Enhancing sense of belonging in parents of adolescents with ASD: Design and assessment of a support group experience

Elisabetta Ghedin\textsuperscript{a}, Debora Aquario\textsuperscript{a}, Simone Visentin\textsuperscript{a}, and Eleonora Zorzi\textsuperscript{a}

\textsuperscript{a}University of Padova, Department of Philosophy, Sociology, Education and Applied Psychology (FISPPA), Padova (Italy)

Abstract. Despite the large amount of research indicating that parenting adolescents with autism spectrum disorder (ASD) is extremely stressful, little research has examined methods for supporting these families with positive thoughts. Parent support groups (PSGs) are one way to help parents cope with their stress, meet other parents and develop a sense of belonging. Previous literature has shown that such parents feel more knowledgeable, accepted and empowered when they are able to share their successes and struggles with parents who are in similar situations. The present study aimed to explore whether involvement in a PSG contributes to parents’ sense of belonging by creating a locus in which they can feel positive emotions and thoughts.

Keywords: ASD, belonging, empowerment, parent support group, good practices

Correspondence concerning this article should be addressed to Elisabetta Ghedin, University of Padova, Department of Philosophy, Sociology, Education and Applied Psychology (FISPPA), Via Beato Pellegrino, 28, 35137, Padova (Italy), e-mail: elisabetta.ghedin@unipd.it; tel 0039 049 827 17 03

Received: 29.03.2019 – Revision: 18.04.2019– Accepted: 23.04.2019
Introduction

This study aimed to investigate what parents of adolescents with autism spectrum disorder (ASD) find helpful about mutual support groups. An increasing number of parents of children with disabilities are participating in mutual support groups, usually in addition to seeking help from professional agencies (Russell, 1997). Studying what they find helpful will advance knowledge in the area of mutual support, may inform professionals about parents’ needs and how to improve professional practice, and may help mutual support organizations to discover more about—and maximize the benefits of—the activity in which they are involved (Solomon, Pistrang, & Barker, 2001).

If we consider literature on parents’ experiences of living with a child with ASD, findings suggest that the parenting stress is “unique” (Schieve, Blumberg, Rice, Visser, & Boyle, 2007, p. 121). Parents commonly report feeling almost permanently in a state of crisis and describe facing non-remitting daily practical challenges. Unable to make changes to their child’s behavior, parents often report changing their lives and selves to make accommodation (White, McMorris, Weiss, & Lunsky, 2012). A meta-analytic study of parenting stress demonstrated large positive effects for parents of children with ASD when compared to those of typically developing children and other disabilities (Hayes & Watson, 2012). A 10-years survey (Barker, Hartley, Seltzer, Floyd, Greenberg, & Orsmond, 2011) found that although parents’ anxiety levels fell over this period, their levels of depressive symptoms remained stable and at times when behaviour was more difficult, they worsened. Further sources of stress are the lack of professional support and social attitudes resulting from a lack of understanding (Glazzard & Overall, 2012), concerns about the child’s future (Faso, Neal-Beevers, & Carlson, 2013), and feeling isolated and stigmatized due to people’s misjudgment of their child (Wallace, Parr, & Hardy, 2013).

The value of Support Groups for families

Transition into adulthood is a particularly stressful time for many parents as they faced increased stressors, such as additional financial burdens, more restrictions in social activities, and heightened parental stress (Taylor, 2009). Most parents worry about how much independence their child can attain and how they will cope when can no longer be available to care from them (Howlin, 2004). Parents also have concerns about behavior and social interactions and communication (Seltzer, Krauss, Shattuck,
This part of literature mirrors evidence about daily lives of adolescents with ASD, which have reported difficulties in establishing or maintaining peer relationship, participating in social activities and often having few friendships (Bauminger & Kasari, 2000; Orsmond, Krauss, & Seltzer, 2004). If compared with typically developing peers, adolescents with ASD spend most of their time alone or with adults, including parents and paid professionals (Ormond & Kuo, 2011).

