Turning disabilities into abilities. Promoting self-management in people with intellectual disabilities

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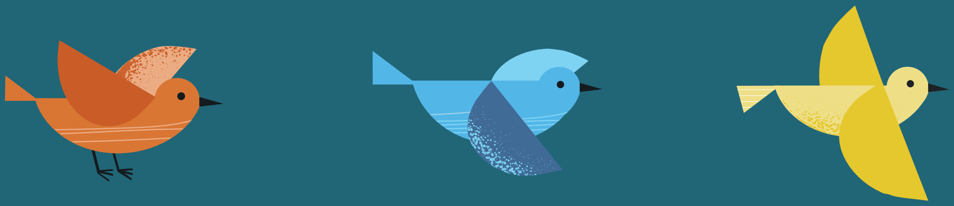
Chapter 7

General discussion



General discussion

People with intellectual disabilities (ID) commonly experience difficulties with self-managing all kinds of everyday affairs, although they generally find it important to be able handle their affairs independently [1-3]. Promoting self-management in this population could not only enhance the overall quality of life of people with ID [4], but also their inclusion and participation as equal co-citizens in our society [5]. The main aim of this dissertation was to obtain a greater understanding of how self-management can be promoted in this population. To this end, we gathered the perspectives of various key informants, we studied self-management interventions for people with ID, and we focused on the role of support staff by evaluating a staff training and developing a staff questionnaire. In this final chapter, we first return to our general research questions, before discussing the findings of the studies in this dissertation in greater detail. We furthermore consider the studies' limitations and the implications for clinical practice, and provide recommendations for future research, before coming to an overall conclusion.

In the General Introduction (Chapter 1) we presented a model of interventions for promoting self-management in people with ID (Figure 1). In this dissertation, we studied the separate components of this model to answer our general research questions. Our first general research question concerned what the attitude is towards what people with ID are able, supposed, and allowed to do, and the level of knowledge and skills of people with ID and of those who can support them towards greater self-management. We conclude that in general, people with ID have a positive attitude towards managing their affairs independently and they possess a wide variety in knowledge and skills, although they all need support to some extent (Chapter 3). The tendency of relatives and support staff to take over (out of fear or overprotectiveness; Chapter 3) might say something about their attitude towards self-management of people with ID (e.g., people with ID need to be protected and taken care of), but perhaps also something about their knowledge and skills. They might not know or be aware of the possibility that their behaviour might limit the opportunities for people with ID to (learn to) manage their affairs themselves, or they might lack the skills to guide people with ID towards a greater self-management. Regarding the independence-promoting behaviours of support staff, we found that staff reported to display many of these behaviours, which can be clustered into three general domains: 1) Communication, Agreements, and Coordination; (2) Positive Encouragement and Tailoring; and (3) Supporting Independent Performance (Chapter 5).

The second general research question regarded the effectiveness of interventions that target the attitude, knowledge, skills, and behaviour of people with ID or their support staff in relation to an improved self-management. To address this question, we reviewed a broad range of self-management interventions for people with ID and we implemented such an intervention ourselves as well. In general, self-management interventions seem to effectively promote the targeted self-management behaviour, regardless of the type of behaviour and the specific intervention and participant characteristics (Chapter 2 and 6). Given the improvement in trained skills, it is presumable that this also implies an increase in knowledge of people with ID (e.g., knowledge of how to execute certain tasks or handle certain situations). In addition to studying self-management interventions for people with ID, we also examined the effects of a staff training (Chapter 4). In this training, staff were encouraged to adopt a positive attitude towards the strengths, abilities, and possibilities of people with ID to manage their affairs themselves. They were also provided with knowledge and skills training on how to promote self-management in people with ID. The effects of the training were limited, both on the level of functioning of people with ID, as well as on the attitude, knowledge, and behaviour of the trained staff members. This suggests that more research is necessary on how staff trainings can promote self-management in people with ID more effectively.

