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Promoting the social inclusion of children with autism spectrum disorders in community groups

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Children with autism spectrum disorders (ASDs) are not easily included in mainstream youth activities provided by the community and voluntary sector (CVS) such as scouts, sports organisations and youth clubs. Two studies were undertaken. First, a survey of over 200 personnel from CVS groups to ascertain their previous experience of these children and reactions to their enrolment. Second, in light of the findings, a short, two-hour introductory training course on ASD targeted at youth leaders was devised and evaluated with nearly 400 participants. Most participants reported changes in their attitudes and perceptions as well as citing a range of information they had gained from attending. Further research is needed into the reasons why CVS groups are disinclined to enrol children with ASD and in targeting awareness raising and training opportunities more specifically within this sector.

Keywords: autism; ASD; social inclusion; training course

Introduction

Throughout the UK rising numbers of children are being assessed as having an autism spectrum disorder (ASD) with rates in excess of 1 per 100 now reported among 9–10-year-olds (Baird et al., 2006). These children – around 80% of whom are male – invariably experience difficulties in communication and social interactions which make it harder for them to interact with their peers. They are often socially isolated with few friends and low levels of participation in community activities and groups (Müller, Schuler, & Yates, 2008; Orsmond, Krauss, & Seltzer, 2004). In addition, many young people with ASD may experience bullying in school and neighbourhoods (van Roekel, Scholte, & Didden, 2010). Social exclusion compounds the difficulties arising from their condition and past research has demonstrated that socially excluded youth with ASD are more prone to health problems, early withdrawal from education, anti-social behaviours and long-term unemployment (Howlin, Goode, Hutton, & Rutter, 2004).

A particular aspiration of parents is for their child to have access to the same opportunities as their non-ASD peers (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008). This is reflected too in government policies for children with special needs

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(e.g. HM Treasury, 2003). In the pre-school years, there is a willingness among leaders of mainstream early years groups to enrol children with ASD and for them to participate in training opportunities (Crawford, Doherty, Crozier, Bhurgri, & McConkey, 2003). Likewise, there is a body of research relating to the inclusion of these pupils within mainstream schools with a focus on the attitudes of teachers and fellow pupils in providing an inclusive environment (Jordan, 2008). However, few investigations have been undertaken with community and voluntary sector (CVS) groups that provide recreational activities for children and teenagers.

Nearly all community leisure pursuits in European society are provided through the CVS and the contribution this sector makes to the creation of social capital is well recognised (OECD, 2001). To date little attention has been given to equipping leaders of CVS groups with the capacity to integrate these children within their groups. Research with preschools suggests that this brings benefits not only to the affected child and family but also to the leaders and peers (McConkey & Bhurgri, 2003). Moreover, with the advent of the Disability Discrimination Act in the UK (and similar legislation in other countries), the sector needs to be knowledgeable about the reasonable adjustments they can and should make to provide equal opportunities for participation of all children and young people in their local community. Empowering leaders and other personnel with key knowledge and skills is central to this strategy.

The aims of the study

The dual aims were:

(1) To undertake a survey of CVS groups in order to establish their past experience of having members with ASD, their levels of interest in enrolling such members and their perceived training and support needs.
(2) To devise and evaluate a short training session designed particularly for CVS personnel that can be easily repeated.

However, the difficulties in accessing informants within this sector were recognised, hence these were also viewed as exploratory studies that would inform future research strategies.

Study 1: survey of CVS organisations
Method

The objectives of the survey were:

(1) To identify past contacts that informants had with children and young people with special needs and with ASD in particular.
(2) To describe their experiences – both positive and negative.
(3) To ascertain their willingness to enrol children with ASD in the future and the supports that would help with this.

A structured, self-completion questionnaire along with an explanatory letter was sent by AutismNI to all the groups and organisations known to have an involvement with children and young people across Northern Ireland. Some regional organisations undertook to distribute the questionnaire to their affiliated groups. Around 2000

questionnaires were estimated to have been distributed. Informants had the option of returning the completed questionnaire using a freepost address at the University of Ulster or by completing it online via the internet.

