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

Sandjojo, J.

TURNING DISABILITIES INTO ABILITIES

Promoting self-management in people with intellectual disabilities

Janice Sandjojo

Turning disabilities into abilities

Promoting self-management in people with intellectual disabilities

Janice Sandjojo

Author	Janice Sandjojo
Cover image	Shutterstock
Cover and layout	Elisa Calamita, persoonlijkproefschrift.nl
Printing	Ridderprint BV | www.ridderprint.nl
ISBN	978-94-6375-275-6

The research as described in this dissertation was supported by Raamwerk and Universiteit Leiden.
Printing of this dissertation was sponsored by Raamwerk.

Turning disabilities into abilities

Promoting self-management in people with intellectual disabilities

Proefschrift

ter verkrijging van
de graad van Doctor aan de Universiteit Leiden,
op gezag van Rector Magnificus prof. mr. C.J.J.M. Stolker,
volgens besluit van het College voor Promoties
te verdedigen op dinsdag 9 april 2019
klokke 16:15 uur

door

Janice Sandjojo

geboren te 's-Gravenhage
in 1986

Promotor
prof. dr. A.W.M. Evers

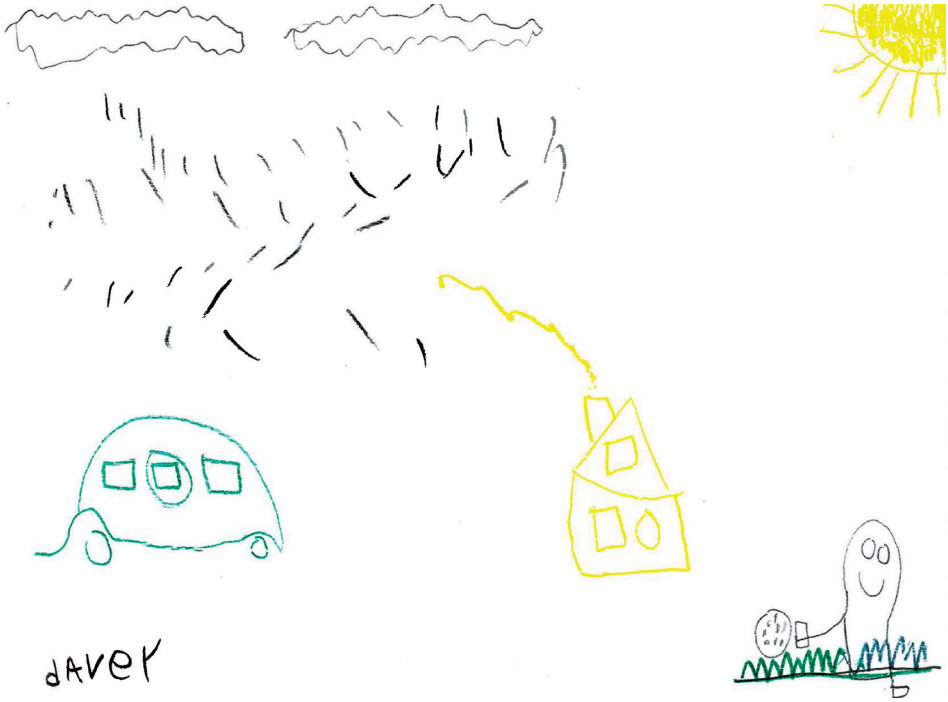
Copromotores
dr. W.A. Gebhardt
dr. A.M.E.E. Zedlitz

Promotiecommissie
prof. dr. P.M. Westenberg
prof. dr. P.J.C.M. Embregts, Tilburg University
prof. dr. C. Schuengel, Vrije Universiteit Amsterdam

Contents

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).

