Experiences of stakeholder collaboration when promoting participation in physical activity among adolescents with autism spectrum disorder

Susann Arnell, Kajsa Jerlinder, Susanna Geidne & Lars-Olov Lundqvist

To cite this article: Susann Arnell, Kajsa Jerlinder, Susanna Geidne & Lars-Olov Lundqvist (2022) Experiences of stakeholder collaboration when promoting participation in physical activity among adolescents with autism spectrum disorder, Disability and Rehabilitation, 44:9, 1728-1736, DOI: 10.1080/09638288.2021.1887944

To link to this article: https://doi.org/10.1080/09638288.2021.1887944
Experiences of stakeholder collaboration when promoting participation in physical activity among adolescents with autism spectrum disorder

Susann Arnella,b, Kajsa Jerlinderc, Susanna Geidned and Lars-Olov Lundqvistab

Faculty of Medicine and Health, University Health Care Research Center, Örebro University, Örebro, Sweden; Faculty of Medicine and Health, The Swedish Institute for Disability Research (SIDR), Örebro University, Örebro, Sweden; Faculty of Health and Occupational Studies, University of Gävle, Gävle, Sweden; Faculty of Medicine and Health, School of Health Sciences, Örebro University, Örebro, Sweden

ABSTRACT

Purpose: Various stakeholders contribute to the development of healthy physical activity habits in adolescents with autism spectrum disorder (ASD). Parents and stakeholders seek collaborative actions but little is still known about such efforts. The purpose of this study was thus to explore how professionals from different services experience stakeholder collaboration when promoting participation in physical activity for these adolescents.

Method: Five focus group discussions were held with 17 professionals from education, health care, community, and sports organizations, engaged in the promotion of physical activity in adolescents with ASD. The data were analyzed with qualitative content analysis.

Results: The discussions revolved around a central theme: Collaboration is needed to promote physical literacy among adolescents with ASD. The professionals though experienced that this collaboration was hampered by the low priority given to physical activity issues within different organizations, by limited resources, lack of knowledge, and unclear roles.

Conclusions: Notwithstanding the professionals’ different roles, all agreed that physical activity issues need to be prioritized and that each stakeholder needs to acknowledge the shared responsibility of collaboration. However, more clear routines for collaboration that include joined efforts but also highlight the organization-specific responsibilities might enhance the collaborative efforts.

Introduction

In order to promote healthy physical activity habits among adolescents with autism spectrum disorder (ASD), the activities need to be tailored to their needs. Unfortunately, current physical activity initiatives are often not sufficiently adapted. This means that they do not achieve the intended effect of increasing physical activity, which means that adolescents with ASD are less fit [1]. They spend less time in physical activity and participate in fewer types of physical activities compared to their typically developing peers [2–4]. Previous research on physical activity participation among adolescents with ASD shows that their participation is often conditional based on their individual needs and wishes and that they feel that participation in physical education (PE) is demanding, which leads to reluctance to participate [5]. The reluctance is shown in different aspects of the concept of participation, such as preferences, attendance, involvement, and engagement in physical activities [6]. This can, for example, manifest itself as an adolescent who is present during physical activity but with passive commitment, low motivation, and perseverance. Socio-behavioral mechanisms, including perceived activity competence, bodily and behavioral impairments, as well as social and contextual processes, have been recognized as important when shaping the individual’s participation in physical activity [6,7]. Promotion of healthy physical activity habits thus becomes more effective when incorporating an understanding of both health behavior and the context in which physical activities occur [8].
Different stakeholders, such as professionals within education, health care, and community services, influence and contribute directly or indirectly to the development of healthy habits in adolescents’ everyday lives. Participation in physical activity is promoted through initiatives during PE and other initiatives before, during, and after school provided by community groups and sports clubs. In addition, counseling on physical activity issues is provided in some countries by health professionals [9]. In Sweden, the responsibility for being physically active in school and in leisure time has traditionally rested on the municipalities. The provision of PE in school, which is compulsory in many countries, is the arena that reaches the most children and adolescents [10]. Other stakeholders contributing to the development of healthy habits in adolescents are the health care service and non-profit organizations, community services experience stakeholder collaboration when promoting participation in physical activity for adolescents with ASD. The aim of this study was therefore to explore how different professionals within education, health care, and community services experience stakeholder collaboration when promoting participation in physical activity for adolescents with ASD.