For families of adolescents with autism, for whom sources of instrumental, informational and emotional support are critical to well-being, support groups can be a powerful adjunctive resource (Davison, Pennebaker, & Dickerson, 2000). In the early 1980s, support groups were identified by several researchers as one of the most noteworthy developments in the field (Schilling, 1988). The value and impact of such groups are based on a solid foundation of psychological and sociological theories (Salzer et al., 2002). Support groups are a relatively cost-effective and easily-implemented intervention in order to support the needs of these families, provide a sense of belonging, reduce stress and increase access to information about appropriate care (Solomon et al., 2001). Moreover, studies have found that parents also report that their parenting skills improve as a result of participation, their sense of isolation is reduced, they obtain important information about services and they feel a greater sense of emotional support (Law, King, Stewart, & King, 2001).

Little research has been conducted on outcomes for families involved in support groups. Bitsika and Sharpley (1999) attempted to measure support group outcomes and found that group members reported value in being understood by others and being able to support others. Participation in these groups is associated with decreased negative mood and stress (Kerr & McIntosh, 2000) and with being able to cope better with the same stressors (Solomon et al., 2001). It is commonly reported that the sense of belonging and sense of community that participants feel once connected with the group is hugely important (Singer, Marquis, Powers, Blanchard, Divenere, Santelli, Aibinder, & Sharp, 1999).

Parent support groups (PSGs) are one way to help parents of children with ASD cope with their stress, meet other parents, and develop a sense of belonging. Given the apparent popularity of PSGs for parents of children with ASD, surprisingly little research has evaluated these interventions. Moreover, previous studies of parent support needs in families of children and adolescents with ASD are almost exclusively focused on mothers (Hartley & Schulz, 2015). The present study seeks also to expand on previous studies by considering the role of fathers in addition to mothers of adolescents with ASD.
Methodology

The research that focused on outcomes of PSGs is exploratory and qualitative (Bitsika & Sharpley, 1999). A social constructivist approach was adopted, which relies on the epistemological position that reality is socially constructed. To gain an understanding of the world, individuals form subjective meanings of their experiences through their interaction with others. Therefore, interaction leads to ‘realities’ through negotiation, synthesis and construction processes that are associated with a particular context and a particular culture (Creswell, 2014).

In particular, the present study aimed to explore whether involvement in a PSG (called PARENT_NET) contributes to parents’ sense of belonging among peers fostering the reciprocal support and the group cohesion as well as if the PSG provides a safe and positive space for sharing resources and good practices and promoting well-being among the participants.

Participants and setting

Participants included 10 females and 8 males (8 couples and 2 single mothers for a total of 18). The majority of the attending participants were mothers. The participants were raising adolescents with ASD ranging in age from 17 to 20. A Network of six Local Services for Families (in Veneto Region, Italy) identified eligible parents through case records.

No formal demographic information was taken on the education and occupations of the participants. However, diversity of experience for the participant was apparent in the discussions. Informed consent for audio recording and for handling any data collected was obtained from all participants involved in the study.

The ‘PARENT_NET Support group’ model

Within the context of the current study, the goal is typically not a therapeutic change. PARENT_NET refers to a group in which participants are encouraged to engage in positive supportive relationships with each other and the goal is to introduce other members as positive role models, share information about resources and coping, and provide a shared understanding and sense of belonging (Singer et al., 1999).

The role of facilitators - in this project they were three researchers in the field of inclusive education and experimental pedagogy - is a key element: they promote a reflective attitude (Bernard & Goodyear 2014),
combined with a natural curiosity for participants’ behavior and the themes they choose to share.

The process, as a whole, becomes a passionate inquiry (Creaner, 2011; Breene, 2011), a learning process based on reciprocity (Adamson, 2011) aimed at changing personal mindset (Carroll, 2011). Consequently, the group could be thought as a community of practices (Wenger, 1998) focused on personal well-being and adolescents well-being too. The richness is the heterogeneity among the members, which fosters the sharing of personal points of view and experiences. The good practices (Canevaro, 2015) are generated by a participated process, where positive experiences – facts, anecdotes from daily life – are documented, even considering that much of the literature to date has focused on the negative aspects (parenting stress) of raising children with disabilities and on factors, such as child challenging and adaptive behaviors, that are related to these negative experiences. Positive emotions can act as a buffer to psychological stress and can help individuals find positive meaning in stressful situations (Tugade & Fredrickson, 2004) and may have positive physiological, psychological and educational benefits for parents (Kayfitz, Gragg, & Orr, 2010).

