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Clinical Child Psychology and Psychiatry 2006; 11; 45
DOI: 10.1177/1359104506059119

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Are Peer Support Groups for Adolescents with Asperger's Syndrome Helpful?

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ABSTRACT

There is very little documentation dealing with peer support groups for people with Asperger's syndrome, and especially about groups for adolescents. This article gives a description of three such groups that were run in parallel with support groups for parents. The great majority of the participants completed the course of the group. In a consumer satisfaction survey, the majority of the participants (76.5%) and nearly all of their parents (95%) rated satisfaction with the group meetings as good or very good. These responses indicate that adolescents with Asperger's syndrome and their parents perceive peer support groups as helpful.

KEYWORDS

adolescents, Asperger's syndrome, peer support groups

Introduction

CHILDREN WITH ASPERGER'S SYNDROME are at increased risk of developing psychiatric problems such as anxiety, low self-esteem, emotional and behavioural disturbances and depression (Tantam, 2000). Adolescence is an especially difficult time since better social skills are required. From the age of 11–12 years many of these young people realize how different they are, when compared with their peers. Because of impairment in comprehension, they need help to interpret social situations and conventions, and in dealing with issues of identity, self-esteem and relations with other people. One possible way to help young people with Asperger's syndrome is through the use of groups. Existing group programmes mainly focus on providing information about the syndrome (Vermeulen, 2000) or improving social skills (Marriage, Gordon, & Brand, 1995; Mesibov, 1984; Williams, 1989). Lord (1995) described different models for promoting social experiences with non-autistic peers, for autistic children and adolescents.

Clinical Child Psychology and Psychiatry Copyright © 2006 SAGE Publications (London, Thousand Oaks and New Delhi) Vol 11(1): 45–62. DOI: 10.1177/1359104506059119 www.sagepublications.com

Broderick, Caswel, Gregory, Marzolini, and Wilson (2002) described a social skills training for 9 young people with Asperger's syndrome within the setting of a youth group, aided by trained volunteers. Mishna and Muskat (1998) presented a group therapy model for boys with Asperger's syndrome and learning difficulties. Savidge, Christie, Brooks, Stein, and Wolpert (2004) reported on a social skills group for socially disorganized children and adolescents, and they discussed costs and benefits of such programmes in a clinical context.

Interventions that promote socialization and social skills for people in the autism spectrum, including group approaches, have been reviewed by Attwood (2000), Rogers (2000), and Rhea (2003). Krasny, Williams, Provencal, and Ozonoff (2003) presented a model curriculum and outlined essential ingredients for group social skills interventions. Howlin and Yates (1999) reported their experience with a social skills group for adults with autism, and discussed the potential effectiveness of this type of intervention. They pointed out the need for more widespread sharing of information on how and for whom such groups can be made optimally effective.

Literature that deals with groups for adolescents with Asperger's syndrome and especially peer support groups is still limited. A literature search in PubMed and PsycINFO carried out in December 2004 on the terms 'peer support group' and 'Asperger's syndrome' revealed in fact no search result. The purpose of this article is to describe three such groups.

Social skills groups, peer support groups, group therapy – what's the difference?

Improving social functioning, communication skills, self-confidence and identity are common goals for group interventions for autism spectrum disorders. There is a broad

ACKNOWLEDGEMENTS: We thank all participants and their parents for their contribution and the permission to tell others about our experiences together. We also thank Kari Steindal from Autism Unity, University in Oslo for encouraging advice and supervision, and for sharing with us valuable experiences from her peer support group for adults with Asperger's syndrome. Furthermore we thank the Regional Centre for Child and Adolescent Psychiatry in Health Region IV for financial support.

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overlap of methods, techniques and educational principles, in the various group approaches. The differences mainly have to do with what is focused upon. Improving social skills requires direct, focused and goal-directed interventions, often provided on a weekly basis. It is unlikely that a group format with monthly meetings will have a strong impact on social skills. However, qualitative improvements in self-acceptance may be achieved within a monthly time frame which is much less demanding for busy parents (and clinicians). Many children with Asperger's syndrome experience failure and rejection in relations with their 'normal' peers. Talking about their problems and sharing thoughts about strengths and difficulties in a positive and accepting environment may contribute to improved self-esteem. From Norway, Steindal (1999) reported a peer support group for adults with Asperger's syndrome, run on a monthly basis. Participants said that they felt calmer and more satisfied. They underlined the importance of being understood by someone, recognizing themselves in others and knowing that they were not alone.