Methods
Design
This is an exploratory study using data from focus group discussions with professionals representing different stakeholders involved in promoting physical activity participation in adolescents with ASD. Focus group discussion was chosen because it is a useful method to explore experiences, approaches, and views among small groups of individuals who have some involvement in the topic under investigation [29]. In order to transparently report the findings, the COREQ-guidelines were used [30].

Recruitment procedure and participants
The previously mentioned socio-ecological model guided the recruitment procedure covering different levels of influence on participation in physical activity. In this study, a purposive recruitment procedure was used in order to gain a more comprehensive perspective from different stakeholders, who were professionally engaged in the promotion of physical activity habits (hereafter referred to as professionals or participants). The participants were recruited by sending an information letter to executives (n = 56) within the education, health care, and community services in two counties in the central region of Sweden. The executives then forwarded the letter to the professionals they considered appropriate for the focus group discussion, based on their knowledge of the topic. A follow-up phone call to the executives was conducted in order to give them an opportunity to ask for clarification about the choice of professionals and the study. Professionals who agreed to participate in the study then contacted the researchers directly for more information. There were no dependent relationships between the participants and the researchers. Seventeen professionals participated in the focus group discussions. They worked in schools, school health care, child and youth habilitation centers, municipal organizations, and non-profit sports organizations. The focus group participants represented diverse categories

---

### Table 1. Overview of the participant demographics and organizational affiliation.

<table>
<thead>
<tr>
<th>Variable</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>13</td>
</tr>
<tr>
<td>Men</td>
<td>4</td>
</tr>
<tr>
<td>Age</td>
<td>Mean 47 years, (range: 26–64 years)</td>
</tr>
<tr>
<td>Organization</td>
<td></td>
</tr>
<tr>
<td>School (PE)</td>
<td>7</td>
</tr>
<tr>
<td>School (health care)</td>
<td>1</td>
</tr>
<tr>
<td>Health Care</td>
<td>4</td>
</tr>
<tr>
<td>Sports organizations</td>
<td>4</td>
</tr>
<tr>
<td>Community/municipality service unit (LSS*)</td>
<td>1</td>
</tr>
<tr>
<td>Profession</td>
<td></td>
</tr>
<tr>
<td>Teacher: (PE/SE/T)</td>
<td>6 (3 PE/2 SE/1 T)</td>
</tr>
<tr>
<td>Health care professional</td>
<td>5</td>
</tr>
<tr>
<td>Municipal official (LSS administrator)</td>
<td>1</td>
</tr>
<tr>
<td>Public health/health promotion</td>
<td>5</td>
</tr>
<tr>
<td>Professionals</td>
<td></td>
</tr>
<tr>
<td>Years of experience</td>
<td>Mean 18.35 years, (range: 2–40 years)</td>
</tr>
</tbody>
</table>

of professionals and organizations, however, the small numbers would not allow analysis by sub-groups [29].

The focus group discussions

The focus groups were heterogeneous, consisting of a range of professionals representing the education, health care, and community services, as well as non-profit sports organizations (Table 1). In all but one of the focus groups, the participants came from different organizations, and in the focus group with two participants from the same organization, these two individuals represented different professions. Even though homogeneous groups are usually recommended [29] the purpose of this study guided the choice of heterogeneous groups since the multi-stakeholder collaboration was in focus. The minimum number of focus groups recommended to be included in a study is three [29] but the number of groups needed is also determined by the complexity of the phenomenon being studied [31]. Therefore, a total of five focus group discussions were planned and carried out. The discussions took place at a research center or a university, four groups in one of the counties and one in the other county.

