

Promoting the social inclusion of children and teenagers with ASD



*An evaluation of the development projects
undertaken by AutismNI.*

Roy McConkey
Institute of Nursing Research,
University of Ulster

September 2009

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Acknowledgements

The Project was funded by BBC Children in Need. Roy McConkey's post at the University of Ulster is jointly funded by the Health and Social Care Board.

A sincere thanks to the Development Officer for the Project, Audrey Mullan (Autism NI) for her meticulous record-keeping; to Pat McConkey for her help with data coding and to members of the Steering Group for their advice and guidance.

AutismNI is appreciative of the assistance provided by the five Education & Library Boards, and by the Belfast, Southern and Western Health & Social Care Trusts in making this project a reality.

Executive Summary

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. These children invariably experience difficulties in communication and social interactions which make it harder for them to interact with their peers and increase the likelihood of their social exclusion in future years. In addition, many young people with ASD experience bullying.

A particular aspiration of parents is for their child to have access to the same opportunities as non-ASD peers. A two-fold strategy is required to achieve this. First, assisting the children to acquire the skills required for social participation and equipping leaders of community and voluntary sector (CVS) children's organisations with the capacity to integrate these children within their groups.

An application was made by AutismNI to Children in Need for a grant to fund this project which commenced in November 2007. This was undertaken in conjunction with the ASD specialists working in the five Education & Library Boards and three Health & Social Care Trusts.

The main aims of the Project were:

1. To deliver training and support to children with Autism that would help them to manage the social challenges they encounter, and to help them and their families manage day to day life skills and deal with anger issues.
2. To deliver Parent Awareness sessions around social skills issues.
3. To deliver Community Awareness training to interested parties across Northern Ireland.

Two strands of work were undertaken.

1. The development and evaluation of a social skills training programme

The social skills programme centred on two age groups: those in Key Stage 2 (8 to 11 years) and Key Stage 3 (12 to 14 years). This overcame the difficulty of mixing children across a wide age range but also meant that learning activities could be adapted to the particular needs of children at different developmental levels.

In all 36 children (90% of those identified) participated in one of seven groups which were held in the following locations: Downpatrick, Newry, Antrim, Belfast, L'Derry, Enniskillen and Cookstown. Three groups were held for young people in Key Stage 3 and four groups for those in Key Stage 2.

Six groups met once a week for a total of seven sessions. The children's average attendance was 6.3 sessions out of 7. A further group met as a summer scheme for five consecutive days. Here the average attendance was 4.4 sessions.

A variety of methods were used to evaluate the impact of the social skills training programme including ratings of the children's skills by the tutor, feedback from the children, the reactions of parents and from co-tutors. A number of conclusions can be drawn from the range of data gathered in the evaluation.

- It was feasible to organise special sessions in various localities across Northern Ireland but this required close co-operation with the education, notably the ASD support teams who identified and invited children to participate.

- Children were easier to recruit for the groups held for pupils at Key Stage 2 (aged 8-11 years) whereas some older pupils were disinclined to join groups despite their parents' eagerness for them to attend.
- Finding a suitable location and time to suit all participants was difficult and some parents had a two-hour return journey to attend the chosen locations. However a central location in the late afternoon was the best compromise.
- A group of around six seemed ideal but a consistent co-tutor was preferable for all sessions. The seven weekly sessions enabled the basic skills to be covered but follow-up sessions and/or the provision of workshops/courses on other topics were requested.
- The sessions were rated highly by the children, their parents and the tutors. There were few suggestions for improvements. They were especially appreciative of the group leader, the range of activities covered, the games approach that was used and the information sent home after each session.
- There were clear indications that the children had benefitted from the sessions as seen in their self-ratings, their parents' reports and in the ratings and comments from the tutors. Their conversations, confidence and communication skills were perceived to have improved.
- Certain children seemed to benefit more than others which may reflect the variation found among children on the Autism Spectrum. More extended or intensive work could benefit all children.
- Parents and families reported that they too had benefited by being less stressed, more family interactions occurred and they had better understanding of their child. However parental attendance at the sessions prior to, and after, the course was variable and mothers commented more on the informal contact they had with the tutors than on the formal sessions as being of benefit to them.
- Not surprisingly, children and families would like further sessions and they were also keen to recommend them to others. However the resources for doing this would have to come from the voluntary sector although in the medium to longer term it is possible that schools could take on more of this type of work.

2. The inclusion of children with ASD in community and voluntary sector organisations.

Two main activities formed the work of Strand 2.

1. A survey of community and voluntary sector (CVS) groups involved with children and young people throughout Northern Ireland. This was to ascertain their previous experience of these children and reactions to their enrolment in these groups.
2. An evaluation of a short training session designed particularly for CVS personnel which ran in 18 locations with attendances in excess of 300 persons.

In the survey, 212 responses were received from a range of organisations; most commonly from uniformed organisations for girls and for boys but also early years groups, youth groups, sports and activity groups, community centres, district council officials, arts and drama groups, church groups, special needs clubs, Cadets and after-school clubs (N=2).

In all 88 respondents (42%) stated they had been approached about enrolling a child with ASD; most (N=81) of whom had attended. If asked in the future, 42% of respondents stated they would be 'very willing' to have a young person with ASD in their

group and a further 39% stated they would be willing. However the need for information and training was highlighted.

In light of the survey findings, a short, two hour training course was devised to provide an introduction to ASD that was tailored to the specific needs of leaders working with the range of groups noted above. Eighteen courses were held around N. Ireland. In all, nearly 400 people attended and evaluation forms were completed by 249 participants.

A number of conclusions can be drawn from this strand of work.

- A range of CVS groups have experience of taking children and young people with special needs. The absolute number is not known and may even be quite small but this is an important foundation for encouraging yet more groups to become more inclusive.
- A proportion of groups have had the experience of taking a child or young person with ASD once they had been approached to do so, usually by the child's parents. This generally was a positive experience for leaders and members as well as the young person with ASD.
- Around half the leaders would be very willing to enroll a child, often citing the desire to provide equal opportunities for all children in locality.
- The need for training and the provision of relevant information were seen as key supports for CSV groups.
- 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.
- Participants would encourage others to take the course and suggestions were made for extending it to members of groups as well as to leaders of other groups that were not so well represented.

Based on these findings, four main recommendations are proposed to take forward the work commenced by this project, namely:

- There is a need to promote the social skills of children and young people with ASD but this can be done in a relatively low cost way in natural settings.
- Multi-agency partnerships are necessary to achieve social inclusion. These need to embrace families, schools, voluntary sector ASD organisations and the community and voluntary sector engaged with children and young people.
- Resources to promote social inclusion should be more readily available. This includes resources for use in social skills training programmes and also training resources for use with leaders of CVS organisations.
- Further research and development is required in this relatively new area of service delivery, especially into the formation of social and friendship networks for young persons with ASD.

In sum, the Project has demonstrated what can be achieved by two complementary and carefully planned educational programmes that address the needs of children with ASD. Various strategies have been identified and resources developed that can be extended to many more children and community groups throughout Northern Ireland and beyond. Autism NI and the funders of the Project are to be congratulated for developing these initiatives.

Rationale for the Project

1. Improving the social skills of children and teenagers with ASD

Throughout the UK rising numbers of children are being assessed as having an ASD with rates in excess of 1 per 100 now reported among 9-10 year olds (Baird et al, 2006). These children invariably experience difficulties in communication and social interactions which make it harder for them to interact with their peers and increases the likelihood of their social exclusion in future years. In addition, many young people with ASD experience bullying.

Most children and young people with ASD can be helped to acquire the various skills that will help them to get on with other people and hence be more socially included. Indeed all children have to acquire these skills but the difference is that those *without* ASD seem to pick them up without having to be taught them, whereas boys and girls with ASD benefit from structured teaching of these skills. As one young woman with ASD put it:

"It's as if everybody is playing some complicated game and I am the only one who hasn't been told the rules." (Sainsbury, 2000, pg. 8)

The term 'social skills' covers a great many individual skills which children not only to have to acquire but more crucially they also have to use them in a smoothly, co-ordinated and synchronised way – otherwise their social behaviours will seem strange or odd. For example: Dr Lorna Wing described four types of social difficulties that children with ASD may show:

- "The 'aloof' child who may appear rather withdrawn and indifferent to other people, and may be difficult to comfort when distressed.
- The 'passive' child who will not make spontaneous approaches to other people but will accept contact if initiated by others.
- The 'active but odd' child who will approach other children spontaneously but this will often be in an odd or inappropriate manner. Often they may pay little attention to the responses of those they have approached.
- The 'over formal, stilted group' often seen in teenagers and adults but could be seen in young children also. This group of people use overly formal language and behaviour and are excessively polite. Can be very rule bound in social situations"

A combination of these characteristics can also be found and children may move from one set of behaviours to another.

