (69% reported no improvements) compared to three year olds (48%) and four year olds (27%) ($\chi^2 = 10.1; df = 2; p < 0.01$). In addition children with lower scores on the communications subscale of the Vineland (mean 60.5) were also more likely to be seen as not progressing (compared to mean score of 65.1 of those who were improving) and also those families living in rented accommodation (67% reported no progress compared to 40% among house owners).

Impact on family

Parents were asked to describe the impact the child had had on the family. Their comments were analysed thematically and cross-checked by two raters. Three parents felt there were no real problems and another six said they adopted a positive outlook with comments such as: ‘I was initially worried but we’re getting on with it. I don’t think about the future’. (62)

However, most parents named one or more impacts that the child had on them and the family and these are summarised in Table 3. The two most commonly mentioned were the stresses and strains they experienced as parents along with the social restrictions the child placed on the family. Example comments were as follows.

Continual stress and strain. It stops you from doing things. You’ve to put him first—we only go to places where he likes. (2)

Constant worry. No time with husband. Not fair on (sister)—he gets more attention. I’m having to give up work—but that’ll bring financial stress. (29)

We’re devastated—it’s a life long disability that won’t go away but hopefully he’ll learn. I worry about friends and relationships. Is he going to be independent? (56)

It’s stops us from doing things we want to do. We’ve nobody to mind him. Worries us who will look after him? What school will he attend, will he have a wife, family. (50)

Socially restricted as a couple and with other children. Could be long term dependency. Unsure how other children cope—embarrassed in front of friends—do not get the same treatment. (25)

A lot of stress on the family. It’s been a hard year trying to come to terms with it and concerns about the future. (112)

Exhausting. It’s a strain on us emotionally and on our marriage. We can’t go to places. Constant supervision. (113)

I hate having to tell people, I’m embarrassed and hurt. (4)

Parents were asked further about any restrictions they experienced on socialising with the child. Overall, 29% felt they could not enjoy outings together as a family, 27% could not take the child to other people’s homes; 23% were not able to leave the child with a childminder/babysitter and 17% could not go shopping with the child. In all, 54 families (51%) experienced one or more of these restrictions. A discriminant analysis
identified three significant predictors (Wilk’s $\lambda = 0.766$; $\chi^2 = 25.2$; $df = 3$; $p < 0.001$). Those most likely to experience restrictions were families who did not own their homes; whose children had behavioural difficulties and whose carers had lower educational attainments.

Parents also completed the Questionnaire on Resources and Stress and on the total scale their scores ranged from 0–28 (maximum) with a mean score of 13.3 (SD: 7.4) which suggests wide variation in how parents respond to having a child with ASD. These scores were somewhat lower than those reported by Hastings and Johnson (2001) with a sample of 141 families with children aged 5 years on average and who were involved in behavioural intervention programmes. However, discriminant analysis identified two significant predictors of parents scoring above the median (Wilk’s $\lambda = 0.861$; $\chi^2 = 12.3$; $df = 2$; $p < 0.005$). They were families who experienced greater social restrictions as described earlier and those families that had a wage earner in them. Hence, higher stress levels were found among families with this combination of characteristics.

Supports available to families. Parents were asked about the support they received from family and friends. This most commonly came from their family ($n = 63$: 61%) and less so from friends ($n = 33$: 32%), neighbours ($n = 12$: 12%) and from church members ($n = 6$: 6%). However, 34 parents (33%) reported that they had no support from any of these sources. No significant relationships were found between these supports and any of the child and parental variables noted above.

Similarly, parents reported on their contact with professionals during the previous 12 months and whether or not they found the contact helpful to them. Table 4 summarises the responses and identifies speech and language therapists as being the most common contact. Surprisingly, the age of the child made no significant difference to professional contacts except that families of four-year olds had more contact with educational psychologists. Overall, the mean number of professionals seen was 4.4 (SD: 1.4; range 0–7). However, the total number of professionals in contact with the family was not predicted by child or family characteristics. In particular, access to

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<th>Impact</th>
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<tr>
<td>Continual stress, strain, lack of sleep</td>
<td>34</td>
<td>39</td>
</tr>
<tr>
<td>Social limitations in family and community</td>
<td>27</td>
<td>31</td>
</tr>
<tr>
<td>Worry about the future</td>
<td>18</td>
<td>20</td>
</tr>
<tr>
<td>Other children in family miss out, treated differently</td>
<td>16</td>
<td>18</td>
</tr>
<tr>
<td>Constant supervision and having to plan ahead</td>
<td>8</td>
<td>9</td>
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<tr>
<td>Financial worries – may have to give up job</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Embarrassment, hurt, devastated</td>
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Note: Parents could report more than one type of impact.
supports was not related to the severity of the child’s problems, parental perceptions of the child improving or their reported levels of stress.