At the beginning of the focus group discussions, participants were asked to fill out a form about their age, gender, profession or position, and years of experience in their profession or position (Table 1). Thereafter, the focus group discussions started by letting the participants read two fictitious cases that described adolescents with ASD of different character and severity, in which the adolescent’s conditional participation behavior in physical activity was evident. The fictitious cases were used to break the ice and stimulate discussion [32]. The cases were developed by the researchers in collaboration with people who were well-versed in the situation of adolescents with ASD and who regularly meet young people with ASD in a physical activity context. The fictitious cases were formulated to cover issues at various socio-ecological levels: the intrapersonal, interpersonal, organizational, and community or public policy levels. The participants in this study were all familiar with adolescents with ASD. All of them recognized to a large extent the challenges that were described in the fictitious case descriptions, such as the decline in levels of participation in physical activity and the gap between the physically active and the physically inactive that increases during adolescence.

The focus group discussions then continued, based on six key questions, which were developed to capture the participants’ perspectives and experiences of collaborative efforts when promoting increased physical activity for adolescents with ASD (Table 2).

The first author (SA), an experienced physiotherapist, had the role of moderator, leading the focus group discussions. The discussions were carried out as a group conversation, using probes and follow-up questions in order to gain additional information from participants and thereby obtain rich descriptions and deeper knowledge [29]. During the focus group discussions, the atmosphere, the balance of speaking time among the participants, and how the views changed during the course of the discussion were noted by an assistant moderator (LOL or KJ); occasionally, the assistant moderator asked follow-up questions in order to clarify the participants’ opinions. A summary of the discussion, which included a member checking, was done at the end of each focus group, where tentatively find issues were presented to the participants for confirmation or clarification. The length of the focus group discussions varied between 110 min and 120 min. Soon after each focus group discussion was concluded, a debriefing was conducted in which notes were compared among research colleagues [33]. All focus group discussions were digitally audio-recorded and thereafter transcribed verbatim by the first author.

Data analysis

The discussions were analyzed inductively using qualitative content analysis for focus group discussions, as described by Krueger and Casey [29]. Since the qualitative content analysis was used the emphasis was on identifying variations and interpretations of the discussion [34] rather than focusing on the number of occasions (numerical data) on how frequently a specific issue/topic was discussed. Analytical questions covering different aspects of collaboration were constructed, such as; How do the participants describe their mission, roles, and other professionals’ roles when promoting participation in physical activity among adolescents with ASD? How do the participants describe the collaboration or lack of collaboration? and How do the participants describe the prerequisites for collaboration?

All of the authors participated in the analysis, which contributed pre-understanding, knowledge, and experiences from different scientific fields, such as knowledge about autism (SA, LOL), physical activity promotion (SA, KJ, SG), and public health science (SG). The analysis procedure followed a series of steps proposed by Krueger and Casey [29]. First, the audio recordings of the focus group discussions were listened to, and then the transcriptions were read through to create an overall impression of the material. In order to improve the dependability of the analysis, one of the most comprehensive discussion transcripts was analyzed by three of the authors (SA, SG, LOL) independently. Content relevant to the aim of the study and the analytical questions was identified in the text, condensed, and provided with a code. All codes sharing a commonality were categorized into tentative sub-categories.

Table 2. The interview guide.

<table>
<thead>
<tr>
<th>Key questions</th>
<th>Examples of questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences of promoting participation in PA</td>
<td>“What experiences do you have from meeting adolescents with ASD?” (opening question)</td>
</tr>
<tr>
<td></td>
<td>“What are the major challenges when promoting healthy physical activity habits for adolescents with ASD?”</td>
</tr>
<tr>
<td></td>
<td>“Measures taken and proposals for solutions?”</td>
</tr>
<tr>
<td></td>
<td>“Whose mission or responsibility is it to promote physical activity among adolescents with ASD?”</td>
</tr>
<tr>
<td></td>
<td>“How do you view the roles you have (your own role and the roles of others) regarding promoting good physical activity habits?”</td>
</tr>
<tr>
<td>Mission and responsibilities</td>
<td>“What does the collaboration look like?”</td>
</tr>
<tr>
<td></td>
<td>“How does the cooperation between different actors work?”</td>
</tr>
<tr>
<td></td>
<td>“Obstacles and opportunities for collaboration?”</td>
</tr>
<tr>
<td></td>
<td>Reflect back on the previous comments and point out the most important topic of the discussion. (closing question)</td>
</tr>
</tbody>
</table>