Within ASD, a range of specialist treatments, therapies and approaches have been developed to address the disorder based mainly around individualized interventions within classroom or clinic settings. Controversy continues around the universal efficacy of any one approach (Charman and Stone, 2006) and certainly the impact of these ASD specific interventions on social skills deficit has not been a major focus of attention. Indeed a research priority identified by Smith et al (2007) is the need for efficacy studies on core features of ASD such as social reciprocity. Moreover to date, few studies have examined the interactions that children with ASD have with their peers in less formal settings such as leisure activities, although Jordan (2003) has pointed out the importance of so doing. Nonetheless the complexity of addressing social skills deficits is well recognised as is the difficulty on effecting sustainable changes in children's behaviours (Bellini et al., 2007).

Eight categories of primary behaviours have been identified that make up what is called 'social skills' or 'social competence' (Sticher et al., 2007). These are:

1. **Functional communication:** this includes verbal and nonverbal communication skill development; e.g. understanding what is said to us and making clear our meaning in what we say to others.
2. **Social initiation** which refers to social initiations with peers, other adults, and parents – how we get their attention, the questions we ask, the information we offer to them.
3. **Response and engagement** as in developing skills in responding to initiations and engagement within social interactions. How we react to what they say or do, the appropriateness of our reactions in maintaining the interchange.
4. **Cognitive development** that includes academic and problem solving skill development and cognitive processes such as memory and concentration.
5. **Play and group skills** covers the development of play skills for younger students and group skills for older students such as co-operating in ball games or in making a collage.
6. **Challenging behaviors** involves targeting any disruptive, aggressive, or aberrant behaviours that can upset other people and get in the way of the person behaving appropriately.
7. **Self-related behaviors** includes building a person's self-esteem, self-confidence and self-management; put more simply – becoming less shy!
8. **Physical/motor skills** refers to targeting any physical development within the intervention such as hand-eye co-ordination and ability to balance or kick a ball when running.

Certain children will experience more difficulties in some of these areas than in others. They will also experience problems with integrating skills from one category with those from another. It's as though they can only focus on one thing at a time rather than coordinate them in sequences of activities.

The above framework provides a basis for developing teaching or intervention programmes to address the complexity of skill deficits that children with ASD may experience.

More strategically, past research and practice suggests that interventions are more effective under the following conditions:

- **Individualised goals and plans** are developed that are based on specific evaluation/assessment undertaken with the child. For example: N (the child) will take turns when playing a game of Dominoes.
- The selected goals should aim at **improving interactions with peers** and not just with adults. This can mean setting up 'small group' activities but in these, it is important to ensure that the child who does not have ASD, gains from participating and not just the children with ASD.
- Making use of '**natural environments**' if possible, rather than constructing 'special' settings. Then the child is more likely to use the new skills in other settings as the supports and cues for these will be present.

- **Encouraging self-regulation.** The learner is encouraged to take responsibility for monitoring and adapting their own behaviour rather than relying on others to do it for them. For example, the learner can watch a video playback of their behaviour and monitor the number of times they asked questions.
- Ensure that **family members** are fully informed about the social skills training programmes that children might participate in with teachers or therapists.

As yet there have been few attempts within Northern Ireland to develop and implement a systematic social skills training programme for older children and teenagers with ASD outside of formal education or therapeutic settings and perhaps even within these locations.

2. Community Groups and ASD

A particular aspiration of parents is for their child to have access to the same opportunities as non-ASD peers (Cassidy et al, 2007). This is reflected too in government policies for children with special needs (e.g. HM Treasury, 2003). In the pre-school years, AutismNI and the University of Ulster have been to the fore in creating opportunities for children with ASD to attend mainstream preschool facilities (Crawford et al, 2003; McConkey and Burghri, 2003). Their research indicated a willingness among leaders to enrol children and for them to participate in training opportunities. However there is limited research as to the feasibility of extending this approach into community and voluntary sector (CVS) groups for older children and teenagers.

Nearly all leisure pursuits within our society are provided through the CVS and the contribution this sector makes to the creation of social capital is well recognised. Lack of opportunities nationally to access social networks is commonly reported for children with disabilities and one that greatly concerns their parents. Social exclusion compounds their difficulties and past research has demonstrated that socially excluded youth are more prone to health problems, early withdrawal from education, anti-social behaviours and long-term unemployment.

Given the rising numbers of children identified with ASD, particular attention needs to be 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.

With the advent of the Disability Discrimination Act (and similar legislation) as well as policy shifts towards inclusive education, the CVS need complementary initiatives to prepare for the challenges that inclusion invariably presents to them. Empowering leaders and other personnel with key knowledge and skills is central to this strategy along with the provision of resources they might use with children and young people. To date, few concerted efforts have been made to equip the CVS sector with a greater awareness of the needs of children with ASD.

Conclusions

This project, initiated by AutismNI and funded by Children in Need is timely and at the very least should increase awareness in this region to the importance of addressing the social skills difficulties experienced by children and young people with ASD but hopefully it will provide pointers as to how this might be done using a multi-sectoral approach.

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Overall project aims

An application was made in November 2006 to Children in Need for a grant to fund this project which was awarded but the start was delayed until November 2007.

The main aims were:

1. To deliver training and support to children with Autism to help them manage the social challenges they encounter, and to help them and their families manage day to day life skills and deal with anger issues.
2. To deliver Parent Awareness sessions around social skills issues.
3. To deliver Community Awareness training to interested parties across Northern Ireland.

As the project unfolded a number of additional objectives became apparent. These were:

- To form partnerships between AutismNI and all major ASD stakeholders in the four local health boards and the ASD teams within Education and Library Boards. A Steering Group was formed of the major stakeholders from health and education.
- To develop an age-appropriate training programme for use with children in Key Stage 2 and in Key Stage 3. This was done with advice from psychologists, ASD teams and other professionals who have experience in delivery of social skills workshops.
- To work alongside statutory personnel and AutismNI Branches to recruit children and teenagers and identify suitable co-tutors to work alongside the project officer.
- To undertake a survey of CVS groups in order to establish their levels of interests and training needs.

A full-time Project Officer – Audrey Mullan – was appointed on a two-year full-time contract supervised by Mrs Jackie Addis, Training Officer, AutismNI. Her main responsibilities were the development and delivery of seven, six-session training courses and associated parent awareness sessions. She also designed and delivered 18 training courses for personnel from the CVS Sector in association with a training colleague from AutismNI.

Evaluation

Professor Roy McConkey from the University of Ulster was invited by AutismNI to evaluate the project. The main aims of the evaluation were:

- To document the processes used to establish and deliver social skills training.
- To detail the content and methods used.
- To describe the characteristics of participants and their families.
- To assess the impact of the training on young people and their families.
- To undertake a survey of CVS groups in NI involved with children and young people about their understanding of ASD, their engagement with these children and their anticipated training and support needs.
- To evaluate the impact of awareness sessions in ASD provided for personnel in CVS sector.
- To identify areas for further research and development and build a case for continuation funding.

The findings of the evaluation are presented within the two strands of the Project's work.

Strand 1: Social and Life-skills Training

Overview

This section of the report gives an overview of the training content; the young people and the families who took part in it, tutor assessment of progress and stake-holders' reactions to the training: namely the young people, parents and tutors.

The training programme

The main considerations in designing the programme to be used in the project were as follows:

- It would address the commonly experienced difficulties experienced by the children as identified in the literature (see p. 5) and by members of the Steering Group based on their personal experiences of these young people and more especially those known to them who were participating in the project.
- The sessions would be held outside of school but in a location that was convenient to the children's home (although this was not always possible). Parents had to transport their child to the sessions which were usually held after school in the late afternoon. The aim was to provide fun activities in a relaxed and child-friendly setting. Each session lasted around 90 minutes.
- The programme would be suited to two age groups: those in Key Stage 2 (8 to 11 years) and Key Stage 3 (11/12 to 13/14 years). This overcame the difficulty of mixing children across a wide age range but also meant that learning activities could be adapted to the particular needs of children at different developmental levels.
- The intervention was designed to be used with a small group of children (around six at most) all of whom had a confirmed diagnosis of ASD. This provided opportunities for mutual learning within the group especially given the differential abilities often found among children with ASD.
- A co-tutor would work alongside the Project Officer to enable one-to-one and sub-groups activities to take place. This person would be recruited from the statutory services and have prior involvement of ASD. This gave the statutory services a tangible stake in the project. Moreover it was hoped that experiences gained by co-tutors could be transferred into school and clinic programmes.
- A detailed lesson plan was drawn up by the Project Officer to guide the lesson and to give structure, continuity and consistency between co-workers. These plans were adapted according to the needs of the children attending and their reactions in the prior sessions. A copy of the lesson guides and the associated teaching resources is available from AutismNI.
- The following topics are covered by the lesson plans: creating group cohesion, awareness of self and others, personal space, volume control, turn taking, asking for and giving help to others, interrupting, starting and ending a conversation, telephone skills, emotions and anger management.
- Parents were invited to attend an information session about the programme prior to its commencement and also a final review session on its completion. These sessions aimed to increase their awareness about social skills training and gave examples of the activities that had been used with their children. In addition, parents had the opportunity to talk with the tutors at the end of the sessions when they came to collect the child.