Self-management in people with intellectual disabilities

People with ID have significant deficits in intellectual and adaptive functioning that lead to limitations in daily life for which ongoing support is needed [9]. Based on the extent of the deficits and the resulting support needs, several levels of severity of ID are distinguished, i.e., mild, moderate, severe, and profound. In our focus group study (Chapter 3), it was reported that all people with ID require at least some help with managing their affairs and that the abilities and skills of people with ID widely vary. The difficulties of people with ID regarding their self-management cover a wide range of domains. They can pertain to difficulties with self-care and performing household activities, as well as to managing oneself in social situations, in the workplace, or in the community [22-24]. Self-management is a broad concept that involves all cognitions and actions of a person that deliberately influence their behaviour in order to achieve self-selected outcomes [25]. This umbrella term includes the autonomy to self-determine one's choices and decisions in order to lead one's life according to one's own preferences, free from external influences [e.g., 26, 27, 28]. In addition, self-management includes the similar concepts of independence and self-reliance, which both concern the capacities to shape one's own behaviour in order to manage one's affairs and to achieve the personally desired outcomes, thereby relying on one's own efforts, resources, judgement, and abilities.

The concept of independence was further studied in Chapter 3, in which we asked people with ID, their legal representatives, and support staff what they understood as 'independence'. From this study, it can be concluded that independence is a broad concept covering various aspects, including knowledge on how to handle things, being able to perform activities, and taking care of oneself. Whereas most respondents expressed that being independent means that you perform such things by yourself, some considered that being independent means that you can draw boundaries regarding what you are able to handle and being able to ask for help if you cannot manage something by yourself. An increased level of independence is desired by most people with ID (Chapter 3). Generally, people with ID want to lead the 'normal' life of other people their age by living and working independently. In addition, they can also have various more specific learning goals, such as regulating one's emotions and obtaining a driver's license. Although at least some support will always be required (especially for people with more severe levels of ID), one can aim at guiding people with ID towards the most optimal level of independence that is attainable for an individual, which could benefit their overall self-management. To this end, more attention needs to be paid in scientific research and clinical practice to the development, evaluation, and implementation of self-management interventions.

Self-management interventions

Interventions for people with ID

In Chapter 2 of this dissertation, we systematically reviewed a broad range of self-management interventions for people with ID that have been previously evaluated. Most interventions specifically targeted a singular practical behavioural skill, whereas little attention was paid to promoting self-management in general or to other quality of life domains such as social inclusion and rights [102]. Another finding was that in most self-management interventions, people with ID were still largely dependent on the intervention provider, as mostly only the provider applied behavioural change techniques (BCTs). It might, however, be more effective and efficient to promote overall self-management by teaching people with ID to apply such BCTs themselves, so they can also apply these techniques in other tasks or settings [66, 99-101]. All reviewed interventions were reported to be effective in promoting the targeted self-management behaviour and, wherever investigated, effects maintained over time and generalised to other tasks or situations. The merely positive effects reported by the various studies however suggest a publication bias [98] and a further high risk of bias stems from the mostly small sample sizes, lack of control groups, and (multiple) case study designs. Also, much data were missing or incomplete, not only on participant and intervention characteristics, but also on (quantitative) results. This not only complicates the interpretation and generalisation of the findings, but also makes it difficult to draw conclusions about which factors contribute to the effectiveness of self-management interventions. Furthermore, as we only looked at the effects of interventions on people with mild or moderate ID, we do not know whether the results can be generalised to people with more severe levels of ID. People with severe or profound ID or with much comorbidity might have more difficulties with learning new skills and applying and generalising BCTs.

To obtain more insight into what needs to be considered in self-management interventions, we conducted focus groups in which we asked our participants what they perceived as barriers and requirements when wanting to promote independence in particular in this population (Chapter 3). The most frequently proposed barrier concerns a lack of time for support staff to teach people with ID new skills. This coincides with a previous study, in which support staff reported to experience increasing difficulties to meet the care needs of their clients [19]. Given the lack of time, staff become more easily inclined to take over from their clients, as it generally takes less time if staff do things themselves. Taking over by both staff and family members is indeed another barrier, which may stem from overprotectiveness and fear. By taking over, one limits the opportunities for people with ID to develop new skills, as a result of which they remain dependent on others. This is turn reduces their level of participation and fosters passivity and a sense of ‘learned helplessness’ [5, 44]. Care organisations thus need to facilitate more support time for people with ID as well as a change in attitude of staff and perhaps also of relatives. This concerns a more positive attitude, looking at the strengths and possibilities of people with ID and encouraging them to handle as much as possible themselves. In addition, a clear, tailored, and step-by-step approach is required, as well as good communication between all people involved to ensure that all family and support staff members are aligned on how to support a person with ID towards a greater level of independence. This stresses the importance of not only focusing on people with ID when promoting self-management, but also on their support network.