Collaboration
and then further categorized hierarchically into categories. Thereafter, the authors met to compare and consolidate the preliminary codes and the coding structure. The first author then completed the analysis in close, continuous discussion with the other authors. During the analysis, the extent and frequency of specific views were noted, as well as inconsistencies. The codes were discussed and revised, compared for similarities and differences, and thereafter abstracted and grouped hierarchically into subcategories and categories that were internally homogeneous and externally heterogeneous. This iterative process continued until consensus was reached. Finally, an overall theme could be derived from the data. Quotes were selected to illustrate the essence of different categories in order to increase the credibility of the study. The NVivo 12 software program (QSR International, 2018) was used for the analysis.

Ethical considerations

The study was approved by the Swedish Ethical Review Authority (approval number: 2019-00194). The participants were informed that their participation was voluntary and that their identity would be handled confidentially in all reporting of the study. All participants gave written informed consent.

A general ethical dilemma with focus group discussions is that only the moderators can promise confidentiality on the part of the researchers, whereas it is impossible to control whether the other participants in the group disseminate confidential information [35]. To address this problem, an oral agreement was obtained from all participants not to disclose anything that emerged in the focus group discussions with anyone other than those who participated in the discussion.

Results

The focus groups revealed multidisciplinary perspectives on meeting adolescents with ASD and gave reflections across a variety of experiences from the participants’ missions, roles in different professional fields. The different perspectives covered voluntary recreational activities and mandatory activities such as PE in school. In the analysis, an overarching theme that corresponded to the aim of this study emerged: Collaboration is needed to promote physical literacy (Table 3).

The participants perceived that promoting healthy physical activity habits among adolescents with ASD was difficult but important. The impact of the actions with the aim of changing the adolescents’ physical activity habits was discussed, revealing a consensus on shared responsibilities with specific roles for different stakeholders, but limited resources, lack of knowledge, and unclear roles though hampered these efforts. In particular, the low priority given to physical activity issues and the lack of organized multi-stakeholder meetings to discuss physical activity in the consultation was highlighted. The overall theme will be presented and discussed in more detail below, through the linked categories and subcategories describing the challenges related to the recognition of the adolescents’ individual specific conditions, the unified mission, the organizational conditions, and other prerequisites for collaboration.

A challenge to incorporate the recognition of individual needs in collaborative efforts

According to the professionals, problems associated with participation in physical activities were common among adolescents with ASD. This circumstance may partly be due to the elements that are commonly found in sports, such as the element of competition and continuous comparison between participants per se. Concepts such as “failure” and “ruin for the others” clarify how such participation had been reported to the participants. The professionals emphasized that anything related to physical activity can potentially be a challenge to the adolescents and thus a challenge for stakeholders to overcome in order to be physically active.

The adolescents with ASD were considered a disadvantaged group since participation in ordinary organized physical activities often was perceived as an overwhelming task for them. Particularly, since the full range of difficulties at various levels, related to participation in physical activity could be hard to notice by staff and sport leaders. A need for staff to recognize the extent of the disability was also stressed, as it can sometimes be problematic due to marked individual differences.

This group of young people is supposed to fit into normal sports clubs, play football, understand instructions, be able to participate like anyone else … but then they do not see the full picture [the adolescent’s abilities and difficulties] (participant 5:2, school)

You don’t see the disability (participant 5:4, sports organization)

So this group is especially vulnerable in the sports world just because you do not see the person as a whole (participant 5:3, health care)
Acceptance and individually adapted activities were two key concepts that emerged and thus considered important components for meeting the adolescents’ unique needs. Finding individual-specific solutions could be a resource-intensive effort because the needs had sometimes to be mapped in detail and the participation thereafter adequately adapted and supported. This recognition of individual-specific conditions was perceived as challenging for organizations and especially difficult to recognize in collaborative efforts.