Evaluation Strategy

The aim was to obtain feedback from all the stake-holders in the Project using a mixture of approaches.

Information about the children: Families completed written questionnaires and rating scales so as to provide information about their son or daughter prior to their involvement in the project and about their child's social networks and leisure interests. Three months after their child's involvement in the Project had ended, parents completed questionnaires that rated changes they had noted and provided opportunities for them to comment on how they had reacted to the training.

In addition to the attendance records kept by the Project Officer, she provided session-by-session ratings of the children's behaviours on selected social skills as a further means of monitoring changes over the training sessions.

Children's reactions: These were sought orally by the Project Officer at the end of each session and at the end of the training course. In addition, children in Key Stage 3 completed simple written questionnaires during and at the end of the course.

Parental reactions: Through self-completion questionnaires, parents reported on the perceived need for such training and on the benefits they perceived for themselves and the families. They also indicated the type of leisure and social activities they would like to see their child participate in.

Tutor and co-Tutor reactions: Self-completion questionnaires were used to obtain the views of the various tutors who had been involved with the sessions. This yielded information on the operation of the groups and improvements that could be considered.

Steering Group: The reactions of members of the Steering group were sought through a group interview regarding the implication and dissemination of the learning from the Project.

Further details of the number of participants and methods for gathering information are given below.

Participants

A total of 44 children were identified by Education and Library Board personnel for inclusion in the project. In all 40 (91%) accepted the invitation to join. However five subsequently did not attend or dropped out after one session. In all 36 children (90% of those identified) participated in one of seven groups which were held in the following locations: Downpatrick, Newry, Antrim, Belfast, L'Derry, Enniskillen and Cookstown. Three groups were held for young people in Key Stage 3 and four groups for those in Key Stage 2.

Characteristics of the children

Information was provided by the parents of 32 children, of whom 27 were male (84%) and five were female. These proportions are in line with children who have a diagnosis of ASD. The mean age when starting the course was 10.6 years (range 5 to 13.6 years).

The mean age at which children had received a diagnosis of ASD was 6.4 years (range 3 to 12 years). In all 29 parents rated their children's ASD behaviours on the Gilliam Autism Rating Scale. According to their ratings: six children had marked features of ASD; 12 had average ASD features; 3 below average features and 8 with low features of ASD. This illustrates the variation found in children's ASD characteristics. Overall on

the three subscales of this rating scale, the children tended to have more problems with social interaction and communication than with stereotyped behaviours

Six children were reported to have visual problems; six had other health problems and four had some form of physical difficulty. However two-thirds of the children had no other problems.

Two were only children; 14 were first born; 11 last born and five were middle children. The mean number of siblings was 2.5.

Characteristics of the families

Of the 32 families, 25 (78%) were two parent families and 7 (22%) were one parent families. Mothers were the primary carer for 28 children (88%); for three children (9%) both parents were the main carers and only one family reported that the father was the main carer (3%).

In all 27 (84%) families reported having a wage earner in the household compared to 5 (16%) which did not and 26 (81%) were home owners and 6 (19%) were not. Two of the families lived in areas that ranked in the top 10% of most deprived areas of Northern Ireland.

The age of the main carer was mostly between the ages of 40-49 (N=16; 50%), with one carer under 30 years of age; 13 (41%) between 30-39 years) and two (6%) aged 50 and over.

Most carers (N=19; 59%) had attended high education; 10 (31%) had left school with A levels or GCSEs but three (9%) had left at 15 years.

Children's social life

Most children (N=22; 73%) were able to be included on family outings. Moreover parents reported that seven children (22%) interacted with their siblings 'very well'; 12 (38%) rated it 'well' but 11 (34%) as 'not very well'. But a different pattern emerged when the question was asked in relation to children of a similar age from the neighbour or family circle. Only one child (3%) was rated to get on 'very well', 10 (31%) as 'well' and 16 (59%) as 'not very well'.

The children were reported to engage in a variety of play activities. When alone, they tended to focus on computers and play-stations, watching DVDs and Lego. A wider range of activities was noted for play with mum, dad and siblings; including more physical pursuits (swimming and cycling), conversations, cooking and indoor games. However play with other children was more constrained and focused in computers or constructional pursuits and only four children were reported to take part in social activities. Mention was made of a preference for playing with younger children. However several children were isolated from their peers:

None- he would not speak or play with other children-he would not even stay in the same room. 5

Doesn't like it when a lot of people come to house. Better 1-1 than groups-is bullied by peers. 7

He doesn't play outside with any children from the neighbourhood. 17

Is very isolated and has no friends in our area at all. His cousins are all much younger. 22

Two-thirds of the children (N=21) were reported to attend a youth club or organisation but 11 did not (33%). Youth clubs and groups were the most commonly mentioned (N=9 children) followed by sporting groups (N=7); music lessons (N=3); youth organisations such as cubs (N=3) and speech/drama (N=3). Dance groups, Sea Cadets and St John ambulance were each attended by one person.

Children's difficulties

Parents were asked to name the aspects of their child's problem they found most difficult to deal with. The top two mentions were: temper and anger outbursts (N=13) and social interactions (N=8).

His temper tantrums are very trying. Becomes very uncooperative and will scream uncontrollably. 6

Unreasonable or inappropriate behaviour; over reaction to certain social situations. 18

Mood swings; inability to listen, comprehend; inappropriate behaviour and language; difficulties with food. 28

When he has a temper tantrum, sometimes he will soil his pants. 34

Not being able to socialise with peers. Repetitive behaviours. 12

She considers herself to be the intellectual equal of adults and so believes she can tell them what she thinks they should do. This is seen as cheekiness and insolence. 6

Constantly asking the same question maybe 150 times a day. No enacting with other children his age. 1

Other difficulties mentioned were having no friends (N=4); disorganised (N=3); being bullied by peers (N=3); repetitive behaviours (N=2); eating problems (N=2) and dislike of school (N=2).

Some parents noted the stresses this caused them. One mother wrote:

I do feel that I try harder than most to be a good parent, and I am better than some. But I feel that to those that don't know me, I may seem to have poor parenting skills; even family members. Discipline is very difficult to implement in our home. 3.

Strategies for coping

Parents reported using a range of strategies for managing the children's difficulties. Examples included setting boundaries, having a routine, focus on positives, calming, giving space and explanations.

Closeness and love are provided so that it balances the negativity that arises. Boundaries are set e.g. no Nintendo or pocket money to show seriousness & gives consequences of behaviours. 13

Giving him his own space when he needs it. Having a routine. 10

Explaining everything in simple terms-letting him have his own personal time. 1

Setting a rigid routine-specific times, specific people to be responsible for her tasks and supervision. Lots of encouragement and giving her feedback. 7

Talking, distractions, rewards, compromising, not shouting or screaming at him! 18

Giving him time to cool off. Talking to him while he is calm and then each time reminding him to stop doing what is inappropriate. 30

Only one parent mentioned using medication, although this question was not explicitly asked.

Training sessions

Six groups meet once a week for a total of seven sessions. The children's average attendance was 6.3 sessions out of 7. A further group met as a summer scheme for five consecutive days. Here the average attendance was 4.4 sessions. (The latter group were excluded from the following analyses).

The project officer rated the children on pertinent social skills from her observations of the children in the first session and then again on the seventh session. The scale used

was 1='very poor', through to 5: 'same as any child of this age. The mean scores given the group of children on the first and last session are shown in Table 1.

