

Helping young people with Asperger syndrome

O'Halloran, M. and Doody, O

Abstract

In Ireland, services for people with intellectual disabilities are increasingly being provided in community-based settings. This article discusses a project in which the social needs of children with Asperger syndrome are addressed by the formation of a local sleepover club that is regulated mainly by the children themselves. Run by a community based learning disability nursing service in County Clare, Ireland, this family- and person-centred form of care is yet to be evaluated fully, but interim outcomes indicate that it has been a success and the initiative is being extended to cover more people with intellectual disabilities in County Clare.

Keywords Asperger syndrome, autism, community-based service

Introduction

Asperger syndrome (AS) is an autism spectrum disorder (ASD) characterised by impairments to communication, imagination and social interaction, and in some cases motor function (Cummins et al 2005). Some people with AS are denied services simply because they are articulate or academically successful (Carter 2009). They may lack social skills, however, which affects their ability to make and sustain friendships, and recognise and cope with bullying (Stichter et al 2010). In addition, they may be abnormally sensitive to sights, smells, sounds, tastes, and textures, which leads them to, for example, wear only specific types of clothing or eat only specific types of food (Lemer 2011).

Other features of AS, such as a good command of language and an interest in making friends, distinguish it from other forms of autism, yet are not part of its diagnostic criteria (Woodbury-Smith and Volkmar 2009). In general, children with AS frequently want to make friends but lack the social skills to engage appropriately, whereas those with autism tend to isolate themselves. Many children and teenagers with AS have marked abilities in unconnected areas, which can sometimes mask the true nature of their impairments, and their parents are often concerned about their children's social survival, inability to make and sustain friendships, and their lack of understanding about the normal rules of social engagement (Stichter et al 2010).

The worldwide prevalence of ASD remained stable until the early 1990s, when an increase in the prevalence of this and all pervasive developmental disorders was recorded (Lauritsen et al

2004). There is as yet no sign that prevalence of AS has stopped rising, although whether this is due to an increase in the number of people with ASD, of a widening of diagnostic criteria or of a greater awareness of autism and AS is unclear (Moore 2008).

Extending services

As nurse manager of Enable Ireland Home Support and Respite Service, the principle author was asked to extend services for the families of children with AS, many of whom attended mainstream schools and colleges. In helping children with AS to acquire social skills, it is important to ensure that they can apply what they have learned to do in one setting to other, similar settings (Lord et al 2005). For this reason, staff at Enable Ireland Home Support and Respite Service arranged a series of consultations about community-based initiatives with the relevant children and families. Participants were encouraged to suggest how the children could be helped to acquire the skills they need in their daily lives and, during one of the initial consultations, some children suggested that a 'sleepover club' should be set up. These clubs involve groups of children with AS spending one day and night together in a safe environment, under the supervision of trained staff. The suggestion was approved by the service on the grounds that the club would help the children develop social skills at their own pace and give them time away from their homes. A house in the local community was leased for the club and part of the funds the service received from Ireland's Health Service Executive was allocated to the project. Children and staff involved in the initiative were insured through Enable Ireland's standard public liability policy. All families and children who wanted to be involved in the initiative completed a service agreement in which they consent to take part in all activities chosen by the group. This agreement is updated each year. Participating children, their families and staff, then drew up a series of objectives for the club. These are to:

- Expose the children to scenarios that they could come across in their everyday lives.
- Understand the difficulties that can arise when they go to, for example, cinemas, restaurants, shops or each others' homes.
- Teach them how to introduce themselves to people and what to say when they meet friends.
- Teach them basic etiquette and how to be cordial to others.
- Offer them opportunities to practise appropriate responses to people and situations

Some of the families involved in the consultations were anxious about their children attending sleepovers, so the principle author ensured that they could contact her by phone at all times. Similar support is extended to staff. It was also agreed that after each sleepover, parents would be given concise reports on their children's activities and achievements. These reports are written by staff with the help of the children concerned in a language that is appropriate to each child's level of understanding and with which each child is familiar. The reports are then signed by the children, if they are aged 16 years or over, and by their parents and the staff. It was decided that groups of children would attend the sleepover club once

each month, from a Friday evening until late the following Saturday afternoon, all year round and for one week during the summer holidays. Each club is run by two members of staff.

Practice

The first sleepover, involving a group of six children aged between ten and 12 years, was held in June 2006. Subsequent sleepovers have involved a total of 24 children and teenagers aged between nine and 19 years, divided into four groups according to their ages and interests. The members of these groups are chosen by the staff in consultation with the children and their families, and the staff designated to each group remain with them, if possible, throughout the members' transitions into adulthood. Group members are then invited to help staff draw up a code of behaviour. On arrival, members greet each other, unpack and share news, before helping to prepare and eat dinner. One member then decides what activities they should pursue during their stay, with members taking turns to decide at consecutive meetings. Supporting the children to take turns and learn to compromise in this way is an essential part of their social-skills training. The children are encouraged to take part in activities that involve collaboration and physical effort, such as bowling, swimming, surfing and a game called Quazer that involves toy laser guns. The children also play board games and take part in group discussions, which encourage them to communicate, and to open themselves to change and new ideas. As members of their local community, they use the local public amenities whenever possible.

