


Family members and health care workers' perspectives on motivational factors of participation in physical activity for people with intellectual disability: A qualitative study

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Abstract

Background People with intellectual disabilities (ID) have lower levels of physical activity than the general population. The aim of this study was to understand the motivational factors of participation in physical activity for people with ID from the perspectives of the family members and staff.

Method An abductive qualitative design was used. Social Cognitive Theory constituted the theoretical frame of reference of the study. Two focus group interviews with health care workers and family members and two individual interviews with health care workers were conducted at their workplace. A thematic analysis was performed.

Results Three main themes were identified.

According to support persons, motivation could be promoted at the individual level by fun, mastery, social setting, technology and knowledge about health behaviours. At a contextual level, physical activity was mediated by engagement with support individuals and available resources. At an interactional level, individuals were more motivated if the interaction was featured by joint activities, predictability and the use of rewards.

Conclusions Motivation for participation in physical activity might be promoted at the individual, contextual and interactional levels. The interactions between individuals with ID and their support persons should work in a supportive way and strengthen mastery experiences. Support and engagement in the context could serve as a prerequisite for motivation and participation in physical activity and should be considered when

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developing interventions for physical activity for individuals with ID.

Keywords intellectual disability, motivation, participation, physical activity, technology

Introduction

Compared with the general population, individuals with intellectual disabilities (IDs) have worse health, lower levels of physical activity (PA) and higher barriers for participation in activities and access to health care (Walsh 2008; Evans *et al.* 2012; Hilgenkamp *et al.* 2012; Balogh *et al.* 2016; Temple *et al.* 2017; Wouters *et al.* 2019). PA is the term used to describe bodily movement produced by skeletal muscles that require energy expenditure (World Health Organization 2004, 2010) and can be further defined by types of activities and intensity categories. As PA has positive effects on cardiovascular and psychosocial health factors, as well as brain health (Piercy *et al.* 2018), the identification of effective interventions for use in everyday settings is important. Specifically, motivation of individuals with ID is a crucial concern (Hutzler and Korsensky 2010).

Motivation refers to a driving force that elicits a particular action and affects the nature of an individual's behaviour in both strength and persistence (Deckers 2005). Several studies have examined the barriers to and facilitators of participation in PA (Heller *et al.* 2003; Temple 2007; Mahy *et al.* 2010). Perceived self-efficacy, social support and peer modelling are factors that facilitate the participation in PA of individuals with ID (Temple 2007; Bossink *et al.* 2017). The identified barriers to participation in PAs include lack of financial, political and/or psychosocial support, as well as a lack of personal interest in PA and a lack of self-efficacy (Dixon-Ibarra *et al.* 2017; Temple *et al.* 2017). The perceptions of PA and other health behaviours among individuals with ID correspond to the carer and staff descriptions of barriers and preferences (Heller *et al.* 2003; Temple 2007; Mahy *et al.* 2010; Kuijken *et al.* 2016). Most research on PA for individuals with ID have focused on mild-to-moderate ID, and future research should include the study of individuals with more severe ID (Bossink *et al.* 2017). The majority of these studies are from

central Europe and the USA, and no studies have been conducted in the Arctic region.

To understand the motivation and participation in PA for individuals with ID, studies have utilised health behavioural theories. In Social Cognitive Theory (SCT) (Bandura 1978), the concept of self-efficacy states that the beliefs people have about their capabilities constitute a basis for action and also regulate motivation. These self-efficacy beliefs can be strengthened through mastery experiences and social modelling influence. According to Self-Determination Theory (SDT) (Ryan and Deci 2000), motivation can be classified as (1) not present (amotivation), (2) leading to engagement in activity because it is enjoyable in itself (intrinsic) or (3) driven by external requests or rewards (extrinsic). Previous research has confirmed that individuals with mild-to-borderline ID can display different levels of extrinsic motivation (Frielink *et al.* 2017). The focus of SDT on autonomy as intrinsically motivating could constitute an interesting perspective in this field of study because of the frequent threats to personal control of people with ID (Bergström *et al.* 2014). Motivation can also be framed as a socioculturally constructed phenomenon (Daniels *et al.* 2007). In this frame of reference, motivation is always already embedded and shaped by particular contexts (Daniels *et al.* 2007).