Table 1: The mean scores given by tutor on social skills ratings (N=27).
(NB Shaded areas indicate significant improvement)

Skill	First session	Last session
Offers comfort	1.6	2.7
Asks for help from students	1.9	2.1
Imaginative play	2.2	3.0
Sharing without asking	2.3	3.3
Maintains conversation with students	2.4	2.8
Head shaking NO	2.5	2.4
Head shaking YES	2.5	2.4
Eye contact	2.6	2.9
Repetitive behaviours	2.9	3.3
Asks for help from teachers	2.9	3.3
Appropriate facial expression	3.0	3.2
Appropriate use of questions	3.3	3.2
Maintains conversation with teachers	3.4	2.9
Interaction (turn-taking) with other students	3.5	3.0
Staying on task	3.5	3.5
Engaged on Task	3.6	3.8
Interaction (turn-taking) with teachers	3.6	3.7
Anger outbursts directed at students	3.8	3.0
Tolerating being with group	4.2	4.2
Anger outbursts directed at teachers	5.0	5.0

Table 1 indicates the skills the participants found especially difficult – reading from the top down. On only two skills (the last two listed) were ratings close to those expected of children of their age. This pattern was largely maintained in ratings given at the end of the seven week period. Hence this data confirms and expands the accounts given by parents.

However on certain skills the children were rated by the tutor as having improved after the seven sessions. These were mainly among the children's weaker skills at the outset. Even so, the children continued to show marked deficits in certain of their social skills; notably in asking for help from other students and in their use of non-verbal signals.

This data needs to be treated with some caution as it was not possible for it to be independently verified. Nonetheless the tutor noted improvement on only certain items

which suggests that she was not inflating the improvements shown by the children. Also seven weeks – totalling around 10 hours of teaching – could not be expected to bring about major changes.

Tutor's reactions

The Project facilitator was assisted at the sessions by a co-tutor employed by education or Health and Social Care with experience of working with children who have ASD. They attended for one or two sessions; hence different persons may have been present with the group of children over the seven sessions. The aim was to provide the co-tutor with some familiarity of the approach as well as using their expertise to assist with the group.

Self-completion questionnaires were received from nine co-tutors including advisory teachers for ASD, psychologists and a specialist social worker. The feature they most liked about the sessions was the relaxed atmosphere, the range of activities used, the break and snack times, and the chance for the children to learn about one another.

The co-tutors were generally unable to comment on changes in the children as most had been present for only a few sessions. However there were comments about more interaction occurring:

Became more trusting of us and spoke out more 5

The boys became more relaxed and trusting as the sessions progressed 8

The workshop seemed to liberate them in many ways as they could fully express their unique personalities without being judged. Many in society (i.e. in schools) would say that these young people have no sense of humour but they made me laugh with their sharp and dry wit. 7

All would recommend sessions like these to other parents. The reasons they gave included:

Good relaxed atmosphere. Supportive and understanding leadership 1

To get the parents to move away from the narrow focus on causation and more towards a mind-set of helping their children to adapt to the social environment with the proviso that the social environment itself should adapt to accommodate these special but different children. 7

Organised and supervised interactions with peers in a safe environment. 9

The main improvements suggested were for a consistent co-tutor to be present for all the sessions and for more in-depth follow-up on the topics.

Having the same person present might have provided more support with behaviour management 9

The topics would need more indepth sessions – we could have spent 6 weeks on one emotion such as anger 3

A pre-group assessment to help create groups based on current levels skills/needs 9

Children's reactions

The children and young people were asked for their reactions at the end of each session as well as at the end of the course. All the children at Key Stage 2 reported that they had enjoyed the session but as Table 2 shows, this percentage was lower for the young people in Key Stage 3. Across both Key Stages, the activities that they had enjoyed most were the games (@ 50%) followed by the snacks for the children at Key Stage 2 (@30%) and by listening (@20%) for those in Key Stage 3. The discussions were mentioned by around 15% of participants.

Few dislikes were reported but they included: particular activities; the food provided; the presence of a certain person and too much randomness.

As Table 2 shows, most children at Key Stage 3 enjoyed meeting other children, the teachers and the activities provided whereas nearly all those at Key Stage 2 reported that they did.

Table 2: The percentage of ratings over sessions for children at Key Stage 3 attending the sessions (N=89 sessions).

Course feature	Very much	OK	Not really
Did you enjoy coming to the workshop?	71%	29%	0
Did you enjoy meeting other children?	79%	21%	0
Did you like the room?	64%	30%	6%
Did you enjoy the activities?	74%	24%	2%
Did you like the teachers?	78%	20%	2%
Would you like to come again?	69%	28%	3%

The young people in Key Stage 3 at the end of the sessions were asked to rate themselves on the following items (see Table 3) and the percentage selecting YES are noted (from 16 persons who responded):

Table 3: The percentage of Key Stage 3 participants rating changes at the end of the sessions (N=16).

Item	% response
It helped you to make friends more easily	100%
It helped you to ask questions or help from your parents, brothers/sisters	88%
Ask questions or help from your teacher/classmates	94%
Do you feel less worried and more able to cope with new situations	75%

Over two-thirds (69%) confirmed that they would like to take part in future sessions.

Parental reactions

Three months after the sessions ended, parents were sent a self-completion questionnaire to ascertain their reactions to the sessions and if they had observed any changes in their sons or daughters that were apparent after their attendance at the course.

Parents noted a range of things they had liked about the sessions including small groups (N=6); the variety of activities provided (5); the children looking forward to going (4); and the skills they had learnt (3).

The size of the group and the personality of the teacher 13

The groups were small. The children involved were able to discuss problems and worries. They had each other in an environment that encouraged them to do so. 15

The fact that my daughter had been given this opportunity to learn basic social skills and to see how much she enjoyed it each week which is unusual 23

How each session dealt with issues which occur frequently each day-all topics were relevant 5

They all felt that their child had found something to like in sessions. The most commonly mentioned was meeting and talking with other children (N=18) and the activities and games they had taken part in (N=10). Also mentioned was the relaxed atmosphere (N=4) and building their confidence (N=3).

Playing games, playing with friend and who she hopes to keep in contact with 2.

Being able to have fun, making friends, no one there to make fun of him 33

The social occasion – the ability of being in a group of similar children 8

Not terribly forthcoming with detail. Took it as positive indicator that she looked forward to going 6

There were few mentions of things that parents did not like. It was suggested that children from the same year group might make up the group to avoid too wide an age range; that homework to be given and one parent would have preferred the child to be unaware of his diagnosis. However the biggest complaint was that the sessions needed to continue.

Wish there were more sessions-he benefited so much and feel he would have improved more if they had been more long-term 30

I would prefer them to be on a regular basis 15

Four parents mentioned aspects that their child did not like:

It was a bit of a rush after school time-not much time to relax after school or get homework done 30

She found one of the children's behaviour difficult to cope with and asked if she behaved like that 23

Parents were asked to mark out of 10, the various aspects of the sessions with a score of 6 and over indicating that they were happy with that aspect and scores of 5 and below indicating unhappiness. Table 4 gives the median and range of scores for the 24 parents who returned questionnaires.

Table 4: The median ratings given by parents to different aspects of the sessions (N=24).

Aspect of the sessions	Median Score	Range
Teachers running the sessions	10	6-10
Activities covered	9	6-10
Information sent home with the child	9	6-10
Meetings held with parents	9	4-10
Letter to be given to child's teacher	8.5	0-10
Activities you could do at home	8	5-10
The mix of children in the group	8	3-10
Time they were held	8	2-10
Location of the sessions	6.5	2-10

Overall parents were very satisfied with most aspects of the course. The items that had greatest spread of ratings were to do with the mix of children as well as the timing and location of sessions. These suited some families more than others and reflects the difficulty in bringing together a group of children of particular age and characteristics living within reasonable travelling distance of one another.

I do feel that children of the same peers, ie a group of 11 year olds – would enable bonding and developing of interests comparable to the same age. 7

Regarding the letter to the teacher, some parents said they had not received one and of those who did, several thought it was very basic and did not like the idea whereas others thought it was great and had explained things clearly.

All parents stated that they would recommend the course to other families. The chief reason they gave was the benefit it brought to the child in terms of social skills and acceptance of their difficulties.

A great social group activity. Boosts child's self-confidence whilst attending 8

Course was very beneficial for child and others like him. Gives them confidence to take on the daily challenge they have in the social environment and makes them far happier children 16

The subjects covered let the children see things from different angles, improved their skills and let them meet other children with similar difficulties 25

For my son, apart from school, this was the only other interaction with others his age 35

A few parents mentioned the benefits the course had brought to them.

Parents of autistic children are left very much to themselves. Support is so appreciated-anything 13

To be aware of various skills used to give information to children with ASD – visual aids, number scales etc. 2

You learn from experience and some people have great learning tips to help you to cope. 1

Perceived changes in children

Parents were asked to rate any changes they had seen in their child during or since attending the sessions. They were asked to give a mark out of ten with 5 meaning there's no change; a score below 5 meaning it has got worse (with a lower score meaning much worse) and a score above 5 meaning it has got better (a higher score means much better). Table 5 summarises the median and range of scores given by the parents.