Parents participation was free of charge to parents. The parents’ accessibility to PARENT_NET was permitted by the fact that, during the same time, their sons/daughters were involved in a parallel activity organized by Local Services for Families. The group was scheduled for six monthly 3 hours-sessions. Attendance at support group sessions ranged from 3 to 6 sessions per participant, with an overall average of 5 sessions attended. The topics of discussion for these group sessions were based on parent suggestions, so as to mirror the approach taken by many PSGs for parents of adolescents with ASD (Bitsika & Sharpley, 1999). The group sessions focused on providing mutual support and a sense of belonging among the participants, with specific topics structuring the discussion.

In Session 0 ground rules were negotiated; family members introduced themselves and shared their experience of being parents. Parents were asked to propose and negotiate, by a deliberative process, a list of topics to be discussed in the following meetings. The shared list was the following:

1. Socialization
2. Falling in love
3. Professional experience
4. “When we are no longer”
5. Living a “normal” life
In Session 1 families debated successes and challenges they faced with their child’s socialization, discussing also their dreams for positive relationships and friendship.

In Session 2 families helped each other to speak about falling in love through an input offered by an extract of the movie “The special need” (Film Director Carlo Zoratti, 2014). Then they completed an activity with signage (warning sign; no-entry; one-way) which helped parents to identify fears and opportunities.

In Session 3 families continued to share skills and resources discussing around the theme “professional experience”. An expert was invited to share his experience as professional of vocational guidance: he offered an alternative point of view about the after-school life (in the direction of a job or a university experience).

The high dependency of the adolescents on parents repeatedly raised concerns regarding the time when they are no longer able to care for them. Following the interest raised by the previous session, Session 4 addressed the parents’ need of being aware about the possibility of an access to the university life. A Representative of the University Office for Inclusion made them aware about different resources and services and how to access these services through self-advocacy efforts.

In Session 5 the discussion about living a “normal life” was facilitated through the extracts of some books (written by young people with ASD). The extracts were hung on the walls of the room and were read. Group members were asked to share their thoughts and feelings. Several parents wanted a normal life for their adolescents and were troubled with the adolescent’s difficulty to secure a job, integrate into society, or get married.

In the final session the facilitators presented an overview of the entire programme and parents shared their feelings about the discussed topics and about their experience of participating to the programme. Finally, facilitators led a discussion of what families could do in the future.

Data collection

Data were collected by means of: semi-structured interviews, systematic observation schedules, audio-transcriptions of the meetings’ discussions, a final reflective writing activity (see Table 1 for an overview of the assessment design).

Semi-structured interview. A written interview was conducted with the Representatives of six local Services belonging to the Network. They met and together answered to the questions about: the origins and the aims of the Network, the socio-cultural context in which the network arose, the
legislative framework in which the aims are grounded, the cohesion level among the different involved services, the perceived and desired changes in the context after the beginning of the network activities. The aim was to obtain assessment data by giving voice to the main actors and founders of the same Network.

Observation. Observations during a process are considered as appropriate measures to assess peer interaction (Webster & Carter, 2007). Direct observation was conducted with the use of the time sampling method, before, in the middle and at the end of the programme. This method focuses on the holistic observation of the parents’ behavior. Observations were carried out by the three facilitators and took place at the room where the PARENT_NET group met during the implementation of the main activities. The types of behavior recorded during observations were confirmed by the notes that were kept, a fact that enhanced internal validity (Koster, Nakken, Pijl, & van Houten, 2009).

The observational schedule included the following types of behavior:
- with regard to occurrence of interaction, recording involved whether the interaction was (1) verbal or nonverbal, and (2) positive, neutral or negative;
- about providing and receiving feedback, if during the discussion there was a clear and respectful feedback vs. hurting feelings or irrelevant comments;
- the dimensions of engagement and participation, recording involved whether there was engagement and an active/non active contribution to discussion and activities;
- the attitude of the participants towards each other, observing if there was encouragement - acceptance / discouragement - non acceptance of the participation of the others.