As previous research indicates that interpersonal and other environmental factors contribute to the promotion of PA for individuals with ID, the authors aimed to explore how the individuals who interact with individuals with ID understand their participation in and motivation for PA. Our additional aims involved an investigation as to how PA could be facilitated in the Arctic regions and the inclusion of family members or staff who represent individuals with more severe ID.

Methods

We conducted two semistructured focus group interviews with family members and health care workers. Focus group interviews are suitable because they facilitate dialogue and the elaboration of experiences and ideas among colleagues (Malterud 2012) and is useful for exploring specific sets of issues as well as permitting the researcher to use the group interactions as research data (Kitzinger 1994). To ensure greater variety in the sample of professionals

and services, we supplemented the data with two individual in-depth interviews with health care workers (Kvale 2015). The interview guide and analyses of results were inspired from the SCT (Bandura 1978), definition of motivation from the SDT (Ryan and Deci 2000), the sociocultural learning theory (Daniels *et al.* 2007) and previous research on barriers and facilitators for PA (Temple 2007; Mahy *et al.* 2010). The interview guide helped structure the interview and ensured that key areas were covered and discussed. Central themes were to describe a regular day and challenges, preferences, facilitators and motivating factors for engaging in physical activity.

Design

An abductive qualitative design was utilised (Kardorff *et al.* 2004). To understand new aspects of participation and motivation for PA, it was relevant to use an explorative, empirically driven approach, with portions of the existing literature on the topic as a basis.

Participants

A purposeful sampling strategy was used to recruit participants (Patton 2015). Health care workers and family members were interviewed separately, as we believed that this would create a more open environment for the individuals to speak freely about the motivational factors and barriers to participation in PA (Malterud 2012). The study was approved by the Committee for Medical Research Ethics (No. 2016/1770).

Health care workers

We invited participants with different roles (leaders/nonleaders) who worked in four different settings (specialised and community-based intellectual disability services, as well as day care centres). The services are predominantly for people with moderate, severe or profound ID. A focus group interview with three participants was conducted (Morgan 1997) in which participants provided important information and were regarded as representing information-rich cases (Patton 2015). Additionally, we conducted two in-depth individual interviews (Kvale 2015) with the leader of a community residence and a representative of a day care centre. The interviews took place at their work place, and the main topics from the focus group interview guide were used. Table 1 provides an overview of the participants.

Family members

We invited family members of individuals with varying degrees of intellectual disability, age and family relationship, as well as living conditions, with the help of user organisations and the networks of the authors. Table 2 provides a full overview of the participants. For the purpose of anonymisation, some characteristics of the participants have been changed.

Data collection

The interviews lasted between 1 and 2 h. C. A. led the focus group interviews (as the moderator) and H. M. observed the interviews, took notes and clarified questions throughout the interviews (as the secretary) (Malterud 2012). The individual interviews were led by H. M.

Table 1 Sociodemographic characteristics of health care workers

Profession	Gender	Work experience (years)	Workplace	Data collection method
Intellectual disability nurse	Male	8, 5	Home-based care	Focus group
Intellectual disability nurse	Male	9	Home-based care	Focus group
Physiotherapist	Female	2, 5	Specialised health care	Focus group
Leader of community residence	Female	7	Community residence [†]	Individual interview
Teacher	Female	3, 5	Day care centre	Individual interview

[†]Community residence: municipal service that provides supportive care around-the-clock.

Table 2 Family members' relations to the individuals with intellectual disabilities and characteristics of the individuals with intellectual disabilities. Some characteristics are changed for the purpose of anonymisation

Relation to person with ID	Gender of person with ID	Age of person with ID	Living conditions of person with ID	Level of ID
Mother	Male	20	At home with family	Severe ID
Mother	Male	19	At home with family	Moderate ID
Father	Female	25	Supported living [†]	Moderate ID
Father	Male	16	At home with family	Profound ID
Father	Male	22	Community residence [‡]	Moderate ID
Mother	Male	13	At home with family	Moderate ID
Sister	Male	52	Community residence [‡]	Severe ID
Father	Female	23	Supported living	Severe ID

ID, intellectual disability.

[†]Supported living: individuals living in their own apartment with part-time supervision from staff.

[‡]Community residence: municipal service that provides supportive care around-the-clock

All participants were enthusiastic about the topic, which influenced the dynamic of the discussions and the richness of the data. As the introductory questions stimulated dialogue and discussion, the interview guide was mainly used as a checklist to ensure that key topics were covered. All participants were found to be information-rich cases. The interviews were recorded using an MP3 recording device and transcribed verbatim by H. M. After the individual interviews, the transcripts were examined, and the investigators concluded that data saturation was reached.