Table 5: The median ratings given by parents to changes in their child (N=24).

Changes	Median	Range
Communication/conversing with you	7	5-9
Confidence to try new things	6.5	5-10
Controlling volume of speech: not too loud/soft	6	5-9
Eye contact/turn-taking	6	5-9
Temper tantrums, anger, screaming	6	5-10
Respecting personal space of other people	6	5-10
Asking for help from another person	6	4-10
Personal hygiene and self-care	5	5-10
Doing homework – reading, writing	5	5-10
Following instructions, keeping to rules	5	5-10
Mixing and playing with other children	5	5-9

Repetitive questions, repeated actions.	5	5-9
Getting anxious	5	5-9
Time spent on computer	5	3-9

On the first six items, most children were rated as having improved and on the other items in the Table some children did show improvements whereas most did not. The last item – spending less time on the computer could be seen as a gain.

Overall 16 parents reported positive changes; 2 no changes and 6 did not answer. The main gains that they reported were in terms of socialising (N=6); confidence (N=4); communication (N=2) and willingness to try new things (2).

I just feel since the course, a light has gone on and it's shining brighter every day 16

We think she is a bit more outgoing, more in control of her emotions, coping better 12

Greater understanding of people and methods to try and help him overcome his difficulties 5

If he is rude and oversteps the mark in front of say, new friends, he'll apologise later (unprompted) 13

He is a different child-fun, happy and confident 16

Has grown up more. Loses his temper less frequently over things he can't change e.g. broken X-Box 30

But one parent commented:

Not a lot (of change). Maybe if the sessions were ongoing it would be more noticeable 17

Family benefits

Parents also reported some benefits to them as parents and to the wider family. These included being less stressed (N=5) more understanding and awareness of their child's difficulties (N=5) being more together as a family (N=4) and ideas for activities (N=4).

The whole living environment has changed- don't feel I need to be so focussed on child and can give attention to other members of family 16

He has had the best summer yet. Overall the confrontations with his 12 year old sister have been down. That could also be because of her ability to deal with conflict 13

Sessions have given us a better understanding of why he behaves in certain ways 34

Greater understanding of people and methods to try and help him overcome his difficulties 5

Few suggestions were given for making the sessions of more benefit to parents and families with parental participation in the sessions and holding them closer to home as the main proposals.

Being with child (in the group) as our child sometimes doesn't convey what was learnt or said in classes 1

If the sessions were closer to me 15

More activities and visual hints to try at home 30

Finally, parents were asked to indicate topics for future workshop sessions. Their responses centred round social and personal relationships (N=9) and dealing with emotions such as anger (N=6).

Sexuality, changes in body, relationships 35

Bullying. being assertive, giving your opinion, relationships, shopping for yourself, complaining, eating new food, smile more 23

Anger management and continuing on rules for friendship. Both of these to prevent isolation 13

Any topic but more time spent on each – maybe 2/3 weeks on a couple of topics. 9

Looking to the future

A further feature of the evaluation was to invite the informants to share their views on the implications for the future. With the tutors and members of the Steering Group the focus was on further training courses for the young people while with parents we **enquired** about their child's involvement in community activities.

Looking to the Future - tutors

The co-tutors were invited to comment using self-completed questionnaires about the future provision of social skills training while a group interview was conducted with members of the Steering Group.

There was unanimous agreement on the need for these workshops to be available outside of school as well as within school, and for parents to be more involved in social skills training.

Among the comments made about providing workshops outside of school were:

Good idea to get a mix from different schools 1

To encourage young people to participate and be active members of their community 4

Some children see school as being formal – as an unfortunate necessity – whereas these sessions offer more relaxed learning. 5

Statutory services are unable to meet this need 8

The sessions are run by staff with knowledge, experience and understanding of young people autism. Such services seem to be limited 9.

It was generally agreed that six weeks was insufficient and that follow-ups were needed. Also personal contact between the tutor and teachers (rather than by letter) would have helped with generalisation of learning as children could practice further in school contexts. Individual coaching between sessions would have been beneficial for some children. Also it was noted that teenagers leaving school required more career guidance and social skills training if they were to be accepted for further education courses and to obtain paid work.

However schools were also seen to have a role in developing social skills.

The revised curriculum should now be covering social skills but not sure if very school is as enthusiastic as they should be 1.

Confusion of what is acceptable and unacceptable can be overlooked at school 5

Children/students with ASD do not have enough opportunity to develop social skills at school 6

All the academic skills and competencies in the world will not compensate for poor social skills but good social skills can compensate for academic underachievement 7

This key area of development needs to be a central feature of all programmes of support for pupils with ASD, With the support of the ELB Advisory service this is improving very significantly. 8

It is not just children with ASD who would benefit from social skills training – the school and other pupils also. 9

Discussion in the group interview identified some of the barriers present in schools such as a reluctance to call on ASD advisory team unless a crisis arises; a lack of concern with social skills in the secondary school curriculum, support needed by teachers to

embark on this type of programme and the school feeling ill-equipped to undertake this style of education.

However schools may be open to ‘outsiders’ coming in to present such a programme; the advent of legislation should encourage schools to make suitable adaptations to meet the needs of pupils with special needs and classroom assistants might be able to undertake this programmes with appropriate supervision.

The main rationale for involving parents was to increase their knowledge and understanding and to assist in the generalisation of skills from the training sessions.

Empowering parents with social skills training will help generalization across many contexts. 7

It is not rocket-science that they need to be taught 3

It will help them to deal with the situations that arise at home 9.

However there were concerns that some parents were not sufficiently motivated or interested in helping their child, possibly due to other problems that they face, whereas others expected schools to do all the work, yet there was only so much that schools could do as these skills needed to be generalised into ordinary living and community settings.

All informants recognised the importance of furthering the young people’s community involvement as they are at risk of being excluded from summer schemes and after-schools activities, and they can have few friends. Branches of AutismNI were proposed as a means of providing more recreational activities for teenagers especially and the provision of specialised training opportunities.

Looking to the future - parents

Parents were asked to report on the community activities that their children participated in at present or had done so in the past year. These included after school activities and those done away from school. They were also asked to note the activities that they felt their child with ASD might like to participate in. Table 6 summarises the number of children from the 24 parental responses.

Not surprisingly, the children with ASD show a somewhat different pattern than their siblings with more emphasis on solo sports such as swimming, rather than outdoor sports. Also they were perceived to have more interest in arts and crafts/chess and computer clubs. Suggestions for other activities made by parents included:

Trampoline lessons 5

Archery 8

Maybe 10 pin bowling. Is all over the place as he throws a shot but somehow does well at it 13

Is very keen to go to the gym. This is something we will do during the summer holidays 33

Anything - just to take part would be a great achievement 1

When asked about the things that generally made it difficult for the child to join in community activities, their explanations were of two sorts – those that emphasised the child’s difficulties and those that recounted barriers in the community. For example:

He just becomes distracted and disruptive 3

His ADHD, making him jump about in a bizarre fashion. Although he can’t dispute anything regarding the score, which makes it suitable for his make up 13

Table 6: The number of children reported to participate in community activities (N=24).

Activities	My other children do this	My Child with ASD does this	My child with ASD might like this
Outdoor sports, e.g. football, athletics	9	5	4
Youth organisations, e.g. Brownies, Cubs	9	7	4
Swimming	9	12	4
Musical activities, e.g. choirs, bands	7	5	5
Indoor sports, e.g. Gym, karate, pool	5	8	6
Dancing	5	2	4
Youth clubs	5	4	4
Arts and Crafts Clubs	2	4	9
Chess/computer classes	0	0	14

She will join and only stick at it for a few weeks. Her perception of situations has often upset her and she is often ignored and bullied 23

Community barriers included:

Lack of knowledge or experience by local clubs/leaders of ASD 29

The leaders not understanding him; transport- I don't drive; childcare-younger siblings at home, I'm a single parent 30

The other children misunderstanding, teasing; leaders unable to deal with this or explain 35

Nothing in our area for children with ASD – activities in our area involve large groups of children 1

Their suggestions for overcoming these sorts of barriers included:

More education for leaders; more structured programmes-he likes to know what they will be doing the following week 30

Leaders and other children involved, need to know and respect the differences in people 35

More training for community organisations 3

Conclusions from Strand 1

A number of conclusions can be drawn from the range of data gathered in the evaluation.