Meetings’ Audio Transcriptions. All the sessions were audio-recorded, transcribed verbatim and analyzed by qualitative content analysis.
<table>
<thead>
<tr>
<th>Dimensions</th>
<th>What (evaluative questions)</th>
<th>How (instruments)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Context</td>
<td>Local Services’ Network</td>
<td>Interviews with Local Services Network’s representatives</td>
</tr>
<tr>
<td></td>
<td>Geographical and cultural context</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Involved professionals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Significance/Relevance of the issue</td>
<td></td>
</tr>
<tr>
<td></td>
<td>National legislative framework</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Needs/desires/limitation s/resources</td>
<td></td>
</tr>
<tr>
<td></td>
<td>When and how the Network was born?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>With which objectives?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>How is the cohesion among involved services?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is the Network’ mission in line with the national laws?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Which are the resources and the limitations?</td>
<td></td>
</tr>
<tr>
<td>Process</td>
<td>Characteristics of the process</td>
<td>Transcriptions of the audio-recorded meetings (content analysis)</td>
</tr>
<tr>
<td></td>
<td>Strategies/Activities</td>
<td>Observation schedules (filled out by facilitators)</td>
</tr>
<tr>
<td></td>
<td>Organization Changes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Which elements are working as facilitators or obstacles for a good functioning of the programme?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are the planned strategies/activities revealing as effective?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Why, and why not?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Would some changes be desirable?</td>
<td></td>
</tr>
<tr>
<td>Outcomes</td>
<td>Expected /real outcomes</td>
<td>Transcriptions of the audio-recorded meetings (content analysis)</td>
</tr>
<tr>
<td></td>
<td>Unexpected outcomes</td>
<td>Observation schedules (filled out by facilitators)</td>
</tr>
<tr>
<td></td>
<td>Which are the expected and the real outcomes?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>And about the unexpected ones?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Did the programme open an horizon of possibilities for the participants?</td>
<td></td>
</tr>
</tbody>
</table>

Table 1. PARENT_NET Assessment Design

Final assessment schedule (reflective writing activity). During the last session a schedule has been provided in order to ask parents to draw an image in which they could represent their feelings about the participation to the entire path. Moreover, they had the opportunity to indicate some perceived facilitators and barriers to their own full and positive participation to the programme.
Findings

Findings are presented separately for each instrument.

Semi-structured interview. The Network’ representatives reported that the project is in line with the National legislation (Law 134/2015, specifically at the article 3) that calls for the promotion of training and support programmes for families. The Network’ main strength is the possibility of developing a common space (a shared culture) for different realities to be together in a project aimed at shared objectives (reciprocal support actions, resource-sharing). Their main concern is a systemic interconnection promotion, aimed at sharing practices and resources and developing a proximity among different contexts. By using multiple methodologies, the collaboration should be oriented to address a lot of issues: raising reflections, transforming emotions, sustaining hidden good practices, gaining new knowledge, promoting the development of spaces of self-storytelling and of respect for the views of the other, supporting the construction of shared and collaborative research actions.

Observation. With regard to occurrence of interaction, silence (concerning non verbal communication) characterized the first two sessions in which the flow of the discussion and more temporal speech markers such as gaps and hesitations were noted. Paralinguistic behaviors linked to tenor, strength, or emotive color of the vocal expression are noted as more connected with parental stress in the first two sessions, than in the others in which the emotional dimension takes on a more coherent meaning with positive affection. Fathers reported less neutral or negative interactions while they reported more positive ones. They generally reported also more positive experiences. They reported that their adolescents were a source of strength and family closeness. Mothers generally reported more parenting stress than fathers.