A shared goal encourages collaboration

Providing opportunities for physical activity and support for participation was considered a community-wide mission. The roles and responsibilities of parents and other stakeholders were perceived to be shared, sometimes overlapping but still unclear. The participants were in agreement that this responsibility lies at several societal levels and thus with several different stakeholders. Some responsibilities were directed at the individual level, while others were directed at an organizational level.

Everyone really has a designated public health mission, at a national level and at a regional level… at a community level. There is no place where this mission does not exist in any form … it’s more about how you get it done. Then you can wish that something more would happen … and then maybe this … physical literacy is something you would need. (Participant 4:3, sports organizations)

The participants unanimously stressed that if adolescents with ASDs’ participation is to be enhanced different types of competencies are required: knowledge about ASD, knowledge about inclusion in physical activities, and experience in how to meet the individual and specific needs of adolescents with ASD. Regardless of which of these competencies each organization possessed, knowledge about the disorder was often considered the most important. However, a concern was raised that there is a risk of missing what is important for each individual if too much focus is given to general knowledge about ASD.

Also, knowledge about how to adapt the physical activities to enable the adolescent to participate in them was considered important. The need to find the individual specific “keys” emerged in the discussions, referring to what adaptations could best support the adolescent’s participation. In contrast, some participants described how solutions that were built around support for specific adolescents were considered vulnerable; the participants advocated more solutions at the organizational level because it was perceived as being more sustainable in the long run. Awareness of this type of organizational challenge was considered essential in order to understand issues related to collaboration.

The participants agreed that there was some variation within and between organizations in the level of knowledge and pre-understanding. Limited knowledge among leaders and coaches in non-profit organizations was often raised as a problem.

When roles and responsibilities were further discussed, the concept of physical literacy was raised as a unifying factor. It was defined as “it is not about physical activity per se but it is about creating a citizen who is active throughout life” (participant 4:2, community). However, the professionals frequently described how they failed to accomplish this mission in the case of adolescents with ASD. The adolescents were considered a disadvantaged group because creating opportunities to increase participation in ordinary, organized physical activities was often described as difficult, sometimes even as overwhelming. Thus, the importance of a multi-stakeholder mission to collaboratively create lifelong physical activity habits in these adolescents was emphasized.

Non-optimal use of resources and competencies to promote physical activity

The low priority is given to physical activity in organizations in general, and particularly PE within the school setting was unanimously addressed as problematic by the participants. It became evident during the discussions that PE is the school subject that is usually prioritized down and removed if a student’s schooling needs to be adjusted. On the other hand, the participants highlighted the fact that, because research has demonstrated the importance of physical activity and the relationship between regular physical activity and school performance, the status of physical activity and PE has somewhat increased.

It was not only in the educational setting that questions regarding physical activity had a low priority. Even within the other organizations, more urgent issues and needs were prioritized, leading to the promotion of physical activity being neglected.

The participants also discussed how the availability of resources within a community or how the prevailing political agenda dictates which issues, and thus also which resources, are prioritized. According to the participants, there is a risk that questions about the physical activity will be a political non-issue, as all parties share the view that physical activity is important. The participants concluded that a political consensus, remarkably, risks leading to physical activity not gaining enough attention, which results in adolescents with ASD being neglected or non-prioritized in physical activity contexts.

The participants pointed out another factor that influenced their collaborative efforts, which was their level of knowledge of other professionals’ roles. The level of this knowledge contributed to how the collaborative actions were designed and how they were accomplished. The role of the education and health care services in the promotion of physical activity was clear. In contrast, the responsibilities of municipalities, especially for leisure activities, were less obvious and even less so for sports organizations. The participants were particularly unsure about where to turn in order to get support for physical activity in leisure time. This became evident since they expressed a lack of knowledge about which stakeholders were responsible for providing such support. In addition, the participants who provide such support reflected on their own lack of knowledge and problematized this shortcoming.