- It was feasible to organise special sessions in various localities across Northern Ireland but this required close co-operation with education and HSC Trust staff, notably the ASD support teams who identified and invited children to participate.
- Children were easier to recruit for the groups held for pupils at Key Stage 2 (aged 8-11 years) whereas some older pupils were disinclined to join groups despite their parents' eagerness for them to attend.
- Finding a suitable location and time to suit all participants was difficult and some parents had a two-hour return journey to attend the chosen locations. However a central location for the participants in the late afternoon was the best compromise.

-
- A group of around six seemed ideal but a consistent co-tutor would be ideal for all sessions. The seven weekly sessions enabled the basic skills to be covered while maintaining attendances. However follow-up sessions and/or the provision of workshops/courses on other topics were requested.
 - The sessions were rated highly by the children, their parents and the tutors. There were few suggestions for improvements. They were especially appreciative of the group leader, the range of activities covered, the games approach that was used and the information sent home after each session.
 - There were clear indications that the children had benefitted from the sessions as seen in their self-ratings, their parents' reports and in the ratings and comments from the tutors. Their conversations, confidence and communication skills were perceived to have improved.
 - Certain children seemed to benefit more than others which may reflect the variation found among children on the Autism Spectrum. More extended or intensive work could benefit all children.
 - Parents and families were also perceived to benefit by being less stressed, more family interactions and better understanding of their child. However parental attendance at the sessions prior to, and after, the course was variable and mothers commented more on the informal contact they had with the tutors than on the formal sessions as being of benefit to them.
 - Not surprisingly, children and families would like further sessions and they were also keen to recommend them to others. However the resources for doing this as per this Project would have to come from the voluntary sector.
 - There are also examples of social skills training occurring within Education and HSC Trusts and in the medium to longer term it may be possible that schools could take on more of this type of work, with CVS and family involvement to support these efforts so that learning extends beyond the classroom and school. Hence joint working between the voluntary and statutory sector is required.

Strand 2: Community and Voluntary Organisations

Two main activities formed the work of Strand 2

1. A survey of community and voluntary sector (CVS) groups involved with children and young people throughout Northern Ireland. This was to ascertain their previous experience of these children and their reactions to their enrolment in their groups.
2. An evaluation of a short training session designed particularly for CVS personnel which ran in 10 locations with attendances in excess of 200 persons.

1. Survey of CVS organisations

There are few published reports of the attitudes which the general public hold to people with ASD and none specifically about the perceptions and reactions of people involved in the provision of community leisure and youth activities. Hence the aims of the survey were:

- To identify past contacts that informants had with children and young people with special needs and with ASD in particular.
- To describe their experiences – both positive and negative.
- 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. Some undertook to distribute the questionnaire to their affiliated groups. Around 2,000 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 range of organisations. The most commonly reported were uniform organisations for girls, such as Girls Brigade and Guides (N=57) and for boys, i.e. 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 75% of responses came from females and 25% males. 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.

Experiences of disability

Over 60% of respondents currently had children with special needs enrolled in their group and a further 21% had in the past with 17% having no enrolments of children with special needs. The children enrolled 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 median number of children with special needs that the respondents had contact with was three children (range from one to 500).

Contact with ASD

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

If asked in the future, half the respondents (42%) stated they would be 'very willing' to have a young person with ASD in their group and a further 39% stated they would be 'willing'. However eight (4%) would prefer not to enrol such a member 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.

All children should be given a chance to be included socially 70

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

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

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

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

We have experience in Scout Group and I work with special needs children in school 197

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 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.

Working with ASD child is both challenging and rewarding for all concerned both leaders and young people 2

Would like to help encourage and benefit from their areas of strength 13

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

Those respondents who indicated they would be '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.

No training in working with children with special needs completed by me or other workers 18

I know little about autism and would have concerns regarding effects on other children 68

As we have special needs girls already on the register, we would have to be sure that resources of staffing and girls could provide appropriate inclusion 109

Would be concerned that behaviour might disrupt the group but we would put concerns aside and welcome the young person into our group 148

As a voluntary unit we have limited staff and can be demanding organising a weekly programme 28

You need the total backing and support of parent/guardian before taking a child with ASD 39

My only concerns are the level off noise in our building- which wouldn't be suitable for all children. 907

Furthermore, 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 7 summarises the responses they gave. The two most preferred options were having information leaflets and the availability of training courses for leaders.

Table 7: 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%

Other supports they mentioned were:

Financial support for particular needs 1

Financial support for 1-1 worker 141

Would be helpful for advice in ordering equipment for children with special needs and also help with a grant for further needs 77

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

Dedicated website advice 159

These are some of the comments that respondents noted in finishing off their questionnaires that captured the tension many felt in wanting to respond positively but realising the practical issues involved. :

Severity of a child's condition would need to be taken into account before enrolling them 52

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

Other parents may not understand and appreciate we are trying to be inclusive of all girls 109

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 137

It has been hard work with some young people but very rewarding to include people with special needs and ASD 147

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.

2. ASD training for community group leaders

In light of the survey findings, a short, two hour training course was devised to provide an introduction to ASD that was tailored to the specific needs of leaders working with the range of groups noted above. The main aims of the course were:

- To give an overview of AutismNI and the services it provides.
- To describe the main features of Autism Spectrum Disorders
- To explain the impact of ASD on children and young people and the difficulties that might be encountered in leisure groups and activities.

The programme and content for the course was as follows.

- Powerpoint presentation on AutismNI and the key features of ASD.
- Social skills – Do's and don'ts.
- Helping children to learn.
- Who's there to help.

The courses were free 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 room in library or leisure centres, and they were generally held in the evenings. The courses were tutored by the Project Officer and by Sue Macleod from Autism NI.

The Figure shows the location of the courses held around N. Ireland. In all, nearly 400 people attended with wide variation among participants in the different locations from two persons to 30 plus.

Evaluation forms were completed by 249 participants. 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 39 persons (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 the following groups:

Leisure centres	41
Youth organisations	27
Special needs groups	17
Schools	9
Church groups	6
Sports groups	4
Community groups	4



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 Autism Spectrum Disorders (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. 15

The examples and person anecdotes that made the theory real. 25

Everything mentioned was generalised to daily situations which improved my understanding; also closing eyes game-brilliant for understanding awkwardness and barriers to communication. 37

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

Advice on how to deal with kids with ASD on various ends of the spectrum. 113

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. 158

When asked specifically about the new information they had gained from the course, 25 persons noted 'everything' and a further 20 stated that it had reinforced what they already knew. However 22 commented on ways of helping; 18 commented on sensory difficulties; 14 on communication problems and 13 persons recalled the 10 second processing rule. Also 10 persons mentioned gaining an insight into how children with ASD think or react; 12 noted social skills; 7 the triad of impairments and 5 the signs to look out for that a child may have ASD.

What having a social imagination deficit means. 25

That vocal conversations are not taken in the same way as another child will understand them. 35

How to act around and keep the environment OK for kids with ASD. 113

How they see and feel things different from us; difficulty with communication, imagination and in social circumstances, how they take things literally. 167

I did not realise that autistic children were sensitive to touch and they took words and actions literally, which in turn will encourage me to be more aware. 183

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, with 134 reporting a change of whom 17 (9%) stated a very great change had occurred. Their descriptions of the change that had occurred could be grouped into four main categories: empathy and insight into the problems they experience (35 mentions); actions that they could take to help the child (29 mentions); greater awareness of ASD and more patience and understanding. For example:

Will try to be more calm and try to think how they do. 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. 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. 12

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

I will not find them strange or different, just understand their needs. 105

My perception would never have been negative before, however, I would be more aware of how I speak to a child with autism. 158

Respondents were also asked to rate various aspects of the course out of 10 in which scores below 5 indicated things they were not happy with and those scored 5 and over, the things they were happy with. Table 8 gives the median and range scores for the 188 respondents. Ratings throughout were high and particularly so for the tutor, the friendly and relaxed atmosphere created, the way the information was presented and the content of the course. Discussions with other participants was not a strong feature of the course.

Table 8: The median and range of scores participants gave for aspects of the course for community group leaders

Aspect of the course	Median Score	Range
Tutors presenting the course	9.5	5-10
Friendly and relaxed atmosphere	9.4	5-10
The way information was presented	9.3	5-10
The information covered	9.2	5-10
Written Information you were provided with	9.1	3-10
Location of the session	9.0	5-10
Suggested actions/activities you could do in your group	8.8	4-10
Time it was held	8.7	4-10
Discussions with other participants	8.1	1-10

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

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

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

The number in the group was too large, some people also had to rush off. 90

Extremely small print on handout. 33

Perhaps get each person attending the opportunity to introduce themselves and why they are interested in the topic. 49

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:

Most certainly- I can take away the tips on what to look for when working with a group. 66

Yes, being able to explain to other leaders as to what they need to do if a situation arises. 159

The strategies were very helpful and precise. 6

The handouts were very clear. 7

I can revise the handouts with them and display the wee leaflet. 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. 15

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

A clearer understanding of ASD by stories, role play and small activities. 36

It's friendly, relaxed and informative. 17

Community centres would need to accept kids with autism as one beside where I live, doesn't accept anyone with any disability. 54

To get some ideas on integrating young people with autism into youth activities; to help staff/volunteers understand behaviours and ultimately the young people. 67

Some final words ...

