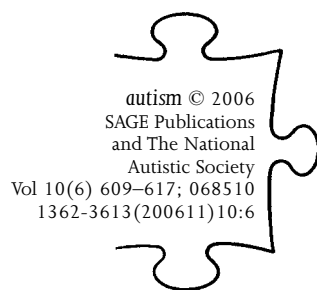


Living with ASD

How do children and their parents assess their difficulties with social interaction and understanding?



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ABSTRACT Social interaction and understanding in autistic spectrum disorder (ASD) are key areas of concern to practitioners and researchers alike. However, there is a relative lack of information about the skills and competencies of children and young people with ASD who access ordinary community facilities including mainstream education. In particular, contributions by parents and their children have been under-utilized. Using two structured questionnaires, 19 children with ASD reported difficulties with social skills including social engagement and temper management and also reported difficulties with social competence, affecting both friendships and peer relationships. Parents rated the children's social skill and competence as significantly worse than did the children themselves, but there was considerable agreement about the areas that were problematic. Using an informal measure to highlight their children's difficulties, parents raised issues relating to conversation skills, social emotional reciprocity and peer relationships. The implications for assessment and intervention are discussed.

KEYWORDS
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Introduction

For individuals with autistic spectrum disorder (ASD), difficulties with social interaction have been postulated to be both central to (e.g. Fein et al., 1986) and the most handicapping area of the triad of impairment (Rogers, 2000). However, although there have been advances for a decade or more in refining and describing key social interaction deficits (Volkmar et al., 1997), there is only limited research describing how high-functioning individuals interact with their peers (Bauminger, 2002). Similarly relatively little

is known about the way the social impairment manifests itself in individuals who can access mainstream education. The current study aims to start to address this gap by examining the social skills and competence of individuals with ASD in mainstream settings using both parent and self-report.

Spence (2002) proposes that in order to understand the nature and consequence of social impairments, it is crucial to differentiate between 'social skills' (i.e. the core abilities such as eye contact that allow individuals to engage in interactions) and 'social competence' (i.e. the outcome of an individual's interaction with others, such as friendships). The social skill difficulties of individuals with ASD are reasonably well understood (see Carter et al., 2005, for a review) but only a few studies have examined in detail the social competence of children with ASD who are in mainstream settings. These demonstrate that, while such children and young people are able to make and sustain friends, the number of friends is reduced compared to typical children (Koning and Magill-Evans, 2001), parents are frequently involved in the process of making friends (Bauminger and Kasari, 2001) and negative experiences such as shunning or bullying (Little, 2002) and loneliness (Bauminger et al., 2003) are common.

In the current study, social skills and competence are explored using self-report as well as parent report for two main reasons. First, the views of young people with ASD are rarely considered and few instruments are available to examine the way individuals conduct and understand their relationships. Second, there is typically a discrepancy between symptoms and/or difficulties as reported by parents and children. Parents commonly under-report symptoms of internalizing disorders such as anxiety (e.g. Mesman and Coots, 2000), while discrepancies are less common in perception of overt behavioural problems (Wrobel and Lachar, 1998). Indeed parents may report greater levels of difficulty than their children in such areas. Individuals with Asperger syndrome have been found to report fewer difficulties than their parents (Koning and Magill-Evans, 2001) but may nonetheless remain acutely aware of the outcome of these difficulties (Pomeroy, 1998). This issue is further explored here.

The current paper uses data derived from the assessment of children and young people with ASD who participated in community-based group work to develop social interaction and understanding (see Dunlop et al., 2002). The efficacy of six such groups, involving 46 children and young people, was examined using a mixture of formal and informal measures. Data from the pre-group assessment are reported here. The first objective is to identify the social skills and competence reported by children and young people with ASD in their normal community setting, and to compare their own assessments with those reported by their parents using standardized measures. Second, using a measure designed for the intervention study,

parents identified the key areas of social interaction and understanding that were problematic for their children.

Method

Participants

Study participants were recruited as part of a project in the West of Scotland to evaluate the use of group work to develop social interaction and understanding in children and young people with ASD (see Dunlop et al., 2002). The children and young people who took part in the social interaction and understanding groups were referred to the project by education, psychological services or health services because of significant impairments in social interaction.

The names of 51 children and young people aged between 6½ and 15 years were put forward to attend a social interaction and understanding group, of whom 46 ultimately attended one of six groups. These 51 children and young people represented all those in mainstream education or known to health services in the appropriate age groups and who had significant social communication difficulties.

The data reported here are from 19 families where both parents and children completed the formal pre-group measures. Seventeen participants were boys (mean age 11 years 11 months) and two were girls (mean age 14 years 2 months). Seven boys were at primary school and the remaining children were at secondary school. Diagnoses were made by clinical psychologists, paediatricians, psychiatrists and other professionals working in specialist teams in the participants' local area and included autism spectrum disorder, Asperger syndrome, high-functioning autism and atypical autism.