Respondents

In all 212 replies were received from a variety of organisations (@10% response). Most came from uniformed organisations for girls, such as Girls' Brigade and Guides ($N =$ 57) and for boys, that is, Boys' Brigade and Scouts ($N = 29$). Early years organisations formed the next largest grouping ($N = 19$); followed by youth groups ($N = 14$), sports and activity groups ($N = 13$), community centres ($N = 13$), district council officials ($N = 10$), arts and drama groups ($N = 10$), church groups ($N = 6$), special needs clubs ($N = 6$), Cadets ($N = 3$) and after-school clubs ($N = 2$).

In all, 75% of respondents were female and 25% male. Just over a third of respondents were aged under 40 years and two-thirds were aged 40 years and over. One quarter reported no prior contact with people who had ASD; just over one-third (37%) had brief contact and a similar proportion (37%) had regular contact.

Results

Experiences of disability

Over 60% of respondents currently had children with special needs enroled in their group and a further 21% had done so in the past with 17% having no enrolments of children with special needs. The children enroled at present were described as having multiple disabilities ($N = 59$) followed by learning disabilities ($N = 29$), ASD ($N = 28$), physical and sensorial problems ($N = 7$) and behavioural problems ($N = 5$).

Over the past three years, the respondents had contact with a median of three children with special needs (range from 1 to 500).

Contact with ASD

In all, 88 respondents (42%) stated that they had been approached about enroling a child with ASD; most of whom ($N = 81$) did attend. The person who made the approach most commonly was a family member ($N = 59$) – usually a mother – but services or professionals such as social workers involved with special needs also made approaches ($N = 12$) as did children/young people themselves ($N = 3$) and other leaders of the group ($N = 2$). Some respondents commented:

> Our club is very ordinary, we emphasise socialising. We try to see the young person and not a 'special need'. The youth club also provides a safe, caring environment to give parents much needed respite. (Respondent 902)

> It has been hard work with some young people but very rewarding to include people with special needs and ASD. (Respondent 147)

If asked, half the respondents (42%) stated that in the future they would be 'very willing' to have a young person with ASD in their group and a further 39% stated that they would be 'willing'. However, eight (4%) would prefer not to enrol such a member (although no reason was given) and a further 31 persons (15%) omitted to answer this question.

The most common reason people gave for being 'very willing' to take a child with ASD was on the grounds of equality of opportunity with 36 respondents mentioning this. For example:

> The arts centre encourages inclusivity and to provide a service for all the residents of the district. (Respondent 903)

> Inclusion is important part of the Christian ethos of our organisation. We are a child-centred organisation for all children. (Respondent 98)

> Because all children should be given the opportunity to mix freely with other children in a safe, warm and manageable environment for them. (Respondent 113)

Other reasons given were that the group had positive past experiences and/or expertise among the leaders ($N = 17$).

> We have had a number of children in the past and have had no real difficulties. We have a number of staff with an education background who are aware of the difficulties. (Respondent 127)

A few respondents commented on the benefits these children could bring to the group ($N = 7$) and others stated that with careful planning it should be possible.

> It should be our problem if we can't deal with it. It's our job and their life. (Respondent 167)

Those respondents who indicated they would be 'willing' (rather than 'very willing') tended to emphasise the supports they would require if a person with ASD was to join their group although others mentioned the impact on the other members and the suitability of the premises.

> We seek to include all local young people in our programme and to date have been welcoming to all those with a disability. However, at present, an ASD young person may be more than we could handle. With sufficient information and training we would aim to be in a position to do this. (Respondent 137)

> Difficulties getting enough committed adult leaders for present needs. Would need more supervision/voluntary help perhaps by someone trained/experienced. (Respondent 58)

> I know little about autism and would have concerns regarding effects on other children. (Respondent 68)

> You need the total backing and support of parent/guardian before taking a child with ASD. (Respondent 39)

> My only concerns are the level of noise in our building – which wouldn't be suitable for all children. (Respondent 907)

All respondents were also asked to identify the supports that might encourage and assist them in having a young person with ASD within their group. Table 1 summarises the responses they gave. The two most preferred options were having information leaflets and the availability of training courses for leaders. Other supports they mentioned were:

Table 1. The number and percentage of respondents identifying the supports they would find helpful.