Overall excellent session. I feel refreshed and confident in greeting, teaching autistic individuals and look forward to meeting more, understanding and learning their unique personalities. 134

From a parent's perspective, I am thrilled that the leaders have received some form of training/awareness of the very real issues affecting young people and adults in our community. Very highly recommended. 163

The course would be well received if delivered in community venues to workplaces and teams in YMCA. 66.

Conclusions

A number of conclusions can be drawn from this strand of work undertaken by the project.

- A range of CVS groups have experience of taking children and young people with special needs. The absolute number is not known and may even be quite small but this is an important foundation for encouraging yet more groups to become more inclusive.
- A proportion of groups have had the experience of taking a child or young person with ASD once they had been approached to do so, usually by the child's parents. This generally was a positive experience for leaders and members as well as the young person with ASD.
- Around half the leaders would be very willing to enroll a child, often citing the desire to provide equal opportunities for all children in locality.
- The need for training and the provision of relevant information were seen as key supports for CVS groups.
- 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.
- Participants would encourage others to take the course and suggestions were made for extending it to members of groups as well as to leaders of other groups that were not so well represented.

Recommendations

In this final some of the wider issues emerging from the project are discussed and recommendations made. The overarching conclusion is simply stated:

There is a need to promote the social skills of children and young people with ASD.

The need for social skills training and the extent of social exclusion that children with ASD can experience as a consequence is by now well established in the international literature and this project confirmed its applicability to young people in Northern Ireland. But equally, the Project has demonstrated that it is possible to address these difficulties and that even a relatively short programme of around 8 hours in all, can make a difference for some children.

Likewise a brief but focussed training course for leaders of community groups can act as a stimulant for them to enrol children with ASD in their organisations or activities. However a great deal remains to be done in order for these opportunities to become well established throughout Northern Ireland. Four possible strategies are noted.

Multi-agency partnerships are needed to produce social inclusion

The experiences from the Project would suggest that partnerships are required among four groups in order to achieve the goal of increased social inclusion.

First, parents have a key role to play in recognising the child's difficulties, creating opportunities for them to socialise and encouraging generalisation of the newly acquired social skills.

Second, schools should be more proactive in assessing and developing the social skills of pupils with ASD. This is inherent in the new schools curriculum with its emphasis on social and personal development.

Third, specialist ASD agencies such as AutismNI have a continuing role to play in providing local opportunities for young people with ASD to socialise and in the provision of dedicated social skills training opportunities both for them and for the people involved with them, such as parents and teachers. The role of the Departments of Education and of Culture, Arts and Leisure in funding the CVS to enable these contributions is probably necessary.

Fourth, CVS groups must be encouraged and supported to become more socially inclusive of children with special needs. Those with positive experiences should be mobilised to share their approaches with others.

It is more difficult to identify how these groups might work more proactively in partnerships with one another but this may well emerge more easily at a local level with partnerships forming among schools, CVS groups and local branches of AutismNI.

In addition the ASD specialist teams in Education & Library Boards and in Health and Social Care Trusts could have a valuable supportive role to these efforts although they are often over-stretched and could find it hard to take on new responsibilities. An extension of the training courses they provide for school staff in partnership with the CVS might be one response they could feasibly make.

Resources to promote social inclusion

All the groups mentioned above could benefit from access to information and training resources that will assist them with their role in promoting social skill acquisition and

furthering the children's social exclusion. The materials developed and used on the Project should be available more widely, perhaps as a resource kit along the lines of similar materials produced by AutismNI for the early years for use by leaders and staff in the CVS sector. Sponsorship for such a resource might be sought from statutory or other funders. This resource could be coupled with a training programme for CVS leaders that might be undertaken in a similar way to the Keyhole training developed by AutismNI with the Early Years Organisation and Barnardos.

Nurturing social skills

The nature of social skills is such that it is unlikely that they can be acquired through didactic instruction. Rather social skills need to be nurtured through interacting with familiar people in a context of trust, safety and enjoyment. The learners need to be active communicators with the learning taking place in natural settings. These attributes stand in contrast with some of the specialist approaches that have been developed for use with children who have ASD. In sum, informal and interactive contexts may prove a superior to nurturing social skills than would structured and formal lessons that were a 'bolt-on' to other curricula topics.

Further research and development

Inevitably a project of this kind raises still further questions that deserve further consideration by Autism NI as well as their service partners. These include:

- What approaches might be used at Key Stage 1 to encourage the development of social skills. Could these grow out of the early intervention approaches successfully developed by AutismNI? This could mean refocusing on social skills rather than on behaviour management and language skills
- For children at Key Stages 2 and 3, what further skills need to be targeted in an extended training course? Likely topics would be on turn-taking, negotiating, forming and maintaining relationships.
- How might children with ASD join with non-ASD peers so that they have role models and mentors to develop their social skills? This could happen within schools but there may be opportunities for this to take place as part of the activity programme in CVS groups. Nonetheless children and young people with ASD may benefit more from being with others who also have the condition.
- Can a network of acquaintances and friendships be developed and maintained for teenagers with ASD as a result of these interventions? What effect might these have on the young people's emotional well-being?
- There is the potential for cross Departmental funding in view of the responsibility currently placed upon DCAL, DENI and DHSSPS in the three main areas covered by this model (in the home, in school and in the community). This may require some legislative action to enable appropriate adaptations and require greater inclusion of families and the CVS alongside statutory provision.

In sum, the Project has demonstrated what can be achieved by a carefully planned and educational programme that addresses the needs of children with ASD that has been largely overlooked to date. Various strategies have been identified and resources developed that can be extended to many more children and community groups throughout Northern Ireland and beyond. Autism NI and the funders of the Project are to be congratulated for developing these initiatives.

Appendix 1: What is autism and what helps?

“Autism is a complex developmental disorder that essentially affects the way a person communicates and relates to people”. It is often evident by two years of age but it affects children in varying degrees of severity. The term Autistic Spectrum Disorders is used to reflect this variation.

Children with ASD share three common impairments. They have difficulty interacting socially and appropriately with other people; they have problems both with understanding and in using language to communicate and their capacity to think imaginatively is impaired.

Their intellectual abilities also differ markedly. Some will have severe learning difficulties whereas others function in the average or above average range. The latter tend to be referred to as Asperger’s Syndrome.

Children with ASD may look like other children but many behave inappropriately for their age.

They can experience a range of additional difficulties in everyday life such as limited attention span, anger or aggression when things go wrong, poor organisational skills, sleep irregularities and clumsiness due to poor motor control. They engage in repetitive play activities and obsessional routines.

Autism appears to be a life-long condition although there are claims that ‘recovery’ or cures are possible for certain individuals. Recent advances strongly suggest that the condition is ameliorable and improvements are possible.

The numbers of children being diagnosed as having an autistic spectrum disorder is increasing in the United Kingdom (Loynes, 2001).

What causes autism?

The short answer is we don’t know for sure. Autism appears to have a strong genetic component that affects the development of the brain and the sites of the possible relevant genes are starting to be identified. It can occur in association with other conditions such as maternal rubella, anoxia and encephalitis.

Debate continues over links with MMR vaccinations although this has been discounted by authoritative sources in the United Kingdom and United States.

Former theories of parenting styles causing the disorder have been discounted.

It is becoming possible to identify those families most at risk of having a child with autism. There is higher likelihood if one child has autism or a member of the wider family circle is affected. Autism is much more common among boys than girls.

Diagnosing autistic spectrum disorders

Delays in obtaining a diagnosis are a particular source of distress for parents (Quine and Pahl, 1987; Howlin and Moore, 1997). Siegel et al (1988) reported that parents most often expressed their initial concerns to paediatricians, noting delays in language and social behaviour by the age of eighteen months. By age 2.5 years, most parents had sought a diagnostic evaluation but their child was aged 4.5 years on average before they received a diagnosis of Autistic Spectrum Disorder.