One would wish that more people called and had questions [about physical activity in leisure time]… just contacted us [but] they don’t know we exist… that doesn’t even … no one does, I was about to say… there are so few who know (participant 4:2, community)

… and that you have that mission (participant 4:3, sports organizations)

However, in this context, it was emphasized that the role of sports organizations was not primarily to support individuals but rather to support sports clubs to include children and adolescents with a disability in physical activity. As a consequence, the participants felt that the promotion of participation in physical activity was further reduced since resources and skills within these organizations are not being utilized optimally.

According to the participants, different organizational conditions affect each organization’s mandate to act but also its obligations. The school’s responsibilities when it comes to promoting healthy physical activity habits, in contrast to the non-profit organizations’ responsibilities, were often highlighted as examples of differences between stakeholder roles. PE is mandatory whereas participation in leisure-time physical activity is optional.
Within the education system, there is a clear mission, and therefore requirements that must be followed, such as a curriculum that includes specific knowledge requirements that are graded. This clear mission also meant that schools were obliged to meet the requirements, such as to provide adaptations based on individuals’ specific needs and to ensure the right level of competence among the relevant staff. This was contrasted with the lack of clarity on requirements that can be set for physical activity during leisure time.

What expectations can you have for an association [sports clubs]? What kind of expectations are possible or reasonable? … How much can you expect … them to adapt to or relate to it [the individual's specific needs]? It’s really, really hard. (Participant 1:3, sports organizations)

With regard to controlling factors such as statutory requirements, steering documents, and guidelines, it was discussed how they sometimes limit the scope for action but on the other hand, they can clarify the mission. Different organizations were perceived to be regulated to varying degrees. For example, the participants perceived the municipal units responsible for support and service for persons with certain functional impairments as tightly controlled by law, while other organizations were perceived as more adaptable.

In order to promote the efficient use of resources, clearer role descriptions were requested, since unclear responsibilities create unclear conditions for collaboration.

Whose responsibility is it? … today we do not really know … who is responsible for what. That is to say, we can certainly point out some things and say that they are responsible for this … but then in general? We need a clearer description of the mission to be able to find the resources that exist in society, both in health care and school and the community … … And then you should try to merge these efforts … but then someone has to do it. (Participant 2:3, sports organizations)

**Need for addressing physical activity issues**

During the focus group discussions it became evident that, in order to be able to support the adolescent’s participation in physical activity, a prerequisite was that the individual’s specific wishes and needs were clarified among all professionals. The participants emphasized the importance of different stakeholders being able to communicate with each other in an appropriate way. However, this was occasionally hindered by the privacy regulations to which some organizations are subject. “When we talk about individual adolescents … it can be a little difficult with confidentiality, I think … not always but … it can be an obstacle in some cases then perhaps in relation to cooperation” (participant 1:2, school). This confidentiality that exists within and between different organizations was considered to partially contribute to “the organizations are working in isolation from each other … and the information doesn’t really go between them even though we actually work with the same children” (participant 1:4, health care).

The participants also addressed another contributing factor that limited collaboration, namely, the lack of arenas for discussion focused on physical activity issues. However, during the discussions, it became clear that some stakeholders do already collaborate to varying degrees and have such an arena for collaboration. Organizations regulated by laws and having a clear mission, such as school, health care, and municipal LSS support services (set up to satisfy the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments, or LSS) often had established procedures for collaboration. In some cases, collaboration was a statutory requirement, such as for the development of coordinated individual service plans, for which multi-stakeholder meetings were common. The participants often took part in such coordination meetings concerning adolescents with ASD.

This statutory right enables parents to initiate coordination meetings and decide which stakeholders ought to be invited, in order for the family to obtain assistance in coordinating various types of interventions for their child. Nonetheless, the participants unanimously highlighted the fact that questions regarding physical activity were rarely raised at these meetings, because of other issues. Which issues were raised was often dependent on the stakeholders involved in the meeting. This was also reflected in the collaboration between different stakeholders, as questions regarding physical activity were rarely or never raised in collaborative meetings.

