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

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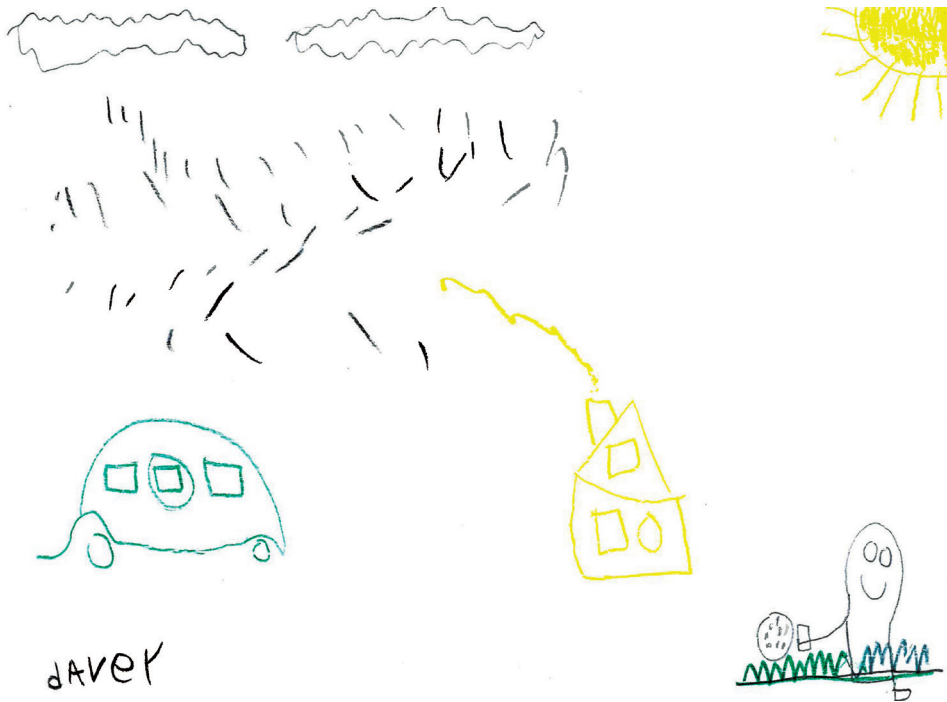
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Chapter 1

General introduction



"To me, independence means that I can travel by bus, that I have my own house, and that I can be outside, on good days as well as on bad days."

(Davey, one of our study participants with an intellectual disability)

People with intellectual disabilities (ID) often experience difficulties with self-managing their affairs, while being independent is something they value and desire [1-3]. By promoting the abilities of people with ID to independently manage their affairs, greater feelings of happiness and satisfaction could be achieved [1, 2], as well as improvements in quality of life and community participation [4, 5]. Therefore, to enhance the lives of people with ID, this dissertation aims to obtain more insight into how self-management can be promoted in this population.

To this end, this dissertation focuses on people with ID and on their support network of relatives and support staff (Figure 1). As people with ID are generally at least to some extent dependent on others, their support network plays an important role in their daily lives [6, 7] and in their self-management process [6, 8]. Within these three groups of stakeholders, we focus on individual and interpersonal factors that play a role in the promotion of self-management in people with ID. We investigate 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 a greater self-management (General Research Question 1, Chapter 3 and 5). We further examine what the effectiveness is 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 (General Research Question 2, Chapter 2, 4, and 6).