In the United Kingdom, children appear to be older before a diagnosis is made. Frith and Soares (1993) found that 76 percent of parents had received a diagnosis by the time

the child was 5 years old. However a more recent study by Howlin and Moore (1997) involving nearly 1300 members of the National Autistic Society, reported that only 53 percent of their children had been diagnosed by this age. Moreover, there were wide regional variations in diagnosis; families in Scotland, Cumbria and Belfast were more likely to receive later diagnosis than their peers in the rest of the United Kingdom.

Christie (1998) in pressing for an earlier diagnosis of these disorders argued that *'to deny parents access to that diagnosis is to deny them a complete under-standing of their child's needs and to restrict their access to information and support'* (p.8). Fraser and Levine (1995) reported that a majority of parents felt relief on confirmation of a diagnosis and they urged professionals to refer parents to appropriate resources.

Nonetheless, the difficulties in arriving at a diagnosis are well documented. Shea and Mesibov (1985) reported that classical cases of autism are greatly outnumbered by cases with mixed, impure and partial characteristics. Happe (1994) noted that it is easier to recognise individuals at the mid-point of the spectrum rather than those at the lower end where the child's level of functioning is so poor that social, communicative and imaginative functioning is in line with general developmental functioning. At the upper end of the spectrum, people may have developed coping strategies that disguise their real problems.

Gillberg (1995) contends that a diagnosis of Asperger's Syndrome should not be made before the child's fifth birthday

Screening and diagnostic tools for use with children under three years are still in the development stage (Votanis et al, 1994). Also reservations have been expressed about the efficacy of primary care services being able to reliably detect such children given the low numbers they are likely to have in their case loads (Peter, 1993).

The value of multidisciplinary working in making a diagnosis is also well attested in the literature, particularly paediatrics, psychology, psychiatry and speech and language therapy (Ellis, 1994). However existing systems often do not allow for this; split as they are between education and health services; with the latter further located in hospital and community settings. Parents often complain of the lack of co-ordination and communication among these agencies and professionals (Stallard and Lenton, 1992; Beresford, 1995).

Although priority would be given to equipping local services for these tasks, the report did foresee the need to have a specialist autism service that could assess 'difficult to diagnose' individuals; provide a second opinion and give a focus to the acquisition of autism-specific expertise.

What can be done to help?

"Education remains the one treatment approach with the best track record for dealing with the difficulties associated with autism". (Jordan, 1997).

Among the important dimensions to educational provision are:

- Recognising and identifying the child's problems from an early age – 18 months onwards.
- Developing an individual education plan to address the child's particular difficulties and needs
- Training families on teaching programmes they can use with their child at home.
- Supporting families with the extra stresses they experience.

- Encouraging the social inclusion of the child in family and community life such as preschool facilities.

Recently the National Autism Plan for Children produced by the National Autistic Society (2003) identified key recommendations include a clear timeframe for assessment, a call for urgent training of professionals in knowledge and awareness of autism spectrum disorders, the active involvement of families in care planning and procedures, better multi-disciplinary and multi-agency working, and the setting up of national networks. However these standards are rarely met by existing services (McConachie and Robinson, 2006).

What approaches are effective?

Various teaching and treatment approaches have been developed to address the needs of children with autistic spectrum disorders. Definitive evidence is lacking that any one approach is consistently better than another. Rather the conclusion reached by reviewers is that “the most effective programs for students with autism are those that incorporate a variety of best practices” (Heflin and Simpson, 1998).

Among the elements which Dawson and Osterling (1997) identified as being common to effective intervention programmes were:

- A focus on specific skills that the child needs to learn.
- A structured environment which includes strategies for generalisation of learning.
- Predictability and routine to help the child transfer from one activity to another.
- A functional approach to analysing and dealing with behaviours.
- Family involvement is central to the overall programme.

In addition the following strategies have been shown to be beneficial (Department of Education NI, 2002).

- One-to-one planning and work with the child.
- An emphasis on promoting communication
- An emphasis on a visual approach
- Developing the child’s skills for independence.

These teaching approaches need to be done skilfully, by competent teachers and with a degree of consistency across teachers and settings. Although some would argue for daily intensive teaching sessions lasting upwards of four hours, this can place major strains on parents. Recent research suggests that the number of treatment hours does not appear to correlate with outcomes (Gabriels, 2001) and that there has been some over-estimation of the minimum number of hours required per week (Luiselli et al, 2000). Moreover teaching programmes need to adapt to family lifestyles and routines rather than the other way round, if stress in families is to be reduced (Jones, 2000).

No one professional presently has the necessary expertise to diagnose and plan intervention programmes for this diverse group of children. Hence multi-disciplinary teams of professionals are involved consisting of specialist doctors, psychologists, speech and language therapists and educationalists. In addition other disciplines such as Occupational Therapy, Physiotherapy and Social Work may be involved. It is not easy to achieve consistent, high quality working across disciplines and agencies.

What helps families?

Although the need for teaching and treatments to commence for an early age is well recognised, experience of doing this remains limited. Nonetheless there are some important indications of what parents value (Christie and Chandler, 2002).

Integrating diagnostic and support services: Providing a diagnostic service is only a first step. Parents value an ongoing support service that will help them to address the specific needs of their child in a practical way.

Home support: Parental preference is for professional assistance to be given in the home. This provides a secure and familiar environment for the child and for the parents as well as being a natural context in which teaching takes place. Weekly visits are preferred.

Flexibility of approach: Parents value having a clearly defined, autism specific approach yet one that is sufficiently adaptable to children's needs and family circumstances over time.

Communication: Difficulties in communicating with the child are often a particular concern to parents. They value practical guidance on how to develop the child's understanding and use of language in communication.

Inclusion: Families are keen for their child to have the same opportunities as their other children, notably in accessing preschool facilities.

For some families, the child with autism is not their only or main concern. They may well have to deal with other problems of both a short and long-term nature. Early interventions programmes need to be sensitive to this and in some instances may need to provide the information and support to deal with these other concerns if no other help is easily available. Latterly increased interest has centred on the use of structured play in home-based interventions (Boucher and Wolfberg, 2003).

What's been happening in Northern Ireland for these families?

In recent years a number of significant developments have occurred.

The formation of Autism NI (formerly known as PAPA): Formed in 1990, Autism NI is primarily for parents of people with Autistic Spectrum Disorders. It has 25 branches and support groups throughout Northern Ireland. Autism NI has developed its role from the provision of advice, information and support to that of a significant provider of specialist training and an effective lobbyist for quality service provision.

Provision of diagnostic services: A review has been undertaken of existing diagnostic services in Northern Ireland; examples of good practice were noted and recommendations made for their development (Moore et al, 1998). This review underlined the need for early diagnosis.

Intervention approaches: Various agencies – mostly non-statutory - have responded to parents' needs by developing a range of training courses and workshops, organising parent support groups, providing specialist preschool facilities and organising intensive programmes for individual families.

Task Group on Autism: The Minister of Education set up this wide-ranging review of services in Northern Ireland and it reported in 2002. Extensive recommendations are made as to how improvements could be made to current provision. Particular emphasis is placed on "developing multi-disciplinary agreement and protocols on good practice in assessment, diagnosis and early/prompt intervention services" (p.109).

Likewise the DHSSPS Action Plan for Autism and Priorities for Action both focus on diagnosis and early intervention.

Even so, many Northern Irish parents and professionals feel that much remains to be done if these children and families are to receive the help they need.

Conclusions

- Autism can be diagnosed in children from 18 months onwards.
- Families need practical guidance on how best to help their child following a diagnosis.
- They value home-based support provided by a professional with expertise in autism.
- Specific approaches have been found to be effective in particular those that promote communication, social interaction, independence and socially acceptable behaviours.
- Multi-disciplinary and multi-agency working is required to meet the needs of these children and families.
- Early intervention services are not readily available throughout Northern Ireland.

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Appendix 2: Membership of the Steering Group

Kate Doherty, ASD Advisory and Support Service, South Eastern Education and Library Board.

Gillian Gamble, Senior Educational Psychologist - Specialist ASD, North Eastern Education and Library Board

Marie-Louise Hughes, Senior Educational Psychologist – Manager of Autism Advisory & Intervention Service, Southern Education and Library Board.

Janet McCann, Assistant Adviser, ASD Support Service, North Eastern Education and Library Board.

Anita McEvoy, Team Leader, Autism Diagnostic and Intervention Service, Southern Health and Social Care Trust.

Geraldine McGaughey, Social Worker (ASD) Western Health and Social Care Trust,

Marie Martin, Senior Educational Psychologist for Autism, Western Education and Library Board

Frances Stewart, Co ordinator, Oakwood ASD Service, Belfast Education and Library Board.

Gerilyn Woods, Senior social worker, Belfast Health and Social Care Trust.