Jerry Newport, author of *Your Life Is Not a Label: A Guide to Living Fully with Autism and Asperger's Syndrome* (2001) was diagnosed with Asperger's syndrome at age 47. A chapter in his book deals with benefits and weaknesses of adult peer support groups. He strongly recommends participation in such groups and gives advice about how to start them. He recommends that meetings be arranged at regular monthly intervals. Newport cautions against professionals who try to 'take over' the meetings. This may be an important point in adult groups, but for adolescent groups this is not the point at issue: Without professional initiative and maintenance there would be no peer group in our region.

Clinical details

Theoretical basis

Based on experience with educational programmes for young people with autistic spectrum disorder, we felt strongly that a self-determined peer discussion group would be too disorganized and therefore not attractive for the young people in the long run. So we adapted organizing principles and strategies for structured teaching from the TEACCH-system (Schopler, Mesibov, & Hearshey, 1995) to the management of our groups. The strategies as outlined by Kuncze and Mesibov (1998) 'include: (1) understanding autism, (2) understanding the unique child through both formal and informal assessment, (3) making events consistent and predictable, (4) clarifying instructions and expectations, (5) structuring tasks and assignments to promote success, and (6) cultivating and fully utilizing students' compelling interests' (p. 230). These strategies were implemented in the following ways:

1. Understanding autism: All three professionals involved in the group management were experienced in educational and therapeutic assessment of adolescents with Asperger's syndrome;
2. Understanding the unique child through assessment: In the majority of cases one of the professionals was familiar with the adolescent from an earlier assessment. All others were invited to an individual meeting with one of the group leaders. In addition professionals had access and went through the medical records;
3. Structuring for predictability and understanding by using routines and schedules: Careful planning of details and clarity of the environment was emphasized. Routines with limited alterations during the course were established: Same room, same weekday and hour, same meeting and communication structure, fixed sitting places and so on. Exceptions from rules, if necessary, were prepared and explained in detail;

4. Clarifying instructions and expectations: Rules for the group were discussed and established; they were presented and repeated in oral and written form (Figure 1). A written invitation with the programme was delivered to all participants the week before the meeting took place;
5. Structuring tasks and assignments: Visual support was widely employed. All participants received a hand-out of the rules for group conversation in the beginning of each meeting. We used an overhead projector to display on a screen written instructions and material such as drawings, made during the meeting or brought along by the participants;
6. Motivating students by using special interests: sharing topics of interest with other participants was encouraged and space to do so was provided.

The same structuring principles and strategies were used to meet the behavioural and emotional needs of the participants. The peer relationship itself created an accepting and safe environment. Group leaders provided help with social perception, interpretation of conventional rules and with the management of inappropriate emotional responses and crises. In addition we applied recreational activities, for example telling jokes, solving riddles, assignments including drawings, and play on words. Our intention was to make the meetings attractive for the youngsters, and not only something they participated in because their parents wanted them to. For example meetings were not used to teach about Asperger's syndrome. Information about this topic was instead presented as a natural aspect of the subjects the young people were interested in.

Aims

We wanted to provide an organizing structure for peer groups of adolescents with Asperger's syndrome and their parents, facilitating meeting with other people in the same situation, and sharing thoughts, interests, experiences and information.

We also wanted to obtain pilot data on the acceptance of such groups by the adolescents and their parents, addressing the following questions: Would this group approach be attractive for the participants? Would the adolescents and their parents be motivated to join the group meetings and if so, would the motivation last? Would they be interested in and satisfied with the programme of a social group context? How could the helpfulness of the programme for the participants be explored?

Recruiting participants

Possible participants were identified by diagnosis and age from the data registration files of our institutions. The therapists responsible for the identified adolescents were given information about the programme and were asked whether their client would be suitable for, and interested in participation. Depending on the therapists' advice, the young people who were taken into consideration were invited to an individual meeting with one of the group leaders, together with their parents. In this session contact was established, written and oral information about the programme was provided, and details and questions about possible participation were discussed. If necessary, families could talk the issue over at home and send back a registration form if they were interested in joining in the group.