About providing and receiving feedback, in the first sessions turn-taking violations (more than one person speaking at the same time) and repair mechanisms (such as one speaker stops speaking before a typically possible completion point of a turn) occurred. Since turn-taking provides speakers with an incentive to listen, to understand the utterances and to display understanding, from an initial difficulty to provide feedback and on the contrary to remain on their own positions, especially mothers have developed the capacity to problem-focused coping strategies referring to efforts directed at solving or managing the problem that is causing distress by gathering information, making decisions, planning and resolving
conflicts. It also includes efforts directed at acquiring resources (skills, tools and knowledge) to help deal with the underlying problem, and instrumental, situation-specific, task-oriented actions. Mothers gradually noted or remembered ordinary events with a positive meaning. They became keyed to respond to the adverse sequelae of loss by turning their attention to their resources and looking for positive aspects of their lives.

The dimensions of engagement and participation, as well as the attitude of participants towards each other are described through the analysis of the audio-transcriptions.

Meetings’ Audio-Transcriptions. Analyzing audio transcriptions allowed to focus on two different dimensions: a process-related one and a content-dependent one.

Process-related dimension. This dimension emerged through the comparison between the first and last session transcriptions’, observing differences about interactions among participants. The first evidence was the increase in exchanges among participants without facilitator’s mediation. In this analysis an “exchange” is a dialogue among 2 or plus participants, composed by more than 2 moves (i.e. question - answer - question), without any facilitator’s intervention. In the first session 29 exchanges were detected; in the last one, 55 exchanges were observed. It is significant to underline not only the increase of the quantity, but also the difference between the exchanges extensions in the first and the last session: in the first, the longest exchange comprehends until a maximum of 12 moves, and the average among the exchanges is around 4 moves; in the last session, the widest exchange includes over 20 moves, and the average is around 8 moves.

Another evidence comes from feedback acceptance or refuse: in the first session participants were more interested in telling their own history and struggles and less open to accept feedback from others (also from facilitators), above all if feedback was negative or in opposition with their opinions. In the last session otherwise, participants were able to complete each other sentences, to accept feedback and providing positive ones, and to formulate personal questions in clear and respectful ways.

Facilitator’s interventions were observed as changed: in the first session, roles covered were monitoring, posing specific questions to promote reciprocal knowledge, sharing information and modulating conversation also with some jokes to create a convivial atmosphere. In the last session the interventions were more connected to organizational aspects; questions were deeper and used to launch topic aspects, then received and managed by participants; many interventions were short confirmations to participants’ contributions (“sure”, “certainly”, “clear”, …etc.).
Another important aspect was the change of spirit and lexical choices. During the first session heaviness and frustration were made explicit also by some words: “today I don’t want to talk, because I had a very bad day... I prefer to give space to positive people”; “I am really, really tired... because my daughter... despite all the energies and resources I have invested... my daughter still has problems”; “when he is in a good day, ok, you can do everything, because you know you have the cross, and you organize yourself... in some way, you are no more ashamed because people look at you as well... but you have always to justify”. The chosen vocabulary and explicit stressful situations were used in the analysis as evidence of an initial participants’ isolation: they were concentrated most of all on listing their personal disadvantages rather than on sharing and constructing with others. During the last session the spirit was changed and also the ability of participants to provide positive feedback and construct on other experiences: “I found these meetings very useful and very interesting, because sharing experiences, sharing pains and heartaches, sharing everyday life, sharing everything with... with other parents who live the same... maybe all this let you understand - if you want - that maybe... I get out this last year... I feel lucky... I am a lucky woman”; “After the last meeting, I poked my husband like that about all the things we shared... till late... that he told me: It seems you have been in holiday! For me it has been a very important occasion...”. Also, in reciprocal feedback, participants used more polite forms:

[talking about the possibility to make sons experiences out without parents]
P8: He is very selective... he has his own routine... he eats just pasta without tomato, and with cheese...
P2: It is ok, he eats just pasta with oil not a particular carpaccio...
P8: ...no but... he wants just extra virgin olive oil...
P2: Maybe he exhibits all these behaviors when he is at home with you, but if you make him live an experience like this, it is different...
P8: ...you’re right... I noticed it...
P2: It is different! Please, don’t believe... don’t be you a barrier for your son! Because, if you have the possibility, you have to... Sorry if I allow myself to tell you...