Well, I can say that I have never discussed [questions about physical activity] (participant 3:5, school)

No (affirmative) … not often … not so … (several participants simultaneously 3:2-6, school, health care, and sports organizations)

… but at the meetings I’ve been to, the primary thing has been wellbeing, actually … There may be something about well-being that has been number one (participant 3:5, school)

I think it is often the school situation … We get into a discussion about it not working in school. They don’t attend and whose responsibility is it … (participant 3:3, health care)

It can also be (affirmative) … (participant 3:5, school)

It is common … but not so much about physical activity … but it ought to be. Just like other issues. I’m thinking of a question similar to this regarding physical activity … it is selective eating that is common in the group of children with autism … and that question comes up more often (participant 3:3, health care)

Nevertheless, the participants suggested that this kind of coordination meeting could be a way to establish and improve collaboration regarding promoting participation in physical activity. Constantly, however, it was noted that stakeholders in charge of voluntary leisure activities, including physical activities, seldom or never took part in these kinds of meetings. The low priority of physical activity issues in these meetings led to professionals with in-depth knowledge in the field of physical activities rarely attending these collaborative meetings.

**Discussion**

The aim of the present study was to explore how different professionals experience stakeholder collaboration when promoting participation in physical activity for adolescents with ASD. This study identified an overall theme related to the participants’ experiences: **Collaboration is needed to promote physical literacy.**

Promotion of enhanced participation in physical activity and enhanced physical literacy among adolescents with ASD was perceived as challenging. The challenges were multifaceted and included various aspects, ranging from the adolescent’s intrapersonal level, for example, the individual’s specific conditions, to the organizational level such as the available range of physical activities in society and stakeholder collaboration. With regard to stakeholder collaboration, the participants’ different roles were seen as an obstacle but also as an opportunity if different actors’ actions were unified. An identified unified mission was to collectively promote physical literacy among adolescents with ASD. The concept physical literacy was raised in several of the focus group discussions. In this context, recognition of the need for different
stakeholder competencies was emphasized. Physical literacy is assigned different meanings in different contexts [36] but a commonly used definition is “As appropriate to each individual’s endowment, physical literacy can be described as the motivation, confidence, physical competence, knowledge and understanding to maintain physical activity throughout the lifecourse” (page 5 in Physical literacy throughout the lifecourse) [37]. Although this concept is inclusive for all individuals regardless of ability [37], a recent review revealed that research on physical literacy among individuals with disabilities foremost focused on ableism, how to correct and improve participation in physical activity [38]. In the same review, the collaboration and stakeholder engagement, as well as the professionals’ impact on development of physical literacy, was highlighted, which correspond to the findings of the present study. Physical literacy is thus an ambiguous concept, which can be seen both as a means and an end [39,40] since it is not only a way to increase the well-being of individuals, but also a concept that connects the health promotion missions of different stakeholders [41]. This is in line with previous research that has highlighted a need for continued interdisciplinary approaches to promote such development among adolescents with ASD [42]. Proficient fundamental motor skills, as Stoddten et al., [43] argue, is a prerequisite to participation in physical activities. In a review [44], this connection between improved motor skills and the likelihood of participation in physical activity was addressed. However, improving motor skills only may not be efficient enough. Increasing the adolescents’ self-efficacy to engage in activities by improving their physical literacy through multidisciplinary efforts may also be required [45].

The professionals also addressed that motor skills and physical activity issues were rarely prioritized within the organizations, even though there is a general awareness of the positive effects of regular physical activity. The low priority of physical activity issues was, as also described by Reinders et al. [46], due to a conflict with other issues given a higher priority, such as the adolescents’ difficulties with communication or stereotypic behaviors. This is further in line with research showing that early interventions often focus on social skills training rather than on physical activity interventions [7].