In Chapter 6, we embedded these various lessons learnt from our focus group study in the implementation of a self-management training for people with ID. In this training, people with ID were provided with more time and support to reach their personal self-management goals (PSMGs) in a step-by-step fashion and they were encouraged to handle things as much as possible themselves. This training was not only tailored to the PSMGs of participants, but also to their abilities, disabilities, and preferred ways of learning. Trainers aimed to involve the support network by informing family and support staff members on what participants were doing in the training and they fostered the transfer of learnt skills to daily life by also practising with participants in their real-life situation. These elements of tailoring, involving the support network, and assisting the transfer of learnt skills to daily life have been found to benefit the promotion of self-management of people with ID [3, 6, 8, 34, 39, 40, 48] and in this study these elements were combined for the first time. The results showed that the training positively contributed to the attainment of PSMGs and to the reduction of support needs. However, the overall level of independence, the occurrence of psychopathological behaviour, and quality of life seemed unaffected by the training. The former might be explained by the fact that participants only attained a few specific PSMGs (e.g., ironing and reading), which does not lead to significant improvements in their overall level of independence. In addition, given the fact that people with ID need more time to learn, significant improvements in the level of independence are not likely within 12 months' time. Possibly, the overall level of independence will only significantly increase if people with ID are provided with more time to attain more PSMGs. Perhaps, only then significant improvements in psychopathological behaviour and quality of life can also be found.

Taking the findings of Chapter 2 and 6 together, we conclude that self-management interventions for people with ID are generally effective in promoting the targeted self-management behaviour, at least for people with mild to moderate ID who are motivated to learn. Continued high-quality research on the development, implementation, and evaluation of interventions remains necessary to study the effects of interventions in greater detail, thereby also including people with more severe levels of ID and with various comorbidities.

Interventions for support staff

As was found in previous studies, involving the support network in the self-management process of people with ID is important [6, 8]. Therefore, we studied the role of support staff in this process in greater detail. We found that staff cannot only hinder the promotion of independence of people with ID out of fear or by taking over, but also because they might lack the knowledge and skills on how to properly guide people with ID (Chapter 3). We therefore implemented and evaluated a staff training that encourages staff to adopt a positive attitude towards clients by focusing on clients' abilities and strengths, instead of their disabilities (Chapter 4). Staff were also taught knowledge and skills to help them stimulate the development of people with ID, by letting them handle things as much as possible themselves, which might reduce people with ID's dependency, passivity, and 'learned helplessness' [5]. In this study, only limited effects of the staff training were found on the level of independence and self-reliance of people with ID and on staff's attitude, awareness, and method of working. This implies that changing staff's attitude, knowledge, and skills in order to improve outcomes for people with ID is not a straightforward task. Therefore, more research is necessary on how staff trainings can be improved to change staff behaviour and promote self-management in people with ID more effectively. This might include more extensive trainings or a whole-environment approach whereby the entire care organisation is facilitative of the promotion of self-management of people with ID. Previous research has put forward the importance of practice leadership. A practice leader is someone who organises, encourages, coaches, and reviews a staff team to put into practice the vision of the organisation in order to ensure good support [128]. By this means, good practice leadership can lead to better implementation of a staff training. Another important component to consider is coaching-on-the-job. It was found that the most effective way to change client behaviour through staff training was by adding coaching-on-the-job and verbal feedback to classroom trainings [110]. With adding an on-the-job component, it becomes more likely that performance of target skills acquired during a training will generalise to the regular work situation [129]. Given these previous studies, including practice leadership and coaching-on-the-job is of interest when training staff to promote self-management in people with ID and the added value of these components therefore deserves further attention in future studies on staff trainings.