Data analysis

After the interviews, preliminary analyses were presented to a reference group (researchers in the project group and some of the family members and health care workers from interviews) for their feedback before continuing with the analysis. Preliminary results were also presented at a seminar with experienced researchers, who commented on and further improved the analysis before it was finalised, to ensure the dependability and trustworthiness of the results (Tjora 2012).

A thematic analysis (Greenhalgh and Taylor 1997) was then conducted. The interview transcripts were read several times by the first author (H. M.) to identify emerging themes. The interviews were then read and commented by A. A. On the one hand, C. A. read and commented on the first analysis of the material. The text of the transcriptions was

transformed into specific codes, which were compared by differences and similarities and condensed into meaningful categories and subcategories. Through discussions among the authors and other researchers and with feedback from the reference group, the main themes were identified by grouping similar subthemes and linking them to theories and perspectives. Throughout the analysis, the SCT concept and sociocultural perspectives became central to understanding motivation as a relational phenomenon and the role of the context in initiating and adapting for individual participation in PA. The authors were from different professions with competence in rehabilitation medicine, behavioural change theories, use of technology and qualitative research methodology, and the setting was an exploration of motivational factors for possible later use in technology-supported activity. Regarding the analysis, the authors had no previous experience with the research problem at hand and few preconceptions and expectations prior to data collection and analysis.

Results

We identified one overarching theme (motivation for participation), three main categories and nine subthemes. The main finding was that motivation could be socially constructed through mediation of engagement in activities and external support. An overview of the findings is given in Table 3 and summarised in Fig. 1.

Table 3 Summary of results

Main themes	Subthemes	Codes
Individual level	Motivation seldom the main challenge	Difficulty initiating activities
		Motivation often present
		Varying levels of exhaustion
	Fun, social rewards and technology	Being social in activities is rewarding for many
		Purpose of the activity is important
		Use of technology rewarding
	Knowledge	Lack of knowledge in what constitutes good health
		Reduced knowledge about healthy behaviours in support persons
		Health education for individuals with ID not a priority for support persons
Contextual level	Support person engagement	Many factors depend on support person's interest in physical activity
		Engagement in support person increases levels of physical activity
	Available resources and weather considerations	Not enough resources/personnel available
		Variation in weather conditions in the arctic climate is a barrier
	Presentation of activity	Willingness to join activities depends on a positive presentation of activities
	Interaction between levels	Being together in activities
Creating predictability		It is important to create predictability in the physical activity
Use of rewards		Rewards can be used to reinforce the physical activities
		Showing achievements to others is very rewarding

Individual level

Motivation is not always the challenge.

Both family members and health care workers identified the main issue as a lack of initiation of PA for individuals with ID, rather than a lack of motivation. Understanding how people with ID were motivated to participate in PA was challenging and could vary in different situations, but most of

the participants believed that motivating the individuals to participate was not the most difficult part.

... there are many, if I speak on behalf of the institution I work in, who want to go hiking and be out in the nature, and who have the motivation to participate. (leader of community residence)

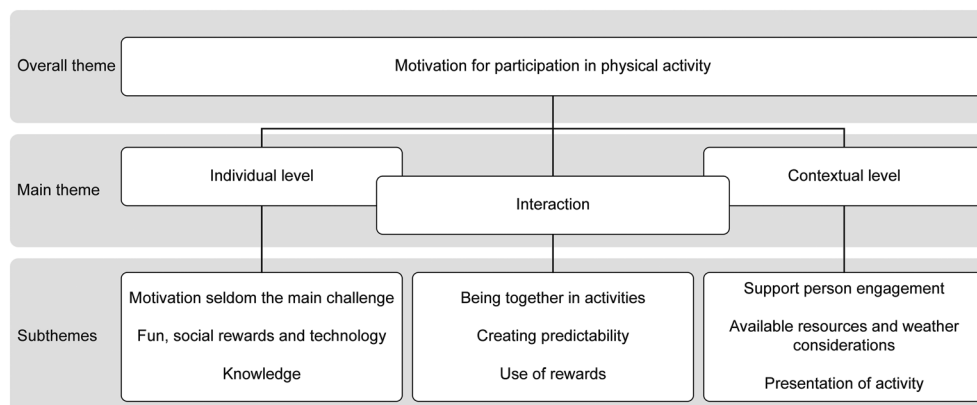


Figure 1. Results from the qualitative study. Themes and structure.