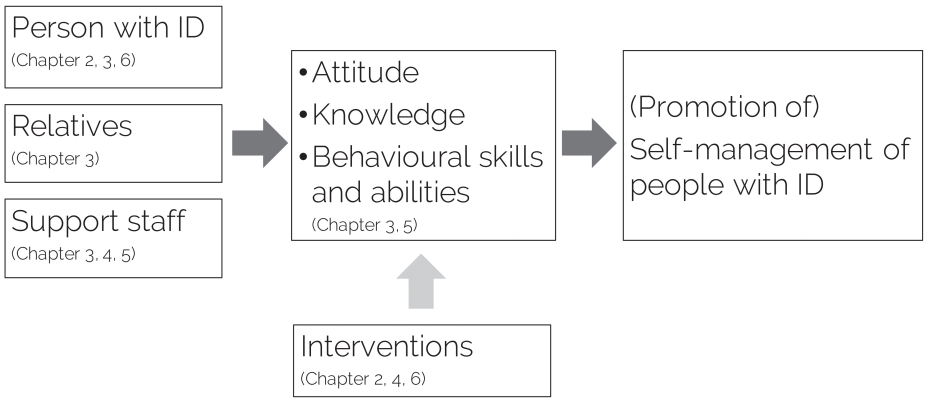


Figure 1. Model of interventions for promoting self-management in people with ID

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 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.

Chapter 2

Self-management interventions for people with intellectual disabilities: A systematic review

Sandjojo, J., Eltringham, E.G., Gebhardt, W.A., Zedlitz, A.M.E.E., Hoekman, J., Den Haan, J.A., Embregts, P.J.C.M., Evers, A.W.M. Self-management interventions for people with intellectual disabilities: A systematic review.
Manuscript submitted for publication.

Abstract

Objective: People with intellectual disabilities (ID) often experience difficulties with managing their everyday affairs. This study reviewed a broad range of self-management interventions for people with ID. We studied the applied behavioural change techniques (BCTs) and interventions' effectiveness.
Methods: A systematic literature search was conducted in seven electronic databases. Data were extracted on study, intervention, and participant characteristics, and on outcome measures and results.
Results: Of the 681 retrieved studies, 36 met the inclusion criteria. Most studies used case study designs and small samples, which implies a low methodological quality and a high risk of bias. Interventions generally targeted a singular practical skill for managing oneself in a specific context. Mostly the provider of the intervention applied several BCTs, only 13 studies trained participants to apply BCTs themselves. Improvements in self-management behaviour were reported in all studies and mostly maintained over time. If measured, generalisation to other settings or tasks was often reported.
Conclusions: Future studies should aim for a higher methodological quality and should consider targeting more generic self-management and a wider application of BCTs by people with ID themselves.
Practice implications: The findings suggests that additional training can aid in the promotion of self-management in people with ID.

Keywords: behavioural change technique, intellectual disabilities, intervention, review, self-management.

Introduction

Awareness is increasing that people with intellectual disabilities (ID) should have equal rights and be included as equal co-citizens in society. This is supported by the United Nations [18], that further declare that people with ID should be enabled to live as independently as possible and to be autonomous with respect to making their own decisions. In the Netherlands, this increasing awareness coincides with the emergence of a 'participation society', where citizens, including people with ID, first have to try to arrange their affairs themselves, before they can turn towards the government. However, people with ID commonly have difficulties with self-managing their affairs [5, 51, 52], which can vary from difficulties with personal care and household activities, to trouble with recreational activities, community participation, and employment [9, 22-24]. Various studies have shown nonetheless that most people with ID would have the desire to manage their activities more independently [1-3, 51]. Increasing the abilities of people with ID to handle their affairs themselves could enhance their quality of life and community participation [4, 5] and could reduce behavioural problems [53]. Interventions that promote self-management of people with ID are therefore of importance.

Self-management is a broad term that refers to processes and activities that are related to deliberately influencing one's behaviour in order to reach personally desired outcomes [25]. This umbrella term includes being independent in handling one's affairs and in taking care of oneself, thereby solely relying on one's own abilities, efforts, resources, and judgement [54]. Self-management is also strongly related to self-determination, which involves having personal control over making choices and decisions to lead one's life according to one's own preferences, without being completely subjected to external influences [28, 55].

Various studies on self-management interventions for people with ID have been conducted and several literature reviews have already collectively analysed some of these previous studies. However, just as the individual studies themselves, these reviews only focused on a specific self-management domain such as self-management at work [32, 34, 56, 57], self-management of chronic disease [12, 58], or the use of activity schedules [59] and self-instructions [24]. Although it was generally found that the reviewed self-management interventions were effective, it is difficult to determine which factors play a key role in the interventions' effectiveness. This is largely due to studies' widely varying self-management goals, outcome measures, and research methods, which hamper thorough comparison.