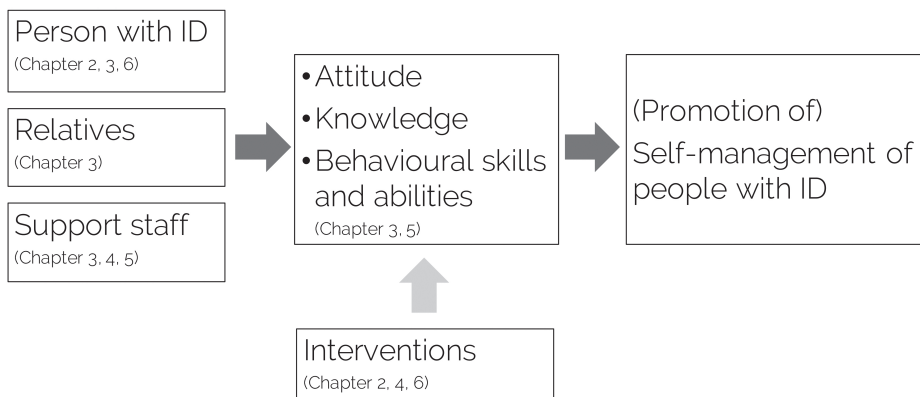


Figure 1. Model of interventions for promoting self-management in people with ID

Intellectual disability

ID are commonly defined as significant deficits in intellectual and adaptive functioning that originate in the developmental period (i.e., < 18 years). These deficits lead to limitations in daily life for which ongoing support is needed. These limitations not only concern functioning at home, at school, and at work, but also functioning in social, recreational, and community activities [9, 10]. Various levels of severity are distinguished, i.e., mild, moderate, severe, and profound ID. The level of severity is based on the extent of the deficits in adaptive functioning and the support needs that result from these deficits. In the Netherlands, the prevalence is estimated to be 0.085% [11], meaning that there are approximately 145,000 Dutch citizens with ID at the moment. Within this population, it is estimated that about 75,000 people have mild ID and 70,000 people have moderate to profound ID. ID can have various causes and it is not always clear what the exact cause is for a certain individual. Genetic factors often play a role, but external influences (e.g., infections leading to meningitis) can also lead to ID. In addition to limitations in intellectual and adaptive functioning, people with ID show higher rates of neuropsychiatric comorbidity (e.g., mood, anxiety, and autism spectrum disorders) [9] and health problems (e.g., diabetes, epilepsy, cardiovascular disease). The latter is, amongst others, due to genetics and relatively more unhealthy lifestyles (e.g., poorer diet and low levels of physical activity) [8, 12-14]. Having such additional conditions can further hinder people with ID in self-managing their affairs, which may require them to be even more dependent on their support network of relatives and professional staff.

Up until the midst of the nineteenth century, ID were viewed as a sin or a punishment. In the western world, this view was gradually replaced by a medical model, in which ID were regarded as a defect or a disease for which medical care and treatment was required. People with ID were seen as defective 'patients' who did not deserve the same rights as other citizens and who were often admitted to large institutions in remote areas [15-17]. In the last quarter of the previous century, this so-called 'defect-paradigm' became rejected, due to an increased awareness that this paradigm did not provide satisfactory solutions to the challenges faced in the care for people with ID [16]. The focus then shifted to 'normalising' the lives of people with ID. Instead of living segregated from the rest of the community, small-scale community group homes were created to facilitate the integration of people with ID [16, 17]. However, at least in the Netherlands, social integration remained limited and a culture remained in which people with ID had little opportunities to function independently [11].

In the beginning of the twenty-first century, awareness further increased that people with ID should have equal rights and be included as equal co-citizens in society. This was supported by the United Nations [18], which further declared that people with ID should be enabled to live as independently as possible and to have the autonomy to make their own decisions. In the Netherlands, this development coincided with a shift from a 'welfare state', in which the government is primarily responsible for citizens' well-being, to a 'participation society', where citizens, including people with ID, first have to try to arrange their affairs themselves, before they can turn towards governmentally provided care. However, handling one's own affairs is commonly difficult for people with ID and in fact, people with ID have been observed to experience increasing difficulties with functioning independently [11]. Explanations for this include social developments such as higher demands at work, the digitalisation of many (public) services, and the weakening of support networks. Partially as a result of these developments, the demand for professional care for people with ID has grown considerably over the past few years [11]. Possibly in relation to this, support staff experience increasing difficulties to meet the care needs of their clients [19] and the costs for the care for people with ID have greatly increased as well [20], while around the same time many Western countries had to cut in health and social care funding because of the global financial crisis, leading to more limited disability services [21]. All in all, this means, at least for these countries, that for people with ID less professional support has become available, while self-managing their affairs has become increasingly difficult.