The participants expressed a clear need to coordinate efforts and interventions to increase the adolescents’ ability and willingness to participate in physical activity, and that this should be on the adolescent’s own terms. As Potvin and colleagues [47] proposed, by developing a “family-centered collaborative teaming approach” the adolescent, family, and environmental factors will be better recognized and, as a result, the adolescents’ participation in recreational activities enhanced. However, as the professionals from sports organizations highlighted in the present study, the difficulty in reaching out to the adolescents can be hampered by limited connections and a lack of collaboration with families and other stakeholders. Identification of “missing links” can be a way to enhance participation in physical activity among children with disabilities [48]. It has been suggested that partnerships established through collaboration between different professionals can overcome difficulties reaching out to the adolescents, but hitherto these kinds of efforts are not widespread [17]. The results of the current study support such efforts by showing that identification of all relevant stakeholders and the creation of lasting partnerships through collaboration covering all socio-ecological levels, including policy-makers, key healthcare decision-makers, managers, and supervisors, are needed to facilitate the promotion of participation in physical activity.

Methodological strengths and limitations

The choice of focus group discussions as a data collection method allowed a variety of professional perspectives to be aired, revealing challenges when it comes to collaboration in practice. Previous researches have, to our knowledge, not focused on this topic in depth when it comes to promoting participation in physical activity among adolescents with ASD. To ensure the credibility, variety, and richness of the data, both women and men of different ages and with different lengths of professional experience were included in the study. However, a risk of bias need to be recognized since only participants interested and engaged in issues regarding the promotion of physical activity among adolescents with ASD may have chosen to take part in the focus group discussions. Another measure in order to achieve credibility was member-checking conducted as a final step of the discussions and the use of quotes from the focus group discussions. The integrity of the data collection and analysis was ensured by including all authors in the process, and accurately and carefully describe each step of the data analysis. The researchers’ experience and pre-understanding were taken into account since the authors’ reflexivity, pre-understanding, and experiences may affect the interpretation process, including how the content is analyzed and what significance is attributed to different data [30,49]. However, it needs to be highlighted that even though there were no dependent relationships between the participants and the researchers, especially the moderator’s role may have had an impact on how issues were discussed. Likewise during the initial analysis, which was foremost conducted by the first author, which may have had an impact on what issues were given priority.

The study has some other limitations as well, of which some may be inherent in the focus group methodology. In this study, five focus group discussions were conducted and after the fifth group, no new issues emerged. When saturation is assessed, both so-called code saturation and meaning saturation should be considered [50]. The number of focus groups was not predetermined and since no new issues arose in the last focus group discussion it indicated a level of saturation (code saturation). It is difficult to assess whether “the meaning saturation” was adequately reached, however, more groups may have contributed to a more detailed comprehension of some issues raised. The number of participants was small but, to increase representativeness, professionals from various organizations with different roles were included, lending greater confidence to the transferability of the findings. The individual focus group size ranged from two to five participants, which could be seen as a limitation. But the small group size, a result of a late cancellation because of an emergency situation, may instead have facilitated the participants to speak more freely about their experiences, thus generating a greater depth in the discussions [29]. In fact, the discussion in this group generated as much and as rich data as the other discussions. Perhaps a more serious problem is that we mainly have the views of those professionals who directly meet the adolescents and their families. If collaboration on the promotion of physical activity habits is to be enhanced, the perspectives of directors and other managers in the organizations also need to be considered.

Conclusions

The findings demonstrate that promoting healthy physical activity habits in adolescents with ASD can be difficult due to their need for tailored activities. These efforts may be further undermined by competing demands and limited resources. Notwithstanding the
professionals’ various roles, all participants in this study agreed that collaborative efforts are required, that physical activity issues need to be prioritized within all organizations dealing with adolescents on the autism spectrum if physical literacy among adolescents with ASD is to be enhanced. The lack of such collaboration entails a great risk that no stakeholder considers himself or herself responsible for or mandated to take action. More clear routines for collaboration that include joined efforts but also highlight the organization-specific responsibilities could be a support for professionals engaged in promoting lifelong participation in physical activity among adolescents with ASD.

Acknowledgments

We wish to thank all the professionals who participated and shared their experiences.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This research was financially supported by Region Örebro County, Sweden.

ORCID

Susann Arnell
http://orcid.org/0000-0001-9074-6559
Kajsa Jerlinder
http://orcid.org/0000-0002-2215-5850
Susanna Geidne
http://orcid.org/0000-0002-5093-4958
Lars-Olov Lundqvist
http://orcid.org/0000-0002-6703-7575

References