Assessing intervention effects

Assessing effects in people with ID

In the self-management studies that we reviewed, intervention effects were mostly measured by assessing to what extent the targeted self-management behaviour was performed properly (Chapter 2). In Chapter 6, we adopted a similar approach, by using Goal Attainment Scaling [GAS; 162, 163, 164] to assess to what extent participants had reached their PSMGs. By specifically focusing on the targeted self-management behaviour, such measures are more sensitive to detect change. In standardised, global measures such as questionnaires, improvements in some specific self-management behaviours may not significantly increase the overall score or the improved self-management behaviours might not even be included at all. This makes it difficult to detect statistically significant improvements in functioning. This might partially explain why mostly no to very little statistically significant effects were found on global measures in our evaluations of a staff training (Chapter 4) and a self-management training for people with ID (Chapter 6). However, the finding that there was no, or very little, change in the overall level of functioning does not mean that the intervention might not be of clinically significant value. Learning to cycle from home to work or learning to use the internet (as was the case for some of our study participants) might seem like small goals, but they are of great personal significance as they substantially contribute to one's inclusion and participation in society [e.g., 121, 175]. This illustrates the importance of looking beyond statistically significant results to clinically significant results, as well as the importance of measuring intervention effects on a smaller, personalised scale.

It is further important to consider the period of follow-up measurements to assess the long-term effects of self-management interventions. Given the overall learning deficit of people with ID [9], significant improvements in overall self-management, independence, and support needs are not to be expected within a short time period. People with ID need to be provided with sufficient time to learn new self-management behaviour and therefore, studies need to include a long period of follow-up measurements to properly assess interventions' effects (e.g., at least a year, as we did in our study on a self-management training for people with ID).

Assessing effects in support staff

Little research has been conducted on developing validated measures to assess staff attitude and behaviour [47], especially in relation to promoting self-management and independence in people with ID. In Chapter 5, we developed and initially validated a questionnaire for support staff (LIQSS) that assesses to what extent staff display behaviours that promote independence in people with ID. The LIQSS was found to consist of three meaningful and internally consistent subscales: (1) Communication, Agreements, and Coordination; (2) Positive Encouragement and Tailoring; (3) Supporting Independent Performance. The first subscale involves communicating and making agreements with people with ID, their relatives, and other staff members about how to guide people with

ID (towards their learning goals), so everyone is attuned to one another. The second subscale concerns staff's positive encouragement during the learning process of people with ID and staff's ability to adjust their support to the needs of each individual. The third subscale relates to staff letting people with ID manage their affairs as much as possible themselves (instead of taking over). The content of these subscales largely overlap with what was reported to be important for the promotion of independence in our focus group study (Chapter 3) and with the findings from previous research [3, 5, 6, 8, 42, 154]. In spite of the promising findings regarding the LIQSS and its high potential for scientific research and clinical practice, further fine-tuning is required to optimise its use. One of the concerns regards the high scores that participants filled in on this self-report questionnaire. Therefore, it could be considered to include a 'social desirability scale' that can detect and control for social desirability [155] or to include vignette scenarios to assess staff's responses in a more ecologically valid manner [150].

Ethical considerations

Research with vulnerable participants always requires careful consideration of ethical issues, such as informed consent. The Medical Ethics Committee of the Leiden University Medical Center evaluated our study protocols and declared that neither formal medical ethical approval nor written informed consent was required, because the studies did not fall under the Medical Research Involving Human Subjects Act. Although we acquired active consent in two studies (Chapter 3 and 5), only passive consent was obtained in two other studies (Chapter 4 and 6). The latter entailed that people with ID or their legal representatives received a letter in which they were informed about the study and the opportunity to decline participation, without being asked to actively agree with participation.

In spite of the judgement of the Medical Ethics Committee and the fact that there was minimal to no burden or risk for participants with ID, a further consideration of the consent procedures would have been advisable. It would have been desirable to provide participants with ID with a more elaborate and comprehensible explanation of the study to help them fully understand what participation would entail. Such an explanation should then include information about the voluntariness of participation and the right to withdraw, how data will be used and stored, and how confidentiality is protected. In addition, obtaining active informed consent from both the participant with ID and the legal representative would have been preferred and would also be in accordance with the new Code of Ethics for Research in the Social and Behavioural Sciences Involving

Human Participants [177], that became effective after we had already started our study. To increase the likelihood of active informed consent, it would be preferred that information about the study is shared in person, perhaps in the presence of someone the potential participants know well who can reassure them and make sure that they understand the explanation.

Limitations

The studies described in this dissertation could be of great value to scientific research and clinical practice as they are one of the first to focus on the promotion of overall self-management and independence in people with ID. Nevertheless, there are also some general limitations to these studies that need to be considered.