Construction of the groups

Inclusion criteria were: age between 12 and 18 years, and a diagnosis of Asperger's syndrome, based on the diagnostic criteria of the ICD-10 (World Health Organization, 1992). Further, it was stipulated that the participants should know about their diagnosis

- Rules for group conversation**
1. Everybody is free to talk.
 2. Put your hand up if you want to say something.
 3. We can also talk in turns – one round.
 4. The chairman decides whose turn it is to talk and for how long.
 5. Try not to interrupt when others are talking.
 6. If you need a break in addition to our common break, you can go to the next room or the corridor outside.
 7. Don't disturb when somebody else is talking (for example don't shout).

Figure 1. Rules for the group conversation (rule no. 7 was added by participants).

and should not have additional problems, which would make group participation impossible (e.g., substantial hearing loss or severe hyperactivity).

Twenty-one adolescents participated in the group programme, divided between 3 consecutive groups, with 7 participants in each. Gender distribution was 14 boys and 7 girls (2 girls in the first group, 2 in the second and 3 in the third group). Average age was 13 years (range 11–16). As one single exception there was an 11-year-old girl included in the second group. Her therapist considered her as relatively mature for her age, compared to boys with Asperger's syndrome. Seventeen adolescents were tested with WISC-R. Average total IQ was 108 (range 70–142), average verbal IQ was 102 (range 85–148) and performance IQ 105 (range 59–137). Three adolescents were tested partially only; based on the results of the subtests IQ was estimated at falling within normal range. One participant refused testing (according to clinical judgement IQ was within the normal range).

Parents' groups

Parents met to exchange their experiences. The theoretical concept was to enable parents to self-help and mutual support. In general discussions were parent-led, but one of the professionals participated in part to facilitate and promote discussion. In addition special parent information sessions were held during the first, third and final group meeting. In the parent information sessions we explained the group programme, described development in the group and answered questions. Additional information was tailored to cover parents' needs and they were encouraged to discuss any topic they wished to bring up.

Common themes covered in all groups included concern about future development of their youngsters, management of emotional crises, educational problems at home and in school, appropriate leisure activities, relationship with siblings, relatives' reactions and resources in community care.

Structure and process of the groups

Since February 2000 three consecutive groups have been conducted with nine sessions spread over a period of 11 months each. Groups met once a month except during the

summer holidays, for about 2 hours in the evening. Two clinicians led the meetings (group leader and reporter). A third clinician attended partly the peer group, partly the parents' group.

The content of the programme was evolved in interplay between the interests and wishes of the participants and the intentions of the group leaders. The adolescents' proposals were selected according to practicability and modified to fit in with the interests of the majority of participants and with the educational principles outlined earlier (see the section on theoretical basis). Group leaders supplemented with topics that had been of considerable interest for an earlier group. As an example Table 1 illustrates the different topics presented for discussion for the year 2002 group. Programme and structure were kept as similar as possible in all the groups, but topics which didn't work in one group were substituted in the subsequent group. For example the topic 'My favourite video clip' (where video clips were brought along by participants) in the first group suffered technical problems, leading to a chaotic and unpredictable structure, and was removed.

Each meeting started with an introduction: the group leader welcomed everybody, gave information and reminded participants of the rules of the group. The first section was characterized by reflection and conversation on chosen topics. The group leader steered the conversation depending on the participants' involvement and ensured that conversation rules were followed. If the discussion stopped or didn't get started, participants were encouraged to talk in turn. As an illustration a dialogue sample from one meeting is given in Appendix A. After the first section there was a break with music and snacks. The second section focused on play and recreation. For example all participants in turn were asked to make a drawing of a given non-literal expression or saying, while the others had to guess the meaning (Figure 2). Participants were also invited to bring along different items, which would fit the subjects of the meetings. For example, they were

Table 1. Programme for the sessions (curriculum for the year 2002 group as example)