Self-management in people with intellectual disabilities

The difficulties in self-management for people with ID can concern various aspects of daily life, such as taking care of their personal hygiene and their household, or dealing with social interactions and employment [22-24]. Self-management is an overarching term involving all cognitions and actions of a person that deliberately influence his or her behaviour in order to realise self-selected outcomes [25]. Self-management relates to concepts as self-determination, autonomy, independence, and self-reliance. Self-determination and autonomy are separate concepts that both concern acting as the primary causal agent in one's life, thereby having personal control over making 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]. Independence and self-reliance are similar concepts that involve the abilities to take actions to manage one's affairs and to provide for oneself, thereby relying on one's own efforts, resources, judgement, and abilities, without requiring help and support from others. Self-management thus includes the

former, making self-selected choices, and the latter, having the capacities to shape one's own behaviour in order to achieve the personally desired outcomes.

Self-management interventions for people with ID

Various studies on self-management interventions for people with ID have already been conducted. The majority of these studies can roughly be divided into studies that focused on the use of a specific behavioural change technique to achieve a greater self-management or studies that focused on a singular self-management domain. Behavioural change techniques are the active components of an intervention that are designed to alter or redirect causal processes that regulate behaviour [29]. Various studies have concentrated on behavioural change techniques such as prompting [4, 30, 31] or self-instructions [24, 32], or on specific skills in the domains of health behaviour [e.g., 6, 8, 13, 33], employment [34, 35], or community activities [30, 36]. Although much can be learnt from these individual studies, more overall insight is needed into what is generally effective in the promotion of self-management, as this could contribute to the further development of self-management interventions for this population. In this regard, this thesis presents a systematic literature review that summarises existing self-management interventions for people with ID and that aggregates their findings on a higher level. In this review, it is investigated what the effectiveness is of such interventions and which behavioural change techniques were used to attain the targeted self-management behaviour (Chapter 2).

Stakeholders' perspectives

In order to develop and implement effective self-management interventions, insight is also needed into the preferences and resources of people with ID, and their individual, interpersonal, and environmental barriers [3, 37]. To obtain this insight, perspectives need to be obtained from those whom it concerns the most, which are people with ID [6, 8] and those who support them [38], i.e., their legal representatives and support staff. Some qualitative studies on self-management of illness and health have already been conducted with people with ID, their relatives, or professional carers [3, 6, 8]. Based on these studies, as well as on others, several factors seem to be generally important: (1) interventions need to be tailored to the needs and personal situations of people with ID [3, 6, 8, 39, 40], (2) attention needs to be paid to the transfer of learnt skills to daily life [34, 40], and (3) the support network of relatives and professional carers needs to be involved in the self-management process [6, 8]. Although these findings provide some important ideas for self-management interventions in general, more specific information

is required on how to design these interventions. Therefore, we conduct focus groups with people with ID, their legal representatives, and support staff to gather their perspectives in particular on the promotion of independence in people with ID (Chapter 3).

Role of support staff - Training and assessment

As mentioned above, involving the support network of people with ID also seems important when promoting self-management. This network does not only consist of relatives, but also of professional support staff [41]. Support staff can both facilitate as well as hinder the promotion of self-management in people with ID. Supporting people with ID concerns walking a fine line in promoting their autonomy, while at the same time protecting them from possible risks [42]. Because of the regulations that result from these perceived risks and the tendency of staff to take over, the opportunities for people with ID to develop independent skills are limited [43-46]. This in turn may actually foster dependence, as well as passivity and even learned helplessness [5]. It is thus of importance to examine how support staff guide and interact with people with ID and to train staff to improve their ways of providing support, specifically in terms of promoting self-management.

There are however some challenges in this regard. First, it has not yet been studied how staff can be trained to effectively target overall self-management in people with ID. Therefore, in this dissertation, a mixed-methods study is presented in which a training is provided to staff that aims to teach them how they can promote overall self-management in people with ID (Chapter 4). Second, little research has been conducted on instruments that assess staff behaviour in relation to promoting self-management in people with ID. The few studies that have targeted this subject used different types of measures and there are general concerns about the reliability, validity, and inappropriate application of such measures to evaluate staff behaviour in the field of ID. This implies the need for the development of reliable and validated measures to assess staff practice [47]. Chapter 5 reports on the construction of such a measure. In this study, the aim is to develop a reliable questionnaire for support staff that measures the degree to which staff display behaviours that promote independence in people with ID.