Measures

The Spence Social Skills Questionnaire (Spence, 1995) This scale was not designed for a population with ASD but has been widely used in assessing the social skills of typically developing young people aged 8–18. There are also some accounts of its use with people with ASD (e.g. Sofronoff et al., 2004). The questionnaire comprises 30 items designed to elicit information about the target child's social skills and is identical in form for both parents and children. There are three correlated factors: conflict resolution/avoidance, warmth and empathy, and social involvement. Scores range from 0 (poor) to 60 (good skill). Normative data for children and young people aged 8–17 report an overall mean of 46.11 (SD 9.03) for parent report; 47.15 (SD 6.59) for girls' self-report; and 43.6 (SD 7.58) for boys' self-report.

Social Competence with Peers Questionnaire (Spence, 1995) Again not designed specifically for ASD, this scale focuses on the consequences of social interaction, relating to outcomes in relationships with peers in children aged 8–18. Items completed by parents and children are slightly different as the scale completed by children and young people covers both school-based and home-based competence. The parents' scale consists of nine items, with a range of scores from 0 (poor) to 18 (high levels of social competence). The child scale consists of 10 items with a range of scores from 0 (poor) to 20 (good level of social competence). Psychometric properties of the scale are good (Spence, 1995). Normative data for typically developing children and young people report a parental mean of 14.82 (SD 3.12) and a mean of 15.53 (SD 3.17) for the young people themselves, with no differences between boys and girls.

Individual parent ratings: 'Three Things' to change Parents were asked to identify three key social skills representing a particular difficulty for their child. As the primary purpose of this assessment was to provide a focus for the social interaction and understanding groups, parents were encouraged to provide specific rather than general items. For instance, the generally worded item 'Get on better with other children' might be changed after discussion to the more specific item 'Be able to play games without getting upset when he loses'.

Procedure

The assessment was carried out by a researcher (TM) who did not take part in the social interaction and understanding groups. Parents were contacted by telephone once they had expressed interest in participating. The 'Three Things' data were collected either by phone or during a home visit according to parental choice. The Spence questionnaires were either completed during home visits or returned by post. Parents were asked to assist their children by reading out the questionnaires where needed.

Results

Social Skills Questionnaire

A paired t-test showed that the mean total score from parents, 26.1 (SD 11.7), was significantly lower than that of the children and young people, who scored a mean of 35.0 (SD 13.6) ($t = 4.4$, d.f. 18, $p < 0.0005$, two-tailed) and were more than one standard deviation below the population mean for typically developing children provided by Spence (1995). Parents' and children's total scores were significantly correlated ($r = 0.65$, $p < 0.002$).

Examination of the way individual items were scored revealed that parents and children classified skills in rather similar ways. Both parents and children gave the lowest scores to items concerning temper management (such as reacting appropriately to teasing by peers and controlling temper during disagreements) and to social engagement with others (such as asking others if they could join in with them, and inviting others to join in). High-rated items, i.e. those in which parents and children felt they were competent, concerned skills that could perhaps be more easily learned such as making requests politely, showing sympathy appropriately and apologizing. Both parents and children reported high levels of skill in conversation with adults.

Social Competence Questionnaire

In order to compare parent and participant totals, the parent scores were prorated to 10. Paired t-tests ($n = 19$) revealed that the parents' mean score (prorated) of 4.3 (SD 3.1) was significantly lower than their children's mean score, 8.5 (SD 4.4) ($t = 5.7$, d.f. = 18, $p < 0.0005$, two-tailed). These scores were also significantly correlated ($r = 0.64$, $p < 0.001$). Compared with population norms provided by Spence (1995), the majority of the parents' scores were two or more standard deviations below the mean, and the majority of the participants' scores were one or more standard deviation below the mean.

Examination of the items showed that 15 of the 19 children, but only 11 of their parents, reported that participants had a close friend at least sometimes. Eleven of the children but only five of the parents said it was easy for them to make friends. Only 10 of the children reported being invited to go to another's house, and eight said they saw friends at weekends, while parents reported these activities for fewer children: eight and five respectively. Eleven of the children felt they had someone to sit next to in class and 11 said that they would be invited to be on a team. Parents, however, perceived peer relationships to be easier than friendships, with 16 reporting good peer relationships.

Individual parents ratings: 'Three Things' to change

Fifty-two items were generated by 17 parents (one parent produced four items) and were examined to identify the areas of difficulty parents raised. In order to impose some structure on the items, they were sorted according to themes. No identifying information, such as the age or sex of the child to whom the items related, was used in this process. Where the item related to two or more criteria, a judgement was made, where possible, about the primary aim of the item. A second rater, a psychology MSc student with experience of ASD who had not participated in the study, sorted the items

a second time. Eighty-eight percent of the items were classified in the same way. Disagreements (which mainly occurred when items covered two or more areas) were resolved by discussion.