First of all, the samples of people with ID in our focus group and intervention studies were relatively small and homogeneous in terms of the level of ID and motivation (i.e., motivated people with mild or moderate ID) and participants were only recruited at one care organisation. This limits the generalisability of our findings and hinders further specification of the effects of the self-management interventions for specific subgroups of people with ID (e.g., mild vs. moderate ID). The lack of large sample sizes was not only the case in our studies, but also in most of the studies that we reviewed in Chapter 2. This is possibly due to high rates of comorbid neuropsychiatric and health-related problems in people with ID, which might complicate participation in self-management studies. In our study on a self-management training for people with ID (Chapter 6), possible candidates were excluded if they were not able to focus on the training, which was often due to psychiatric or behavioural problems. Because of the small samples and the high rates of comorbidity it is difficult for studies to include control groups that are matched or randomised, which lowers studies' methodological quality and increases the risk of bias. Another type of bias concerns a possible publication bias regarding self-management studies in the field of ID. The finding that all reviewed interventions in Chapter 2 were reported to be effective could suggest that only studies with significant findings get published and that studies with null findings thereby become underrepresented in scientific literature.

Second, the measurements that we used were mostly indirect measures of client and staff behaviour. Such measures are more likely to lead to subjective and socially desirable answers. More direct and objective measures, such as observations of client and staff behaviour, might be a more valid way to assess interventions' effects. Furthermore, the contribution of people with ID to the data collection was limited. It was mainly the support staff who provided information about the level of functioning of the participants with ID. Although this was done to minimise the burden on the participants with ID, it would be of additional value to gather their perspectives by including self-reports or by conducting interviews with people with ID.

Another general limitation concerns that the implementation of our staff and client intervention (Chapter 4 and 6) was not always optimal. Although the interventions were generally well received by participants, the actual implementation in everyday practice appeared to be challenging, especially for staff, as was seen in previous ID research as well [128]. A barrier to implementation possibly concerns insufficient encouragement from within the organisation to put the learnt knowledge and skills into practice [38]. This encouragement could have been provided by a practice leader or by a coach [110, 128, 129]. Although our initial aim was to include coaching-on-the-job and peer meetings for trained staff, it was unfortunately not feasible for the care organisation to arrange this at the time. Adequate implementation could also be fostered by closely communicating with all people involved, whether they are staff or family members. Proper communication is important to get aligned on how to guide a person with ID and to develop a clear approach (Chapter 3). It appeared however in our studies (Chapter 4 and 6), that communication amongst staff members and between staff and family members was not always optimal, which might have limited the implementation of the interventions and therefore also their effects. It might be recommended to adopt a whole-environment approach where the entire care organisation and all involved relatives are supportive of the promotion of self-management of people with ID in a similar manner. This does not only require trainings, but also an ongoing, careful consideration and discussion within care organisation about how the trained attitude, knowledge, and behaviours will be applied and implemented in everyday practice.

Implications for clinical practice

The findings of this dissertation show that people with ID generally have the ability and the desire to manage their affairs more independently. As this can positively contribute to the lives of people with ID, it is recommended that care organisations pay more attention to promoting self-management in this population. This can first of all be achieved by regularly addressing this issue in team meetings and in individual support plans, and second of all through a broader implementation of self-management interventions for people with ID. As long as people with ID are provided with more time and support in an additional self-management intervention, they can improve the targeted self-management behaviour. Such interventions should adopt a step-by-step and tailored approach and could consider to teach people with ID to apply BCTs themselves (e.g., self-monitoring) instead of through an intervention provider. Teaching people with ID to apply BCTs could be a more effective and efficient way to promote overall self-management because it requires fewer proximity of a support provider and because such BCTs may be more easily applied to other tasks or situations.

A second implication concerns that interventions also need to be targeted at the support staff of people with ID, as was found in our focus group study (Chapter 3). Staff can have the tendency to take over from people with ID out of fear or due to a lack of time. Furthermore, staff might sometimes lack the knowledge and skills on how to properly guide people with ID towards a greater independence and therefore further training is required. Although the staff training that we evaluated had limited effects on client and staff behaviour, it could serve as a starting point for the further development of similar kinds of trainings as several lessons can be learnt from that study. Perhaps such lessons could already be incorporated in the education of those who are studying for a job in the field of ID. In addition, relatives of people with ID might also profit from such a training as they can also have the tendency to take over, thereby limiting the opportunities for people with ID to (learn to) manage things themselves.