This dimension proved a cohesive and comfortable group’s creation supported by the exchanges’ intensification among participants, by the reduction and modification of facilitators’ interventions, by the use of more polite and respectful vocabulary and feedback, by participants’ ability of
constructing upon one another ideas and completing sentences each other, and by explicit requests to continue the meetings.

*Content-dependent dimension: Good Practices.* Through the meetings, good practices emerged as shared pragmatic principles among parents. Even if they were aware of the different starting situations, parents in every session proposed some reflections about their way to cope with different situations. The progressive community creation, along the experience, allowed to welcome practices proposed by others. All the shared suggestions were connected to concrete and pragmatic situations experienced by parents with their sons and were aimed to observe possible ways and strategies to solve complex scenarios.

Three macro areas emerged: a first one connected to participants’ features as parents of ASD adolescents; a second one connected to their way to stay in relation with sons; a third one connected to the context.

*Parents’ features.* Flexibility habit has been the main explicit prerogative they shared as parents, from an organizational, cognitive and creative perspective. They are used to move, with and for their sons, from one place to another (school, cooperative, medical centers, local realities); to dovetail appointments and movements every day. They are also used to concentrate their attention on finding strategies to solve possible triggering situations for their sons, to dilute their reactions, also in creative ways (i.e. “Do you know how many times I try to solve situations? Even because otherwise they go under pressure…also the last time, we were waiting for his father…and I had understood that he was in late, so I began to anticipate questions, telling my son that his father was in late because of the ambulance, or because of the red traffic lights,… and when his father arrived, the boy was perfectly quiet and relaxed because I suddenly thought to tell him some reasons for the late. I found the solution inventing some possible excuses… but it is not always easy to find strategies and solutions in time”). They tailor their energies to mediate and facilitate communications and contexts, without adding limits or barriers to the starting situations.

They usually look for facilitating tools (i.e. beds on sights to ease sleeping procedures; audio-books to support reading; ear phones to face noisy situations; searching instrument for facilitated communications). In the end they emerge as parents very sensitive to sons’ emotions and difficulties, they always try to understand what sons experience and live, even if it is distant from their perspective.

*Educational relations with sons.* Observation is considered as an important practice. They observe sons’ non-verbal language to understand
their emotions and to reveal in advance possible stressful bursts. Parents are able to grab sons’ growth, they don’t infantilize them because of their situations, they notice changes and unpredictable ripening shots. They are engaged in valuing positive goals and in reasoning upon possible improvement’s expectations. Another important good practice is reasoning with them in a concrete way, involving them in thinking aloud, explaining situations, playing down with them about crisis, figuring with them future and possible (“Sometimes he asks me if he can get married or have sons... it is difficult... but I answer him: Are you working? No, so how to you think to maintain a son? and then, when the child cries and you get annoyed by this and you feel angry, how do you think to manage this? And he tells me: all right mum, you’re right... I want just lots of friends, no marriage, no sons”).

Relations with the context. Providing sons with occasions to live and experience new situations (with peer group above all) seems very important. These experiences can be lived by sons with them but better without them: new situations can allow to develop and exercise autonomy, also forcing their limits, and can allow old practices to change (because contexts and reference figures change) and new practices to emerge (providing new relational instruments). In this way the relation with the context changes: from one side experiencing new contexts - without parents - invites sons to “normalize” their practices and behaviors, and from the other side allows parents to reflect about which contexts can be “normalizing” for their sons’ practices, without necessarily resort to “special” contexts and without necessarily consider “atypical” or exaggerated sons’ practices (“they tell him that he cannot scream in the classroom, because it is not correct, and this is the rule; [...] but every time they go with him just in another room in which he can scream, telling him ‘it is ok, here you can scream’; “He hates waiting in line, but during the school trip, with classmates and support teacher, he made all the queues without any problems! There are two different attitudes: at home and outside!”).

Final assessment schedule (reflective writing). 18 schedules were collected. The most frequent word (11) was sharing: a “climate of sharing”, “sharing of life stories”, “sharing of experiences and situations”, “sharing of emotions”, followed by the word freedom (8), of thought and of speech and expression. This feeling of “free sharing” has allowed parents to recognize each other, to feel welcomed and accepted by the peers and happy to be there. In fact, the drawings focus on this sense of being together, like the drawing that is also a sentence: “an hand towards another hand”.