Staff assess the effectiveness of activities and encourage the children to have fun at all times. Humour can be a source of intuitive understanding and, by ensuring the children enjoy themselves, staff can help them to manage their anxieties. Staff always bear in mind that the lives of the children are intertwined with those of their families (Latib et al 1984, Doody 2012), and involve and consult with them as much as possible. The results of the sleepover club project have exceeded all expectations. The children have gone far beyond their comfort zones to be part of their groups. They have become more confident in accessing mainstream activities, trying new experiences and developing lasting friendships, while having fun and learning in a safe environment. Their families confirm that the children are applying what they have learned to other settings and, as a result, are better able to express themselves and achieve a fulfilled quality of life. The children have a sense of complete ownership of the clubs, which means they are responsible for ensuring they succeed, and for working hard at engagement and compromise.

At times, the children have attempted to resist change by refusing to take part in activities, or have found working together and compromising difficult. In these situations, the objectives and rules of the group became helpful, and the children's attempts to manage their difficult feelings allowed everyone involved to form lasting, honest and trusting relationships. In addition, many of the children became anxious about working in groups, and needed regular reassurance and encouragement. Staff have learned to recognise the stress and anxiety that is

often masked by avoidance strategies or negative attitudes, and how ingenious some children can be at avoiding the things they fear.

Reflection

Staff involved in the development of the sleepover clubs have bridged a gap between theory and practice, and have learned to deal with complex issues as they arise, thereby gaining insight into the complexities of AS. By reflecting on how they have acquired knowledge and skills in this way, staff can enhance their competence in delivering holistic care (Fawcett et al 2001). In moving through levels of proficiency (Benner 1984), staff have acquired a deeper understanding of the ethical issues that can arise in caring for young people with AS, particularly in deciding when clients require advocacy, and have acquired empirical knowledge, especially on children's and families' perceptions of care services. Staff have also had opportunities to put their personal and aesthetic insights into practice (Carter 1978). Person- and family-centred care involves making sure that clients and their families take the lead in activities (Duffy and Sanderson 2004).

Staff should encourage clients to communicate what is important to them, and help them to get what they need and take control of their lives, so that they can achieve their potential and become as independent as possible (Matousova-Done and Gates 2006). Clients and their families must often take part in a process of discovery to identify what is important to them and what they have to do to achieve it (Kilbane and McLean 2008). To help clients and their families in these processes, nurses must actively listen to them, and understand and respect their views (Mansell and Beadle-Browne 2004), so that they can encourage them to become their own advocates (O'Brien and O'Brien 2002, Jenkins et al 2006). It becomes easier to help clients and families in these ways when they are involved in decisions about their own care.

Evaluation

In June 2011, Enable Ireland commissioned a large-scale study of its services, including the sleepover club initiative. The study includes the opinions of the children and families involved in the initiative, and will inform plans to extend it to include more children with AS in the service's catchment area. By undertaking, and responding to, such studies, staff can ensure that the changing needs of participants are met as soon as possible. One family member said of the sleepover club: 'It lets my son relax and be himself with like-minded children and gives him independence away from family.' Another parent said: 'It has helped my child to develop socially that she would not have done without sleepover club' One parent was pleased by the 'opportunity the club gives my child to socialise with children of the same age and the chance to experience new activities'. Another noted: 'My son gets to meet other children with similar interests as him.'

All families involved were pleased with the initiative. One said: 'My daughter is treated with respect, not simply as a person with a disability. She is well looked after while in their care and she loves them. There is a great relationship between them. I am totally satisfied it is a wonderful service.' Children's sense of ownership of initiatives such as the sleepover club can be enhanced by their inclusion, with their families, on planning boards. These boards, which would also include staff, managers and representatives of advocacy organisations, would decide on the structure, development, implementation and review of similar initiatives.

The creation of a planning board for the sleepover club comprising children and their families, service managers, staff and representatives of family support groups is therefore the next stage in the club's development. Other initiatives based on the work of Pearpoint et al (1991), Forest and Pearpoint (1992), Smull and Burke-Harrison (1992), Mount et al (2002), and Sanderson and Acraman (2004) include a person-centred plan and a circle of support, or group of friends and helpers who meet regularly, for each child. Learning disability nurses are responsible for gathering evidence from practice and research, and meaningful consultation with clients can provide nurses with insights into the services they should offer and how they should be provided (Wicke et al 2004). By developing and promoting community-based services such as the one described in this article, nurses can assume leading roles in their profession while meeting the evolving needs of people with intellectual disabilities and of their families.

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