	Definite help to me	May help me	No help to me
Information leaflets on ASD	128 (72%)	46 (26%)	4 (2%)
Training course(s) on ASD for leaders	123 (69%)	51 (29%)	4 (2%)
Having a person/helper accompany person with ASD	112 (65%)	54 (31%)	9 (4%)
Advice from visiting ASD specialists	103 (61%)	57 (34%)	10 (6%)
Contact with similar groups who have this experience	79 (49%)	70 (44%)	12 (8%)
Awareness session(s) for other children on ASD	79 (48%)	69 (42%)	17 (10%)
Telephone helpline to give advice	71 (45%)	77 (48%)	11 (7%)

Financial support for 1-1 worker. (Respondent 141)

Library of specific resources, equipment, books, DVDs that may be available for parents and children to access. (Respondent 120)

Dedicated website advice. (Respondent 159)

Study 2: ASD training for community group leaders

In light of the survey findings, a short training course with accompanying information leaflets was devised to provide an introduction to ASD that was tailored to the issues identified by leaders of CVS groups in Study 1. The content and training approaches drew on the courses that AutismNI provided for other parents, preschool personnel and the police.

The main aims of the course were:

(1) To give an overview of AutismNI (the local society for Autism) and the support services it provides to families and communities.
(2) To describe the main features of ASDs and ways of adjusting demands and environments.
(3) To explain the impact of ASD on children and young people and the difficulties that might be encountered in leisure groups and activities.
(4) To provide information on sources of advice and guidance.

Method

The two-hour programme was delivered jointly by two experienced tutors from AutismNI through illustrated talks, video extracts, success stories from CVS groups, small group discussions and question and answer sessions. The courses were free of charge and were widely advertised by posters in the locality. In some instances, the directors of leisure centres were approached directly and training offered to their staff. The meetings took place in a community venue, such as a room in the library or leisure centres, and they were generally held in the evenings. In total, nearly 400 people attended in the 18 locations with numbers ranging from 2 persons to 30 plus.

Evaluation

Structured evaluation forms were completed by 249 participants (an estimated return of 65%) at the end of the training session. Of these, 129 (74%) were female and 46 (26%) were male. In terms of age, 70 (39%) were under 30; 33 (19%) were aged 30–39 and 75 (42%) were 40 years old or over. Around one quarter ($N = 41$: 23%) had a family member with Autism/Asperger's syndrome. In terms of prior contact with persons who had ASD, 39 (22%) had very little or no contact; 65 (37%) reported brief contact now and again, and 74 (42%) had personal and regular contact.

The participants were associated with a range of organisations including leisure centres ($N = 41$), youth organisations ($N = 27$) and special needs groups and schools ($N = 26$).

Results

Reactions to the course

Respondents were asked to describe the most helpful aspects of the course to them. The most common comment was learning more about ASDs ($N = 75$ mentions) followed by strategies for managing the children ($N = 43$) and learning about the difficulties that people experience ($N = 25$). A further 43 persons mentioned the general helpfulness of the course and how well it had been presented. Sample comments follow:

> Gaining an insight into improving social skills in children with autism – a clear and understandable explanation. (Respondent 15)

> The insight into the spectrum of autism; what life is like for the person with autism and how best to communicate/support them. (Respondent 74)

> Having no previous experience with anyone who has ASD, I found the whole course very helpful and would feel more confident in providing the help and support required to allow a child with ASD to integrate comfortably in our organisation. (Respondent 158)

Respondents were asked to reflect on how their attitudes or perceptions about children with ASD had changed. In all, 31 persons (17%) reported no change but 134 reported a change of whom 17 (9%) stated a 'very great' change had occurred. Their descriptions of the changes could be grouped into four main categories: namely, empathy and insight into the problems the children with ASD experience (35 mentions); actions that they could take to help the child (29 mentions); greater awareness of ASD (28 mentions) and more patience and understanding (14 mentions). For example:

> Will try to be more calm and try to think how they do. (Respondent 77)

> Learning about delay to speech processing helps understanding; it's improved my ability to try to learn from watching the person in order to understand their experience and adapt this; it's my approach that needs to change to see improvement. (Respondent 37)

> I've learned that these children have a lot of anxiety and they are not actually aloof but anxious and have difficulty expressing their emotions. (Respondent 12)

> To be more understanding and sensitive in the way I use language when dealing with such children. (Respondent 92)

Respondents were also asked to rate various aspects of the course out of 10 and scores throughout were high; particularly so for the tutors, the friendly and relaxed atmosphere created, the way the information was presented and the content of the course. However, discussions with other participants in 'buzz groups' were not so highly rated.