I am of the impression that Sophie could walk on water if she was motivated to do so. It is just very difficult for me to figure out what actually motivates her nowadays ... (mother)

Difficulties in completing an activity could reduce motivation, such as problems with getting dressed, difficulties in travelling to the site of the activity, or problems in executing the physical movements.

It depends on practical stuff, like how to put the skis on. That is the most difficult thing when going skiing. For most of the ski trips that are unsuccessful, everything goes wrong when he struggles with putting his ski boots or skis on, and gets tired and gives up. (sister)

The participants also questioned the level of intensity of PA, with many stating that individuals with ID participated in activities but rarely achieved a level of moderate or vigorous PA.

... it's difficult finding physical activities that would improve her fitness shape. She rarely breaks a sweat or feel out of breath when she exercises ... (mother)

Fun, social rewards and technology

Individuals with ID were more likely to participate in PA when the activity was fun and enjoyable. Activities were observed to be enjoyable if they were in a social

context, described as being part of a team, meeting peers and identifying with a group.

He loves his friends and being part of a team. He could go to the North Pole if that was the case, as long as he was part of the team ... (mother)

Several individuals were more motivated to perform PA when the activity had a different purpose than the activity itself, such as enjoying a meal at the end of a trip or doing practical chores as part of the PA.

... we always have to find things to recycle and walk by a container and throw it in. And there is no lunch before we have been out walking for a while, and then it's just a matter of how long you can stretch it. (mother)

... it's the same for our boy, as I hear others talk about, that it should be another purpose with the activity than the activity itself. The best is to bring a good lunch to eat on the top of a mountain or do practical chores like walking by the grocery store to a recycling bin. (father)

Several individuals enjoyed swimming and horseback riding. Others enjoyed listening to music while moving around or while watching a programme on a tablet or a TV. It was reported that most of the individuals with ID (especially the

younger individuals) were interested in technology. Some used technological devices in PA settings.

She has two, an iPhone she uses to find things she wants to watch on her iPad (music videos), and a PC as well ... (mother)... he is allowed to sit on a small trampoline whilst watching his iPad or the TV, and if he gets excited, he starts jumping. And he can watch the film to the end whilst jumping if the film is very funny... (father)

Knowledge, interests and misunderstandings

Some of the health care workers mentioned that as individuals with ID may lack knowledge of risk factors for ill health, they could benefit from learning more about health and how PA will have a positive impact on their lives. In some cases, individuals with ID would misinterpret bodily signals from PA as signs of sickness and associate the activity with something negative and harmful.

... they might be frightened if they feel their heart pounding harder than they are used to, and think that they are ill or something ... I think it has to do with the knowledge basis they have. How much knowledge they have will affect how they interpret the body's signals. If they have more knowledge about how the body reacts to excessive physical activity, they might not react this way. (leader of community residence)

In contrast, family members were more concerned about the level of knowledge, interest and enthusiasm that health care workers had concerning PA and how that could influence the individuals with ID. They believed that it would not necessarily help individuals with ID gain knowledge.

... he cannot just understand for himself why it is important to exercise, that it is important to be physically active. He can say that he is using energy when he is active, but that is because I have triggered him to think that it is important. (mother)

Contextual level

Support person engagement

All participants agreed that the contexts surrounding the individuals with ID played a large role in their

motivation and execution of PA. The attitudes concerning PA and health in the people close to the individuals with ID were observed to be important predictors of PA by all participants.

... Some of my staff are really active and like to do new things, and if they do not manage to get the user interested, they try a different approach. They always bring the right clothes according to the weather ... I think it has a lot to do with the attitude of the staff. Do not get me wrong, but I think if the staff want to be inside and relax, it is very easy to do so. (leader of community residence)

... When it comes to those with ID, maybe moderate or severe ID, I think the staff plays a much larger role. Because the staff needs to be motivated as well. (physiotherapist).

Most of the family members were worried that the staff would never show the same interest and enthusiasm as the family members did in supporting a physically active lifestyle.