<i>Session</i>	<i>Main topics and activities</i>
1.	Information and group planning. Presentation of the participants and their interests to each other. Play with words – hit upon and visualize homonyms (drawings).
2.	How to tell others about Asperger's syndrome? Telling jokes to each other (everybody was asked to bring along a joke).
3.	Unwritten rules and misconceptions. What does 'private' mean? Solving riddles (everybody was asked to bring along a riddle).
4.	'What is a friend?' Showing cartoons to each other (everybody was asked to bring along a cartoon). Play with words – visualize literal expressions.
5.	Closing session before the summer holiday: 'Beach party' at a swimming pool.
6.	Planning for the autumn sessions. What did you do during your summer holiday? (Everybody was asked to bring along a souvenir.) Interpretation of facial expressions and feelings (video clip and drawings).
7.	Movie interpretation. A movie ('Glasskår', Norway 2001) about 'friendship, falling in love and mourning' was shown divided in sequences. Every sequence was discussed with regard to understanding/misunderstanding details and feelings presented.
8.	Personal computer and information technology: Exchange of programmes and ideas.
9.	Closing session: Bowling. Afterwards a get-together with parents and adolescents at a pizza restaurant. Evaluation and summary.

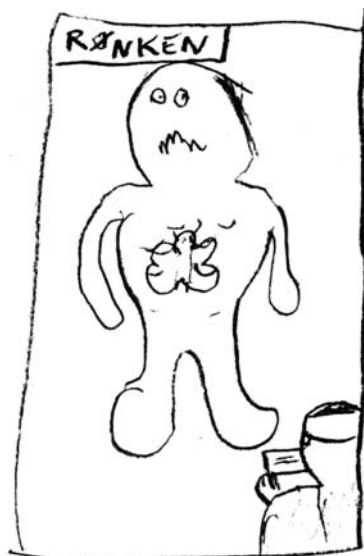


Figure 2. Literal visualization of the phrase: 'To have butterflies in the stomach', detected by X-ray ('Roentgen' in Norwegian language). Drawing of a participant, published with kind permission.

asked to bring along a cartoon (a joke, a holiday souvenir, a riddle) to the next meeting. All meetings ended with a conclusion including expression of thanks for participation, a short summary of the meeting, and a plan for the next meeting. After finishing the group each participant got a booklet with a short summary of the content of all the meetings.

Participation and drop-out

Almost all the invited parents expressed their interest in the programme. The majority of the adolescents, on the contrary, showed no real interest, but decided to give it a try, and to join at least the first group meeting. Five invited adolescents clearly refused the offer; while some others couldn't participate for practical reasons. Of a total of 22 adolescents who had decided to give the group a try, 3 dropped out (14%). One boy in the first group said that he felt uncomfortable with the group (too much talk and theoretical discussions) and dropped out after the third session. In the second group one girl attended only three meetings. Parents reported loss of motivation due to a higher level of social functioning, compared to the other participants. In the third group one girl was present only at the first meeting. In reality she had no interest in the programme, but had been persuaded to try once by her parents.

The 19 completers came to all meetings with few exceptions (attendance rate was 93%, see Table 2). Three times the reason for missing a group session was a genuine competing commitment.

All parents attended the sessions at least with one representative. Parents were grateful for the chance to meet with other parents. During the course of the group some of the parents got to know one another quite well.

Consumer satisfaction survey

A questionnaire for both the adolescents and the parents was used to record their opinions about the group programme (Appendixes B and C). The questionnaire

Table 2. Number of attended meetings (of a total of 9) per participant

Participants	P1	P2	P3	P4	P5	P6	P7	P8
Group 2000 (N = 7)	9	9	9	8	8	7	3	
Group 2001 (N = 7)	9	9	9	8	8	6	3	
Group 2002 (N = 8)	9	9	9	9	8	8	8	1
All groups (N = 22)	166 of 198 possible turnouts, corrected for 3 dropouts 159 of 171 (93%)							

consisted of scales for rating degree of motivation to attend, and satisfaction with the programme, combined with space for comments and open questions. In addition parents were asked whether they had observed changes in the adolescent's behaviour, attitudes or other changes during the period of the peer group. Adolescents were required to answer independently from their parents, but could obtain advice, if needed. All adolescents and parents completed the evaluation questionnaire, except one young person who didn't want to answer the questions. The adolescent who discontinued the course after the first meeting did not complete the questionnaire.

Motivation As we knew from the initial recruiting session the majority of adolescents did not show great interest in a group programme. This is reflected in the adolescents' rating, where only 5 of 21 recorded high motivation to attend the first meeting (Table 3). However, motivation increased considerably: 13 participants reported high motivation to attend subsequent meetings (Table 4). Parents' rating of their youngsters' motivation agreed with this. The pattern of initial poor motivation improving during the course was similar in all three groups.