Although the questionnaire that we developed could profit from further fine-tuning, it was still found to be a reliable (internally consist) instrument with good face validity that measures staff behaviour in relation to promoting independence. As such, care organisations or coaches could evaluate staff and provide feedback with the help of this questionnaire for training purposes. Furthermore, it could be used as a self-reflection instrument to increase staff's awareness of which behaviours contribute to the promotion of independence of people with ID. Filling in the questionnaire can make staff more aware of their role in the self-management process of people with ID and can enhance their knowledge of what they can do to promote the level of independence in this population. This increased knowledge and awareness could in turn lead to positive changes in staff's behaviour and thereby in client outcomes.

Future research

Based on the studies that are presented in this dissertation, several recommendations for future research can be made. First of all, this concerns a further theoretical study of the conceptualisation of self-management and how it relates to other concepts and theories such as self-regulation theory [178] and self-determination theory [179].

In addition, the lack of high quality studies on the promotion of self-management in people with ID calls for studies with larger sample sizes, including a more heterogeneous group of people with ID, and randomised control groups, preferably by collaborating with several care organisations across countries. Such studies can facilitate the generalisation of findings and a further inspection of what is particularly effective for which subgroup of people with ID. A greater understanding of which factors contribute to the effectiveness of interventions will enable the development of tailored interventions that can promote self-management in people with ID more effectively. These factors can concern participant characteristics, such as the level of ID or the presence of comorbidity, but also intervention characteristics, such as the applied BCTs or the length and intensity of an intervention. Also of interest is to study the cost-effectiveness of interventions. Although providing self-management trainings to people with ID and their support staff naturally requires a financial investment, in the long term it might lead to a reduction in the costs for the care for people with ID if less professional support is required. If this can be supported through scientific research, this might serve as a further incentive for care organisations to stimulate the promotion of self-management in people with ID.

Aspects to consider in future interventions include the wider application of BCTs by people with ID themselves, thereby targeting the promotion of overall self-management and quality of life, instead of solely a specific practical skill. The transfer and generalisation of the target behaviour to daily life and across settings must also be considered in future interventions, as well as in the assessment of the intervention outcomes. Future research may also look into how intervention effects can best be assessed and into the further development and validation of measures, especially for assessing support staff behaviour. In this regard, more direct and objective measures of client and staff behaviour could be considered (e.g., behavioural observations) as well as measures that include the perspectives of people with ID.

In order to improve the effectiveness of staff trainings, the content, format, and implementation should be carefully considered in the development and implementation of future trainings. This could be achieved by teaching staff new knowledge and skills that are also easy for them to apply in their daily practice. Adding coaching-on-the-job to a classroom training can furthermore facilitate the actual implementation of what was learnt, just as appointing a practice leader. Further research is required on how to facilitate a whole-environment approach, whereby the entire care organisation is facilitative of the promotion of self-management of people with ID. In this regard, involving and perhaps training close relatives of people with ID also deserves further attention. Support staff and relatives need to be in line with one another on how to guide a person with ID, as was indicated in our focus group study (Chapter 3). If support staff encourage people with ID to handle their affairs as much as possible themselves while relatives constantly take over, this can hinder the development of self-management in people with ID. Thus, relatives may also need to be taught how to stimulate the development of people with ID, as they might not yet dare or know how to do this. Little research has however been conducted on how relatives can contribute to the promotion of self-management in children and adults with ID and this therefore warrants further investigation.

Conclusion

In sum, this dissertation highlights that people with ID generally have the ability and the desire to manage their affairs more independently, which can positively influence their lives. Promoting self-management in people with ID therefore deserves more attention in clinical practice, scientific research, and governmental policies. Our findings provide evidence for the effectiveness of self-management interventions for people with ID and suggest that especially more time and support are necessary, next to a clear, tailored, and step-by-step approach. Fostering the transfer of learnt skills to daily life also needs to be considered in such interventions, as well as involving the support network of relatives and support staff who can both facilitate as well as hinder the promotion of self-management. Future studies may build upon the findings of this dissertation by conducting larger scale studies to further elucidate which factors contribute to the effectiveness of self-management interventions, so these can be more effectively tailored to the target population. By conducting further research on the development and implementation of self-management interventions for both people with ID as well as their support network, we can contribute to the further enhancement of the lives of people with ID and their participation and inclusion as equal co-citizens in our society.

English summary
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