The majority of items fitted into three main themes: 'conversation', where concerns about initiating and maintaining conversation were paramount; 'peer relationships', particularly mixing skills and sharing interests; and 'socio-emotional reciprocity', which especially concerns the modulation of behaviour according to context. Ten items could not easily be classified or did not fit into main themes (e.g. 'very negative: everything he's asked to do he says no'; 'making silly noises'). Themes are further illustrated in Table 1.

Discussion

This study demonstrates that children and young people with ASD, drawn from typical school and community populations, recognize that they have significant difficulties with both social skills and competence. The competence scale painted a particularly bleak picture of many of the

Table 1 Number of items generated by parents in each category, with examples

<i>Main theme</i>	<i>Subthemes (number of items)</i>	
<i>Conversation</i> 21 items	<i>Initiating conversation (8)</i> To initiate a conversation appropriately without, for example, jumping in inappropriately <i>Listening, maintaining, turn taking (7)</i> To be able to take his turn in conversation without butting in	<i>Choosing topics (3)</i> To be less repetitive in a conversation and not go over the same things in the same words again and again <i>Non-verbal skills (3)</i> To moderate the volume of his voice – he often talks excessively loud without realizing it
<i>Peer relationships</i> 11 items	<i>General mixing skills (6)</i> To be able to mix better with other children in his own age group (no friends, no-one calls, no-one phones)	<i>Share interests with others (5)</i> To extend his interests beyond bin bags and wheelie bins to things others might be interested in
<i>Socio-emotional reciprocity</i> 10 items	<i>Inappropriate language or comments (6)</i> Not to say things inappropriately (like asking people straight off how old they are)	<i>Inappropriate behaviour (4)</i> To cope with an interview situation appropriately – e.g. if asked why he wanted a job he would appear uninterested and give no feedback

children's lives. Only about half of the parents reported that the child had a close friend at least sometimes, and while more children said they had friends, only about half said it was easy for them to make friends. Only about half of the children reported being invited to others' homes or to social events and even fewer parents said that this happens. Using the 'Three Things', where parents were given free rein to describe areas of particular concern, conversation skills, peer relationships and socio-emotional reciprocity, particularly regarding inappropriate behaviour, were repeatedly mentioned and highlight the day-to-day difficulties faced by children with ASD and their families.

As expected, parents reported lower levels of social skill and social competence than did their children with ASD, though the children's responses on the questionnaires demonstrate that they do have some awareness of the nature as well as the outcome of their difficulties. Indeed, they agreed closely about the kinds of areas in which children displayed relative weakness, noting problems in areas relating to temper management and assertiveness and those relating to social engagement.

Although friendships were frequently described as problematic, the children and young people in this sample reported that they had more friends than Koning and Magill-Evans's (2001) teenage sample, in which nearly half of a group of adolescent boys with Asperger syndrome reported having no friends. However, our sample included children younger than those in the Koning and Magill-Evans's study. Friendships change throughout childhood in both their function and expectations about their meaning (Gifford-Smith and Brownell, 2002); friendships in adolescence rely on intimate, reciprocal exchanges, while in middle childhood they are based more on shared norms, conversation and games. Children with ASD may have more success in developing friendships in middle childhood but lack the necessary socio-emotional skills to sustain friendships in adolescence.

Limitations and future directions

The main limitation of this study stems from its opportunistic nature, arising as it did from another study, rather than being designed for the purpose of examining social skills and competence. A primary need is therefore to replicate these findings and to compare them with a matched group of typically developing children and young people. A second significant limitation arises from the fact that the participants were recruited from a typical community sample, without reassessing the diagnosis or clarifying the participants' developmental levels. Caution must therefore be exercised in terms of generalization of the findings. Furthermore, the Spence Social Skills and Social Competence Questionnaires were not designed for an ASD population, and the 'Three Things' instrument lacks any formal

validation. Replication using a variety of measures will be beneficial in clarifying the way children and young people with ASD view their own skills and competencies.

Nonetheless, the data provide a compelling picture of the social difficulties experienced by children and adolescents with ASD in the community, and suggest implications for both assessment and intervention. The nature of the items generated by parents, for instance their concerns about the inappropriateness of the children's interaction, gives a clear focus for interventions that would be relevant to families. The children demonstrated that they are able to self-reflect using structured questionnaires, but the discrepancy between parents' and children's ratings of social skills and competence suggests that some individuals may have inaccurate perceptions of their abilities. Attempts to equip children with the necessary skills to make and sustain relationships with others will not necessarily succeed if children's beliefs about their skills are not taken into account. Further exploration of the ways in which children and young people with ASD see themselves, and examination of the way in which concepts such as friendship are defined and develop over time, would assist in the development and implementation of effective interventions.

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