Satisfaction The therapists' impression was that the adolescents in general felt comfortable in the group meetings. This was confirmed by the answers in the evaluation forms (Table 5). High or very high satisfaction was reported by 16 participants (76.5%), three rated 'don't know' and only one reported dissatisfaction with the group meetings. According to parents' judgement, all youngsters, except one, were satisfied with the meetings; in their ratings the figure for high or very high satisfaction was 20 (95%). There were no substantial differences in ratings between the three groups.

Choice of topics and frequency Fourteen adolescents (67%) expressed satisfaction with the choice of topics for the group programme, 5 rated 'I don't know'. One participant was dissatisfied and 1 didn't answer the question. Concerning meeting frequency there was a great difference between ratings of the parents and the adolescents. In all three groups all parents were satisfied or very satisfied with meetings held once a month. In contrast 7 young people rated dissatisfaction, because they would have preferred to meet more frequently. Seven participants were satisfied with the frequency of the meetings and 5 rated 'I don't know'.

Comments and open questions The adolescents' comments and answers on open questions were in general short, direct, sometimes surprising and a few times contradictory. Ten participants gave a one- or two-word answer to the question 'How do you feel about meeting other young people with Asperger's syndrome?', for example 'nice, okay, fine, pleasant, interesting' or 'a bit strange'. Three adolescents commented on the different degrees of Asperger's syndrome they perceived as present in the group as 'interesting, a little bit strange' or 'okay'. Four others gave a one-sentence positive comment: 'Okay to

Table 3. Motivation to attend first meeting evaluated by adolescents and parents

Motivation	Group 2000 (N = 7)		Group 2001 (N = 7)		Group 2002 (N = 7)		Total (N = 21)	
	Adolescents	Parents	Adolescents	Parents	Adolescents	Parents	Adolescents	Parents
High	2	2	2	3	1	1	5 (24%)	6 (28.5%)
Some	2	5	2	2	2	2	6 (28.5%)	9 (42.5%)
Don't know	1	0	1	0	0	0	2 (9.5%)	0
Poor	1	0	2	0	1	3	4 (19%)	3 (14%)
Very poor	0	0	0	2	2	1	2 (9.5%)	3 (14%)
Not answered	1	0	0	0	1	0	2 (9.5%)	0

Table 4. Motivation to attend the subsequent meetings evaluated by adolescents and parents

Motivation	Group 2000 (N = 7)		Group 2001 (N = 7)		Group 2002 (N = 7)		Total (N = 21)	
	Adolescents	Parents	Adolescents	Parents	Adolescents	Parents	Adolescents	Parents
High	3	4	6	6	4	3	13 (62%)	13 (62%)
Some	2	1	0	1	2	4	4 (19%)	6 (28.5%)
Don't know	1	0	1	0	0	0	2 (9.5%)	0
Poor	0	2	0	0	0	0	0	2 (9.5%)
Very poor	0	0	0	0	0	0	0	0
Not answered	1	0	0	0	1	0	2 (9.5%)	0

Table 5. Satisfaction of group meeting evaluated by adolescents and parents

Satisfaction	Group 2000 (N = 7)		Group 2001 (N = 7)		Group 2002 (N = 7)		Total (N = 21)	
	Adolescents	Parents	Adolescents	Parents	Adolescents	Parents	Adolescents	Parents
Very high	2	3	4	4	3	4	9 (43%)	11 (52.5%)
High	3	3	1	3	3	3	7 (33.5%)	9 (43%)
Don't know	1	0	2	0	0	0	3 (14%)	0
Low	0	1	0	0	0	0	0	1 (4.5%)
Very low	0	0	0	0	0	0	0	0
Not answered	1	0	0	0	1	0	2 (9.5%)	0

see that I'm not alone; nice, because I don't like normal people; fine to meet others with the same problems'. One comment was negative: 'I don't need to know anyone who has the same condition as I have'. Two participants had no comment. In the column for general comments/praise and blame, 8 participants had no comment. Three expressed satisfaction about the serving of snacks. Six adolescents had a general positive comment (for example 'nice to have been there, everything was fun'). Three gave differentiated comments (both positive and negative) and suggestions (bigger group, more variation, more activities, longer course).