Interdisciplinary Journal of Family Studies, XXIV, 1/2019
Only one participant reported a barrier encountered during a particular session: feeling uncomfortable with speaking about sexuality.

When asked to rate their experience with the group at follow-up (1 month after the conclusion of PARENT_NET), the parents indicated that they very much enjoyed participating, they found the group very valuable, and they would recommend that other parents participate.

**Discussion and implications for practice**

Findings show that PARENT_NET experience was helpful and parents were satisfied with the support they received from their members; they also described the group as high in cohesion, expressiveness and self-discovery. As noted in the review of the literature, the isolation that parents of children with ASD experience can be profound. This support group allowed parents to help one another in a time of uncertainty like the end of the school and the transition in the after-school life and share a space in which they can feel and express positive emotions and thoughts, considering the group as an opportunity to give and receive emotional support.

Parents gained knowledge and felt empowered to support their adolescents, as the emerged good practices show. They welcomed the opportunity to interact with other parents facing similar challenges and the chance to get new information about local services and the educational system, reporting an increased sense of power in their ability to advocate on behalf of their adolescents. Families benefited from being in a group in which they were able to discuss the best ways to cope with daily difficulties: they felt increased knowledge and skill in dealing with behavioral issues and other day-to-day concerns. The findings highlighted the need for parents to have more explicit conversations about these issues, so group support appears to be an effective means for meeting the needs of these families.

According to this perspective, people who are more socially connected to family, friends, and community are happier, healthier, and live longer than people who are less well connected, so PARENT_NET experience could be a starting point to knit this sense of connections.

The present study has taken in consideration the role of fathers in addition to mothers of adolescents with ASD. Although findings in literature are mixed, as compared to mothers, fathers report lower levels of parenting stress and spend less time providing childcare (Hartley & Schulz, 2015). The PARENT_NET data confirm that parenting is not gender neutral. Mothers and fathers tend to play different roles in their adolescents’ lives. Relationships between adolescents and their fathers have
significant influence on the well-being of the adolescents, but mothers still are more likely to work less, do more caring, and be the primary carer in the early years.

In addition to the formal outcome data, it is important to review the strengths and weaknesses of the model for the delivery of intervention to parents of adolescents with ASD. Strengths include that the facilitators used a model in which the participants were encouraged to engage in positive supportive relationships with each other. Groups may have an advantage over 1:1 support in that they involve more participants, thereby increasing the pool of information available, the chances of interactions with others who share specific experiences and opportunities to give and receive support (Mandell & Salzer, 2007). Such support could be helpful along three broad domains: (1) the sociopolitical, which involved developing a sense of agency in the outside world; (2) the interpersonal, which involved a sense of belonging to a community; and (3) the intrapersonal, which involved self-change. A greater focus on the positive aspects of their adolescents helped parents focus less on the negative aspects and their perceived limitations as parents.

Trying to reach a broader base of families is important to future practice. The families who attended the group were likely highly motivated to seek out the type of information provided in a support group. Reaching families that are not inclined to participate in a support group is crucial for improved outcomes. The group was of value and helpful to participants. However, a larger group of participants and the use of standardized measures, could offer richer and wider facets of the phenomenon.

Further research is required to evaluate the effectiveness of such support groups, although the results at this point are promising. With further research on the use of PSGs for parents of adolescents with ASD more effective systems of support can be developed for these parents who report experiencing more stress and poorer psychological well-being than other parents. Future evaluations should focus on the ‘flourishing’ outcomes of programmes such as increasing well-being, resilience and other positive attributes, as well as more traditional outcomes such as reducing anti-social behavior, or attendance at school. Evaluations should incorporate not just the views of the parents and carers, but also those of the adolescents. Group support offered parents the knowledge, understanding, and acceptance they seek. Findings suggest that one of the greatest needs for families coping with a son/daughter with ASD is finding a sense of connection with the others.
References


Interdisciplinary Journal of Family Studies, XXIV, 1/2019