In all, 15 families (14%) reported that were regularly using ‘special treatments or approaches’ for ASD and these included applied behaviour analysis (ABA), visual communication strategies (treatment and education of autistic and related communication disorders [TEACCH]) and special diet, or a mix of them.

In all, 49 parents (47%) reported having contact with families who had similar children to theirs. The main benefits they gained from this contact were getting advice, information and a better understanding of their child (mentioned by 14 parents); feeling supported (mentioned by 11); having someone to talk to (8 mentions); not feeling alone (6 mentions) and opportunity to socialise (5 mentions).

A further, 33 parents (32%) who had no contact with other families stated they would like this and gave similar reasons to those noted above. However, 22 families (21%) did not wish to have contact and they gave a number of reasons including a desire for privacy, not having the time, not being ready and feeling that it would not help. There were no significant relationships between contact with families and any of the predictor variables.

Improvements to services. The majority of parents (n = 82: 79%) mentioned one or more ways in which education, health and social services could be of benefit to them. Two main themes were apparent in their responses. First, improved access to services of which the most frequently mentioned was speech and language therapy (n = 18 mentions) followed by more respite provision (n = 11); availability of specialist playgroups and schools (n = 8); more places in playgroups and nursery schools (n = 7) and the provision of learning support assistants (n = 7); home teaching services (n = 5) and better access to Occupational Therapy (n = 5).

The second theme related to service processes in which the availability of more information, support and advice to parents featured (n = 20 mentions) along with improved knowledge, communication and co-ordination among professionals (n = 10) and the need for prompt follow-up after a diagnosis is given (n = 6).
Parents were also asked to specify topics that puzzled them about their child and on which they would like to have further information. In all, 70 parents (67%) mentioned one or more topics. The two dominant themes were coping with the child’s behaviours \((n = 25)\) and the causes of the ASD or aspects of it \((n = 23)\). However, three parents commented on the difficulty they had encountered on applying general information to their child. For example: ‘We sent away for information and got some on the Internet. Quite confusing as the spectrum is so wide it is hard to find a lot of stuff specific to your own individual problems.’

Future school attendance. In all, 88 parents were asked an open question about their views on future school placements. The majority \((n = 63; 72\%)\) favoured a mainstream school placement with a learning support assistant and gave as reasons the fact that they had attended that school, siblings went there, it was close to home and the school had already taken children with ASD. Twenty families mentioned either a placement in a special school \((n = 15; 17\%)\) or in a special unit attached to a mainstream school \((n = 5; 6\%)\) and gave as reasons their child’s inability to cope with mainstream schooling; the school’s reputation in managing children with ASD and small class sizes. Two parents (2%) wished for a school specifically for children with ASD and three parents were undecided between special and mainstream provision.

Discriminant Analyses identified only one significant relationship with choice of schooling. Parents of children who were rated higher on the Daily Living Skills subscale of the Vineland test were more likely to express a preference for mainstream schooling \((\text{Wilk’s } \lambda = 0.905; \chi^2 = 5.0: df = 1; p < 0.05)\).

Discussion

Although this study involved a large sample of preschool children with ASD, one significant limitation must be noted. The sample was confined to families who been referred to specialist clinics and who had received a diagnosis. This leaves an indeterminate number of children who may have an ASD but whose families have not sought help or community service staff have not referred them for assessment. The characteristics of this group of children and families may differ from those reported here.

All the families who did participate in the study had one thing in common: a preschool child with a diagnosis of ASD. Thereafter, the families varied in terms of their characteristics with a sizable proportion of single mothers within the sample (17%). However, this is lower than the proportion of single parents in Northern Ireland with dependent children which was 31% as reported in the 2001 Census. Also more of the single parents in this sample lived in rented accommodation and were not wage earners.

Most of the children with ASD had older siblings and over one quarter of them were reported to have similar problems and for a third of families, similar difficulties
were also found in the wider family circle. This confirms previous suggestions of genetic linkages with these conditions (Muhle, Trentacoste, & Rapin, 2004). It also constitutes a further pressure on families.