Training people with intellectual disabilities

For the final chapter of this dissertation (Chapter 6), we return the focus to self-management interventions for people with ID themselves. As mentioned above, such interventions for people with ID already exist, but these only target a specific domain. A self-management

intervention that can be applied to a wide range of self-management goals has not yet been researched and it is thus unknown whether such a broad intervention is just as effective as a specific intervention. For our study, we implement and evaluate a self-management intervention for people with ID in which we embed the lessons learnt from our literature study and focus groups. As mentioned above, tailoring to the individual, fostering the transfer of learnt skills to daily life, and involving the support network seem to benefit people with ID [3, 6, 8, 34, 39, 40, 48]. In our study, these elements are combined. The intervention that we implement is tailored to individuals' self-management goals and preferred ways of learning. Due to this tailored approach, the intervention is not limited to a single self-management domain or a specific behavioural change technique, which makes it more widely applicable. By letting participants with ID determine themselves which self-management goals they would like to pursue, it is also more likely that goals will be achieved [49]. The training fosters the transfer to daily life by also practising with participants at their home or work locations or in the community, and actively involves their family members and support staff. In order to evaluate the effectiveness of this self-management training, we study whether the training positively contributes to the attainment of personal self-management goals, the level of independence, and the reduction of support needs. It is also explored whether the training leads to reductions in psychopathological behaviour and to improvements in quality of life.

Aim and outline of this dissertation

In short, the main aim of this dissertation is to identify how self-management can be promoted in people with ID. To this end, we examine what factors need to be taken into account when developing and implementing self-management interventions for this population, we further study the role of support staff, and we implement and evaluate two self-management interventions, one for people with ID and one for their support staff. By obtaining a greater understanding of what contributes to the promotion of self-management in this population, we aim to benefit the further development of self-management interventions for people with ID and to educate the support network on how to optimise their support in the self-management process. This could not only improve the community participation and overall quality of life of people with ID [4, 5], but could also reduce the burden on family members and the demand for and the costs of professional care [7, 50].

Chapter 2 concerns a systematic literature review that summarises and describes of a broad range of self-management interventions for people with mild to moderate ID that

have targeted their level of knowledge and skills. The effectiveness of the interventions is examined, next to the behavioural change techniques that were used. To this end, we aim to create a more overall insight into the effects of self-management interventions for this population. Next, in **Chapter 3**, the current level of knowledge, skills, and abilities of people with ID in relation to independence are investigated through focus groups with people with ID, their legal representatives (mostly relatives), and support staff. Here, we also examine what the needs are of people with ID when it comes to independence and which factors need to be considered when promoting independence, both on the level of the person with ID, as well as in relation to their support network. The possible outcomes of a greater level of independence of people with ID are also explored. In **Chapter 4** and **Chapter 5**, we focus on the question how to improve the interaction between support staff and people with ID in order to increase self-management and independence in particular. We focus on the attitude, knowledge, skills, and behaviour of staff in relation to guiding people with ID towards improved self-management and independence. **Chapter 4** reports on the implementation of a staff training that we evaluate by means of a mixed-methods study. In this training, staff are taught how to promote overall self-management in people with ID. The training is evaluated quantitatively through questionnaires that measure the level of independence and self-reliance of people with ID, their support needs, and the occurrence of behavioural problems. In addition, qualitative data is collected by conducting focus groups in which the training is evaluated with trained staff members. In **Chapter 5** it is examined which staff behaviours are important when wanting to promote independence in people with ID, with the purpose of developing and initially validating a reliable questionnaire that measures the degree to which staff display these behaviours. **Chapter 6** presents the results of an evaluation of a self-management training that targets the attitude, knowledge, and skills of people with ID. The aim is to investigate whether the training supports people with ID in reaching their personal self-management goals and whether it increases their independence and reduces their support needs. The training's effects on psychopathological behaviour and quality of life are also explored. **Chapter 7** summarises the main findings of this thesis and provides a general discussion of the implications of the studies' findings for clinical practice and future research.