A greater understanding of the key elements of effective self-management interventions could benefit the further development of such interventions and subsequently the quality of life of people with ID. In this regard, further identification of the applied behavioural change techniques (BCTs) and their respective effectiveness could contribute to our understanding of how self-management interventions work and how their effects can be optimised [60]. BCTs are active components of an intervention that are designed to alter or redirect causal processes that regulate behaviour [29]. People with ID can learn to apply BCTs themselves to attain a greater self-management, but they can also be applied by an intervention provider. Recently, Willems et al. [61] examined how BCTs were applied in interventions for people with ID that targeted physical activity and nutrition. They found that in most cases, several BCTs were applied in the reviewed interventions, such as 'providing information on consequences of behaviour in general' and 'planning social support/social change'. The application of BCTs in self-management interventions for people with ID has not yet been studied.

The aim of the current systematic literature review is to summarise studies that have evaluated the effectiveness of self-management interventions for people with mild to moderate ID. In contrast to the abovementioned reviews that only focused on a certain type of self-management interventions, this review analyses a broad range of interventions that aim to promote self-management in daily life. We aim to examine the BCTs that were used to promote the targeted self-management behaviour, as well as the effectiveness of the interventions. Hereby, we aim to create a more overall insight into the effects of such self-management interventions for this population.

Methods

Search strategy and inclusion criteria

In order to identify relevant studies for our review, PubMed, PsycINFO, Web of Science, Embase, Emcare, Cochrane, and ProQuest (Social Services Abstracts and Sociological Abstracts) were systematically searched from inception to 18 September 2017. The search strategy was based on the Population, Intervention, Comparison, and Outcome (PICO) approach. Search terms (including major headings, Medical Subject Heading terms, title words, and text words) were used that are indicative of intervention studies (Intervention) aimed at promoting self-management (Outcome) for adults with ID (Population), excluding studies that solely included children or adolescents (see Appendix A).

Studies were included if they evaluated the effect of an intervention for adults with mild to moderate ID that aimed to improve their self-management in daily life. Inclusion criteria concerned that articles were original and published in English (i.e., no reviews, dissertations, and book chapters). Exclusion criteria concerned intervention studies aimed at family, staff, or minors with ID (< 18 years). In some studies, not only adults with mild to moderate ID participated, but also minors, adults with severe ID, or people with other disabilities or psychiatric diagnoses. These studies were only included if the effects of the intervention on adults with mild to moderate ID could be distinguished from the people in the other groups. Studies were excluded if the interventions were aimed at managing challenging behaviour or emotions, or if outcome measures focused on physical outcomes (e.g., body weight, oral health status). These latter studies were excluded because improvements in physical functioning would not directly indicate improved self-management skills of participants in daily life.

Study selection

After excluding all duplicates, retrieved references were loaded into Endnote. Titles and abstracts were independently screened by two reviewers (JS and EE) without blinding to authorship or journal (see Figure 1). An 83.2% agreement was achieved. The full texts were retrieved and examined of the articles that potentially met the criteria, including the articles for which there was disagreement. After screening the full texts, reviewers agreed for 95.9% of the articles that they should be included or excluded. Disagreements between reviewers were discussed until consensus was reached. For three cases for which disagreement remained, two other authors (AZ and WG) were included in the discussion.

Data extraction and analysis

From the included studies, two reviewers (JS and EE) extracted information about the study characteristics, participant characteristics, outcome measures, intervention characteristics, BCTs, and main results (both direct and at follow-up). Regarding the BCTs, it was analysed for each article which BCTs were used to target the self-management behaviour and whether these fit the taxonomy of BCTs as described by Michie et al. [60]. For 12 articles (33%), this was done by two reviewers (JS and EE) who initially agreed for 92.1% of the BCTs and who agreed for 100% after discussing the disagreements. Because of the high agreement rate, the other articles were only analysed by one of the two reviewers. Applied BCTs that we came across that were not described in taxonomy of Michie et al. [60] were defined separately based on the descriptions in the articles that

we reviewed (Appendix B). A distinction was made whether BCTs were applied by the participant (e.g., participants use self-instructions while performing a task) or by the provider of the intervention (e.g., the provider gives verbal instructions on how to perform a task). This allowed us to examine to what extent participants were trained to execute the targeted self-management behaviour completely by themselves or whether they were still depended on the provider during the intervention.