... it is hard to make the staff see his skills when it comes to physical things. It's just too easy to see his epilepsy as a problem and be anxious about it. (father)

Several individuals also mentioned that they wished that they had an 'instruction manual' for their family member, so that staff would know how to motivate and make adjustments so that the individual with ID could be more physically active.

... I have said to the staff 'come join us on cross country skiing and see how easily it's done'. And some actually do so. But then you have people working on shift and some are quite old and ... it's just very complicated and exhausting for the family to always teach new staff how to do things. (sister).

Available resources and weather considerations

In the group of health care workers, the availability of resources was often mentioned as an important condition to be able to take individuals with ID to perform PA. Insufficient staffing, a lack of time and

insufficient preparation for changing weather conditions were mentioned as barriers.

The challenge is for those who do not have many resources around them. You're at work and have maybe five people to look after during your shift. And everyone should get dinner and have individually adjusted activities in the afternoon. So that is where the problem is, because one of the users might want to go swimming and you cannot leave the other four users behind. And is just hard sometimes ... (leader of community residence)

Presentation of activity

Many of the participants, especially the health care workers, pointed out that if they identified the right way of presenting the activity to the individual, then it was more likely to motivate the individual to participate in that activity. By simply asking the

individuals with ID if they wanted to exercise, the workers observed that this would most often lead to a negative response.

... asking 'do you want to go for a walk', you are more likely to get a negative reply, because it is a personal question. If you say 'let us go for a walk' or 'what should we do today? Should we go for a walk?', it helps motivate the individual to participate. It's easier to bring them with us. (teacher)

Interaction between individual and context

Examples of cites in relation to subthemes are given in Table 4.

Being together in activities

Many of the stories concerning success factors for PA focused on the interaction between individuals with ID and their environments. If the support personnel and/or family members were successful in influencing

Table 4 Examples of interview cites from the theme Interaction between individual and context

Theme: Interaction between individual and context

Subthemes	Cites
Being together in activities	... the support person should not just get the individual into the pool – he should join him in the pool. In our home, the support person shows up, brings my son to the arena and sits on the scaffold and pays attention to what my son does. I wish that he could actually join him in his workout. Many of the individuals with ID will have much greater advantages and better workouts if they had their support person with them all the time to motivate them and help them. (father)
Creating predictability	... one thing I've been thinking a lot about, and that is making the activity predictable is very important. And there is of course a challenge to understand how this would work. After a while, in my experience, he has learned that if he is prepared for what's coming next, and we help him to do so, it's so much more fun for him to participate. (mother)
Receiving rewards	... in my experience it seems like it should be something there. If it's not something very concrete. My son needs to understand why he should do different things. What the goal or intention is for doing these things. Either it is the good lunch afterwards or he can use his iPad when we are done doing the activity. (mother)

the individual with ID in a motivating way, the individual would have a positive attitude towards the activity. Motivational support could include performing the PA with the individual, providing positive feedback, cheering the individuals on when they were active and reinforcing their positive experiences with the PA. Other types of support, such as practical support and economical support, were also mentioned as contributing to participation in PA.

Creating predictability

Making the PA predictable and creating a sense of control for individuals with ID were also important aspects of motivation for PA. The use of different tools, such as visual support in communicating about the PA, going to the arena and examining it beforehand or making PA a part of their daily routine, also helped the individual to feel more in control. One father said that it was more likely that his son or his peers would feel excited about participating in athletics when they had been there a few times before and knew what they were getting into.

Receiving rewards

Rewards could make PA more interesting. However, many of the participants believed that it was difficult to identify rewards that were not unhealthy foods. The other rewards that were mentioned as effective included a high degree of praise or positive feedback to the individuals. If they received a medal after participating in PA, the reward was not the medal itself, but the praise when showing the medal to the staff or family members afterwards.

Discussion

The findings of the current study suggest that individuals with ID could be more motivated to participate in PA if the activities occur as an interaction between the individual and their context, which could be mediated by engagement with support people and available resources. At an individual level, individuals with ID can be motivated for PA if they experience the activity as fun, occurring in a social setting or used in combination with technology. An interaction through joint participation in activities, predictability and the use of rewards appears to have the strongest influence on participation in PA.