Equally, the extent of the child’s difficulties varied greatly; from those who were mildly affected to those with marked problems. Even the most common indictors of ASD were not reported by parents in all children and wide variations existed in their standard scales of development and autism symptomology. This illustrates the difficulties that surround assigning a diagnosis of ASD and it could be that certain children were misclassified within this sample (Charman & Baird, 2002). But even if that is so, it does not negate the parents’ concerns about their child’s difficulties and the supports they need to cope with them. If these happen to be the same supports and management strategies required by children who definitively have an ASD, then perhaps the allocation of this label is better seen as a signifier of service needs rather than a condition within the child. This is in keeping with evolving notions of disability and impairments promoted by the World Health Organisation (Bickenbach, Chatterji, Badley, & Ustin, 1999).

A sizeable number of the children were assessed formally as having ASD before or around three years of age which is in keeping with aspirations in policy reports toward earlier identification, although in many areas further service improvements are needed if all children are to be identified before three years of age (National Autistic Society, 2003). Indeed in a parallel study to this one, 90% of families had identified their child’s problems prior to two years of age (McConkey, Truesdale-Kennedy, & Cassidy, 2007).

The main focus of service provision centred on speech and language therapy although families had contact with an average of four of the professionals listed in the interview schedule but this may be an undercount as other professional contacts were not included in the pro forma. This raises issues around multi-disciplinary working and level of expertise in ASD among the various professionals; an issue that some parents commented on (Law, Hanna, King, Hurley, King, Kertoy, & Rosenbaum, 2003). Moreover, very few parents reported that they were using any specific therapeutic programmes that have been developed for preschoolers with ASD, such as ABA, TEACCH or Hanen (Frances, 2005). Again, most parents are dependent on professionals informing them about these options.

Surprisingly, no correlates were found between the type and number of professional contacts with a child’s difficulties or family characteristics. This suggests that those children and families who face greater problems were no more likely than others to receive professional supports.

Not surprisingly, families wanted more services of which speech and language therapy was the most frequently mentioned but a wish for respite and preschool placements was also common. Future studies could usefully explore the targeting of various professional supports and their impact on families whereas to date attention has focussed mainly on therapeutic interventions (Charman & Clare, 2004). Alternatively, access to a single, specialist support worker seems to be welcomed by families (Whitaker, 2002).
Likewise, greater attention might be paid to the impact on parents of having a child with ASD. This study suggests wide variation among parents in how they react but with few indications as to the reasons for the variation. The stresses and strains of coping with the child’s behaviour problems and of the social limitations they experienced as a family were the most commonly mentioned and there were indications that these were found in certain families more so than were others. However, the support available to families either from professionals or informally from family and friends, or from other parents who had a child with ASD, was not associated with reduced stress in this sample of parents as has been found in studies with families whose children had ASD (Hastings, & Johnson, 2001) or who have other developmental problems (Dempsey & Dunst, 2004). However, a better test of the efficacy of parental support would be a deliberate attempt to provide this to families alongside a focus on the remediating the child’s difficulties. Certainly this would be in keeping with family-centred approaches that are now advocated for preschool interventions (Department of Health, 2004).

Finally, the parents appeared to be striving towards having an ordinary life for their child. This is most evident not only in their views on future school placements but also in their inclusion of the child in a range of social and community activities. Similar aspirations about schooling have been reported in other studies with ASD children (Jindal-Snape, Douglas, Topping, Kerr, & Smith, 2005) and they are shared by parents whose children have other special educational needs (McConkey, O’Connor, Hartop, & Madden, 2004). This highlights the need to prepare personnel in mainstream educational settings—both preschool, nursery and primary sectors—to adapt the curriculum and teaching methods to meet the needs of children with ASD (Jordan, 2005). Resources for doing this are now available (Crawford, Doherty, Crozier, Bhurgri, & McConkey, 2003).

Conclusions

In conclusion, the findings highlight the need for strategic planning of services for preschoolers with ASD that are family-focussed and which offer practical guidance and support to children and to their parents. Although, much of this support is similar to that required by other children with special educational needs, specific features have been identified, notably in behaviour management, communication and social relationships. As others have argued, ongoing evaluation of these services is vital for evidence-based practice to develop (Webster et al., 2003).

Acknowledgements

This research was supported by a grant to Autism NI (formerly known as PAPA) from the Department of Health, Social Services and Public Safety and by special project funding from the Southern Health and Social Services Board. We are grateful to Elaine McGreevy, Michaela Reavy, Sue MacLeod, Nova Workman and Florence Trotter for assistance with data collection. Roy McConkey’s post is jointly funded with the Eastern Health and Social Services Board.
References