Few suggestions were made for improvements but some comments were as follows:

Too much information in such a short time (2 1/2 hours). (Respondent 163)

More info on including kids with ASD in group games/activities would be useful. (Respondent 115)

Most participants also agreed that they had been given information in such a way that they could pass it on to other leaders in the group; for example:

The strategies were very helpful and precise. (Respondent 6)

The handouts were very clear. (Respondent 7)

I can revise the handouts with them and display the wee leaflet. (Respondent 75)

Nearly all the participants felt they would recommend the course to others. They applauded the practical and concise information they had been given and the personal gains it had brought to them.

Short informative and realistic sessions like this provide more meaningful ideas and knowledge that will stay with you. (Respondent 15)

It gives examples and covers situations that you are already coping with, without realising it. (Respondent 35)

Discussion

Both of the exploratory studies reported in this paper relied on self-selected participants hence they may provide an over-optimistic picture of the attitudes of personnel from the CVS. Nonetheless, it is apparent that some CVS groups have experience of taking children and young people with special needs in general and a few with ASD in particular. They were approached by others for the child to join, usually by the child's parents. Generally, it seems to have been a positive experience for leaders and members as well as for the young person with ASD based on their reports. Around half the leaders commented they would be 'very willing' to enrol a child, often citing the desire to provide equal opportunities for all children in their locality. However, the need for training and the provision of relevant information were seen as key supports for CVS groups. In sum, this evidence is an important foundation for encouraging yet more groups to become more inclusive as they follow the example of their colleagues. However, future studies may need to focus on groups who have not enroled children with special needs and seem disinclined to do so. Equally the experiences of groups who had tried to include children with ASD but failed would also be informative. With these two groups of informants, indepth qualitative interviews would yield a richer account of issues that present barriers to the children's inclusion and identify possible strategies and supports for overcoming them.

The short, two-hour training course was very well received by the participants who reported changes in their attitudes and perceptions as well as citing a range of information they had gained from attending. However, the biggest challenge was the recruitment of participants, and not just in terms of the relatively low numbers who volunteered to attend. Nearly half of those who came already had contact with children and young people with ASD: indeed a quarter of attendees were relatives. In some ways this was indicative of the need identified in the first study for more training opportunities. It appears that most groups enrol members with special needs without any prior training or supports. But as some participants noted, these leaders would benefit from more specific training than could be provided in a two-hour session.

By contrast, the training was intended as awareness raising of ASD for those participants who had little prior contact and although the numbers falling into this category were small, they did seem to benefit from the session. Further studies could establish the durability of these changes and more especially whether the leader's attendance resulted in increased enrolments of children with ASD in the groups which were represented and the extent to which participants shared their learning with colleagues.

Other means of awareness raising among the wider CVS sector need to be explored as generic sessions as used in this study have limited reach even when delivered locally. A more promising strategy is to embed ASD awareness within the wider training and supports that particular CVS groups, such as youth uniformed organisations provide for their leaders. This could mean training their trainers to provide the awareness sessions or doing so as co-tutors with ASD specialists. This model has proved effective with pre-school groups (Crawford et al., 2003).

These studies go some way to identifying a strategy for promoting the social inclusion of children and teenagers with ASD within CVS groups. The rationale for doing so is clear but the means for bringing this about are less so. A promising starting point is for groups with positive experiences to share their approaches with others. A second aspect is access to information and training resources that will assist the groups with furthering the children's social inclusion. These training materials need to be publicised within the sector. Information resources specifically targeted for various CVS groups could be coupled with the third strand, namely a training programme for CVS leaders so that they can incorporate information about ASD into the induction and ongoing training they provide within their group or organisation. These actions need to be underpinned by closer linkages between the CVS sector and schools, specialist ASD services and Autism charities.

As was intended, these studies have identified useful topics for future research and yet there are still more questions that deserve further consideration. What are the features of community groups who successfully include children with ASD? What impact does participation in inclusive activities have on both sets of children and young people? Are there longer-term gains in terms of people's quality of life? A new agenda of enquiry in the field of ASD is opening up.

Notes on contributors

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