Parents' feedback All 21 parents were positive about meeting other parents. In particular they emphasized that they felt understood by others for a change, that they met people who knew what they were talking about, and that they exchanged useful experiences and got tips and ideas from each other. Three expressed somewhat ambiguous feelings: 'It was very useful but also demanding to talk about your own child', 'Meetings

Table 6. Parent reported changes during the period of the peer group for adolescents with Asperger's syndrome (N = 21)

Changes	Group 2000 (N = 7)	Group 2001 (N = 7)	Group 2002 (N = 7)	Total (N = 21)
Yes	4	4	3	11 (52%)
Uncertain	1	2	2	5 (24%)
No	2	1	2	5 (24%)

Comments of the 11 parents answering 'yes':

- He has become more confident and happy.
- He can more easily accept that others have strong opinions too.
- She felt especially confident since she had no need to pretend.
- He can easily talk about Asperger's syndrome today, which was taboo earlier.
- She can accept herself more easily; she has got more self-confidence.
- He has become a little bit more open.
- He has become more open in some areas, listens more and 'plays' more with others.
- It has become easier to let his school class know about his difficulties.
- He has become more extrovert and he is more together with school friends.
- Maybe there were some changes in mood and self-confidence, he takes more chances now.
- She has become more open, found friends who are like herself. She accepts herself more.

can activate deep-seated feelings: I was often tired but content afterwards', 'It was okay, but maybe there can be too much focus on negative sides of our children'. Five parents commented that they would prefer a greater involvement of professionals in order to focus and structure the discussions. Not surprisingly, based on the experience from the individual preparation and information sessions, where the majority of adolescents expressed poor motivation (see section on participation and drop-out), parents in general had more enthusiastic comments in the overall rating, compared with the adolescents.

Development of identity and self-esteem To get feedback about possible effects of participation in the peer group, which can be studied in subsequent groups, parents were asked: 'Have you observed changes in behaviour/attitude/other changes during the period of the peer group?'. Half of the parents recorded changes, mostly improvement of identity and self-confidence (Table 6). In addition three parents gave the following comments: 'We think it was extremely important for him to meet others since he was recently diagnosed', 'Good to see that he can look forward to an activity together with other young people' and 'He will not recognize in public that he has Asperger's syndrome, but he was relieved to discover that there were so many others affected'.

A mother had the following anecdotal observation: Her son was initially not motivated but could be persuaded to join the group. The day after a group meeting, this mother overheard a conversation between her boy and a classmate, asking: 'Where were you yesterday?' Her boy answered: 'At an Asperger meeting'. The mother was very surprised, as he had never used the word before. At least three other parents said that the 'Asperger word' wasn't taboo any more. Other observations told by parents were: As a direct consequence of a discussion in a group meeting, one boy decided to inform his class about his diagnosis. Another accepted a planned information process for his class more easily than expected by his parents.

Discussion

The scientific literature says little about peer support groups for people with Asperger's syndrome. This article describes such groups for adolescents. With a consumer satisfaction survey, we explored the helpfulness of the programme for the participants.

Adolescents experienced the group meetings as a positive activity and met regularly, with few exceptions. For some adolescents the group was the only social activity involving peers on a regular basis, apart from school. Parents expressed their gratitude for the opportunity to meet others with the same problems and to exchange experiences and information with each other and with professionals. We observed informal benefits of the group programme, such as enhancement of networks and parents' mutual support. Feedback from the parents may indicate qualitative benefits for self-esteem (see Table 6). Unfortunately we have no objective measures to confirm this, due to the pilot character of the project. On the other hand we have several clinical observations suggesting improvement of identity and self-confidence for the participants during the group process (see section on development of identity and self-esteem).

We believe the main reason why the groups in general worked as intended, was that the conceptual basis of adult self-help groups with their participant-perceived impact on self-esteem was modified by applying organizing principles and educational strategies as outlined earlier (see section on theoretical basis). This approach provided the necessary secure base for organizational, behavioural and emotional needs to make the groups practicable and attractive for adolescents.