In this study, the main source of information was from the environment around the individual with ID, not the individual himself or herself. By emphasising the sociocultural frame of reference (Daniels *et al.* 2007), we found that motivation is an interpersonal emerging phenomenon continuously shaped by particular practice. This makes it difficult to capture the intrinsic motivational factors involved in participating in physical activity. Positive emotions such as engagement and excitement might be observable features that can be interpreted as an expression of motivation. However, based on our results, the definition of motivation according to the SDT (Ryan and Deci 2000) does not capture the complexity of this cognitive feature. Motivation can be seen as a socially driven interaction between individuals with ID and their support persons that can increase or decrease depending on the responses from the individual or the context. These findings can be important when developing interventions for PA and adjusting the everyday contexts for individuals with ID.

Consistent with previous studies (Temple 2007; Mahy *et al.* 2010), motivation is dependent on how fun and interesting the PA is perceived to be. It is likely to believe that the motivation individuals with ID show towards PA is displayed as an interest for the activity or enjoyment during participation. Another potentially useful finding for intervention development is the interest in technology by the group of youths and young adults with ID. Technological developments, like serious games, have previously been proven to be effective interventions for improving social, practical and conceptual skills for individuals with ID (Tsikinas and Xinogalos 2018).

The results demonstrate that engagement in PA by support persons is particularly important. Support persons or others who interact with individuals with ID on a daily basis should have an initial interest for PA or be concerned about increasing PA levels for the individual with ID. Heller *et al.* (2003) underlines that support persons should be motivated to perform PA themselves, as this would influence the individual with ID to be more active. Activities should be planned in cooperation between support persons and the individual with ID while considering motivational factors. In contrast, a lack of available resources functions as a contextual barrier for participation (Mahy *et al.* 2010; Bergström 2014; Bergström *et al.*

2; Kuijken *et al.* 2016). Inadequate staffing, little knowledge about the health benefits of PA and unclear PA policies in the community residence or day care centre could influence the participation in PA of individuals with ID. Dixon-Ibarra *et al.* (2017) argue that a lack of clear PA policies in group home settings creates a barrier to health-promoting environments for people with ID. Individuals with ID rely heavily on support from others in their everyday life, and possibilities to maintain good health will therefore vary depending on the services and care that they receive (Krahn *et al.* 2006).

The findings are consistent with SCT (Bandura *et al.* 1999), in that self-efficacy appeared to be related to the intention to perform PA. Self-efficacy was positively influenced by previous mastery experience with the PA, as well as modelling by other individuals. This emphasises the need for preparation and explanation of the activity to ensure high self-efficacy and opportunities to strengthen it further through more mastery experiences. Conversely, the results of this study demonstrated that where the individuals with ID had a negative experience with PA (e.g. skiing) early in the process, then many individuals lost their motivation and stopped participating in the activity. Therefore, the planning for progressive mastery by the individual is essential.

Arctic weather conditions may require extra human resources and equipment for outdoor activities. Many participants found the planning and execution of outdoor PA during winter to be challenging. For both the support person and the individual with ID, changing weather conditions and preparations for outdoors could disturb motivation and participation in PA. Individuals with ID who displayed sedentary behaviour often mentioned weather as a barrier. This research suggests that individuals with ID may not have the strategies to cope with this adversity alone and need assistance to overcome this barrier.

Study strength and limitations

The present study had several limitations. Most of the participants who participated in the study had an initial interest in PA, as well as being physically active themselves. Additionally, as the initial aim of this study was to understand the motivation for PA

participation through the perspectives of family members and health care workers, we did not interview individuals with ID themselves. Future studies could explore the motivation for PA from the perspective of less active participants and could also focus on interviews with individuals with ID themselves. Nevertheless, our findings are consistent with previous studies (Heller *et al.* 2003; Mahy *et al.* 2010). Furthermore, while there were relatively few participants who completely contributed with information, a strength of the current study is that the participants represented a varied sample of individuals with ID. These findings could be relevant outside this research context.

Conclusion

Promotion of PA should include both individuals with ID, family members and staff, and it should work in a supportive way to strengthen mastery experiences. Fun, social rewards, predictability and the use of technology as motivational factors for participation in PA on an individual level are interesting possibilities that should be explored further. The promotion of PA in individuals with ID should also take a contextual approach by exploiting the cooperation and interaction between individuals with ID and their support persons. Future PA interventions for this group should focus on engaging the support persons in physically activities themselves and on increasing their knowledge about the importance of PA and ways to motivate individuals with ID.

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Conflict of Interest

The authors declare that they have no conflict of interest.

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