Limitations

The main limitation of our programme is the lack of empirical evaluation. Given the limited resources within an outpatient clinical setting it was difficult to establish matched control groups. The reason for running the groups consecutively and not in parallel as controls was the limited number of accessible adolescents who fit the inclusion criteria. The participants of the 2001 group for example were not available in 2000 and so on. Some adolescents were diagnosed subsequently, some were not informed about their diagnosis at this time or not motivated to participate in a group. To avoid bias, selection of the controls should consist in equally strongly (or weakly) motivated peers. Based on the relatively small number of accessible adolescents, we gave the development of the programme priority instead of running an intervention and a control group with only few participants in each. In addition, we wanted first to find out whether the adolescents would be interested in this service and able to maintain their interest over time.

The consumer satisfaction survey was clearly based on very subjective data. It is a challenge to ask reliable questions and to interpret the answers of the adolescents in the evaluation questionnaire correctly. Nevertheless evaluation by the parents and the adolescents in the first group were quite encouraging. Programme and structure were kept as similar as possible in subsequent groups to test whether these results could be reproduced or were due to a favourable composition of the groups. There were no substantial differences in evaluation between the three groups.

Further work

Much-needed empirical evaluation in this field is a difficult and resource-demanding task. This is reflected by the fact that there exists to date only one empirical evaluation of a group approach that included a comparison group (Ozonoff & Miller, 1995). They compared a social skills training programme for 5 normal-IQ adolescent boys with

autism to a no-treatment control group, providing evidence of improvement for several social skills.

Barry et al. (2003) demonstrated the effectiveness of teaching specific social skills such as greeting and play skills to a group of 4 high-functioning children with autism. This research required a quite sophisticated and resource-demanding design that included training of typical peers for assessment purposes, and social skills-teaching sessions (8 weekly conducted sessions in all) led by 2 advanced graduate students, 1 research assistant and 1 supervising psychologist. Both research groups described poor generalization of skills trained in the programme to real life.

To trace measurable effects of a group approach and to delimit them from other factors such as individual maturation processes is a challenge. Anecdotal comments and observations by the parents in our groups suggested qualitative changes, such as enhanced self-confidence of the participants. These observations are supported by other work, for example that done by Marriage et al. (1995), likewise on an anecdotal level only. In a currently ongoing group we are exploring the applicability of questionnaires assessing quality of life and self-esteem as possible outcome measures for pre and post-intervention ratings. A further step could be comparison with a group without professional management, or randomization to a waiting list serving as controls. This can be an achievable goal in the setting of a resource-limited clinical outpatient service. At the very least we can rely on a sustainable compliance by the consumers, since a group programme is now established and expected by parents.

Conclusion

The organizing structure described for peer support groups for adolescents worked as intended. Of the participating adolescents 86% completed the group sessions, there was an attendance rate of 93%. Feedback from adolescents and parents expressed spontaneously and obtained in a consumer satisfaction survey, was very positive in all three groups. The responses indicate that the peer support groups were perceived as helpful by adolescents with Asperger's syndrome and their parents. We believe that facilitators experienced in educational and therapeutic assessment of adolescents with Asperger's syndrome should organize the groups, in view the special needs of the participants.

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Appendix A

Dialogue sample based on minutes of meeting nr. 2. P1–P7 is the code for the participants

Topic: How to tell others about Asperger's syndrome?

Group leader: Who told you about Asperger's syndrome? P7: Don't remember.

Group leader: Was it a parent or a professional? P7: Professional. I didn't listen very much.

P6: I was told when I was in 5th form. The assistant told me in the gym: 'YOU have Asperger's syndrome'. Until then I didn't understand why there was an assistant following me all the time.

P2: B. (a professional) told me. She is working in a pink building here in the neighbourhood. I don't remember what she said.

P5: Mum told me, or mum and dad. They said a lot of babble. They explained what it means. About a syndrome and why it is named Asperger's, about 6 months ago.

P1: Mum told me, in January this year. Don't remember what she said.

P4: I don't remember. Dad and maybe mum told me some time ago. It is named after a man called Hans Asperger. It is a syndrome.

P3: Foster mother told me. About two months ago. She told me a bit about what it was. That you are a little bit different from other youngsters. Have different behaviour.

P 1: We don't have so many friends. I have just noticed that.

Group leader: Was it ok to hear about it?

P3: It was ok, compared to not knowing if you have something.

P4: It was ok.

P1: I wasn't sorry about that. I knew for quite a long time that there must be something, but not what it was.

P5: It was no big surprise for me. I thought, what in hell is that? Why is it called Asperger? Some things are pretty difficult: for example to write quite nicely, copy-book writing. [He gives a detailed explanation how he usually holds the pencil.] Mum and my teacher are concerned about me handling the pencil in the right way.

P2: It was ok to hear about it, I was just wondering what it could be.

P3: We have difficulties in talking with people.

P2: I'm often shy.

P6: I have done things people think are awkward, for example to pick my nose. I have learnt this little by little. It was ok to hear about it; I have never known or thought about it, I was surprised.

P2: Mum noticed it. First she thought it was anxiety.

P5: Because you were shy?

P2: Mum says that I am fumbling with things, when I'm stressed.

P3: I had noticed it for a long time. First they thought I had another condition, I thought this was bad.

P7: I didn't think there was anything special.

Group leader: Has anybody here told someone about your Asperger's syndrome diagnosis?

P6: No, they don't need to know.

P7: No, my teacher is going to tell my class. I will not be there then.

P3: I was halfway to telling, but I didn't know much about it.

P5: I have told my best friend, she can keep a secret. I didn't say much. It was good to have said it.

P4: I haven't told anyone.

P5: I haven't told anyone.

P2: I have told a friend. She asked me all the time, why I had an assistant, why I went to the outpatient clinic. I didn't know what to say. She promised not to tell others.

P3: I don't know how it is not to be this way. I am myself; neither bad nor good.

Group leader: Do your teachers know?

P2: Yes, they behave differently if they don't know, for example a new supply teacher. There is one more with Asperger at our school. I don't know who he is.

P5: Once my teacher got angry very quickly, so I asked dad to tell him.

P6: I have an appointment with my teacher every week. Very nice, there we can clear away misunderstandings.

P3: My teacher knows, but hasn't told my class.

Appendix B

Evaluation questionnaire for adolescents

PEER SUPPORT GROUP FOR YOUNG PEOPLE WITH ASPERGER'S SYNDROME

Evaluation form for **young people**:

1) Motivation

How strong was your motivation to come to the first meeting?

Great motivation some motivation don't know little motivation very little motivation

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How strong was your motivation to come to the subsequent meetings?

Great motivation some motivation don't know little motivation very little motivation

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Comment:
.....

2) Satisfaction

How satisfied were you with the group meetings?

Very good good don't know bad very bad

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Comment:
.....

3) Subjects

Were you satisfied with the subjects, which were presented during the meetings?

Very satisfied satisfied don't know dissatisfied very dissatisfied

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Comment:
.....

4) Frequency

Were you satisfied about meeting once a month?

Very satisfied satisfied don't know dissatisfied very dissatisfied

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Comment:
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5) How do you feel about meeting other young people with Asperger's syndrome?

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6) Space for general comments/praise and blame:

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7) Do you have any suggestions of subjects we can present during the group meetings?

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8) Do you have any suggestions of activities we can do during the meetings in similar groups?

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Appendix C

Evaluation questionnaire for parents.

PEER SUPPORT GROUP FOR YOUNG PEOPLE WITH ASPERGER'S SYNDROME

Evaluation form for **parents**:

1) Motivation

How strong was the motivation of your adolescent to come to the first meeting?

Great motivation some motivation don't know little motivation very little motivation

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How strong was the motivation of your adolescent to come to the subsequent meetings?

Great motivation some motivation don't know little motivation very little motivation

--	--	--	--	--

Comment:

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2) Satisfaction

How satisfied was your adolescent with the group meetings as far as you know?

Very satisfied satisfied don't know dissatisfied very dissatisfied

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Comment:

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3) Subjects

Were you satisfied with the subjects which were presented during the meetings?

Very satisfied satisfied don't know dissatisfied very dissatisfied

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Comment:

.....

4) Frequency

Were you satisfied with meeting once a month?

Very satisfied satisfied don't know dissatisfied very dissatisfied

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Comment:

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5) Have you observed changes in your adolescent's behaviour/attitude/other changes during the period of the peer group?

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6) How do you feel about meeting parents of other young people with Asperger's syndrome?

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7) Space for general comments/praise and blame:

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.....
.....

8) Do you have any suggestions of subjects/activities we can do during the meetings in similar groups?

.....
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