Results

Main findings are presented on the study characteristics, participant characteristics, outcome measures, intervention characteristics, and findings on effectiveness. While reading the full texts, it quickly became clear that most studies were of poor methodological quality, which suggests a high risk of bias. For example, there were only five studies with a randomised controlled trial and five studies with a no-treatment control group, whereas 24 studies had a (multiple) case study design with very small convenience samples. In addition, little to none information was available about possible blinding of participants, staff, and outcome assessments, and quantitative data on results was often missing or incomplete. Such low methodological quality of studies is common in the field of ID [61, 62]. As the reported effectiveness of studies with a low quality (e.g., case studies) did not seem to differ from the studies with a higher quality (e.g., studies with a randomised controlled trial), no further in-depth assessment of the quality of studies was conducted.

Search results

The literature search yielded 681 potential publications, of which 483 were unique articles. Of the 121 full texts that were retrieved after screening of the title and abstracts, 36 met our inclusion criteria. Articles were excluded based on a hierarchical approach; if an article was already excluded based on a previous reason, it was not further assessed whether it would also be excluded based on other reasons. Detailed information about the selection process is presented in Figure 1.

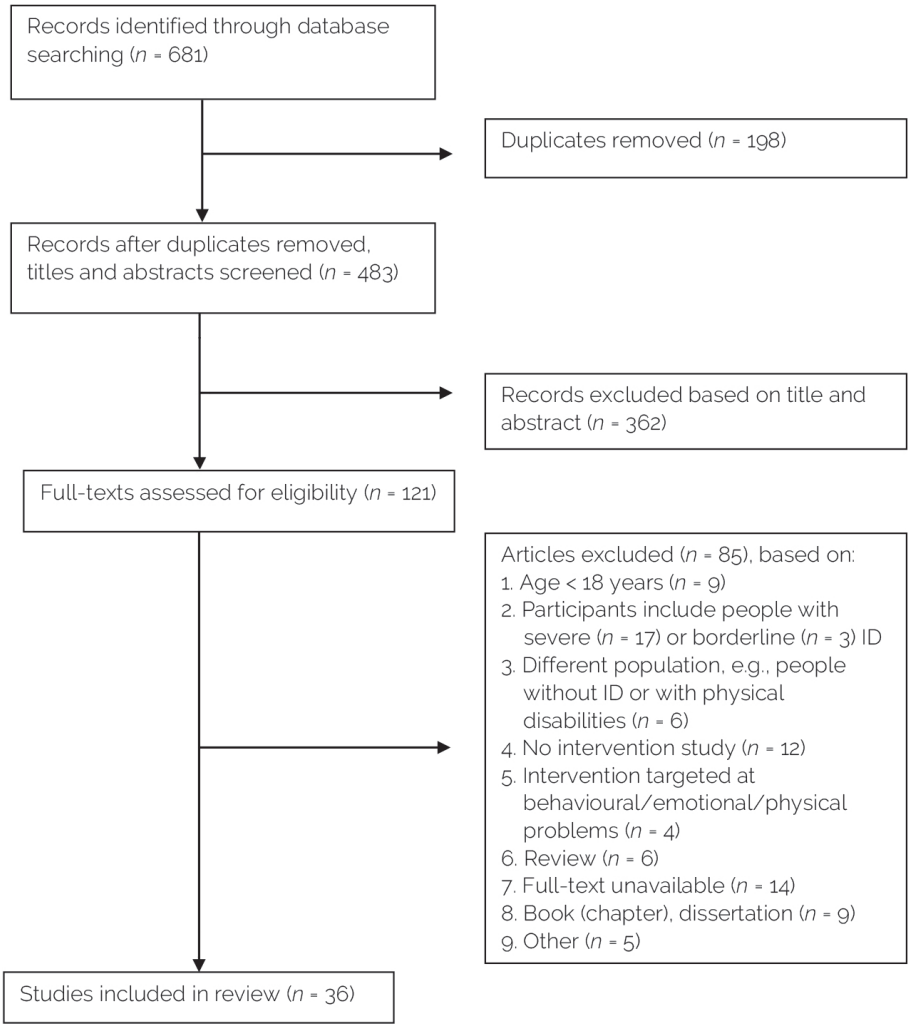


Figure 1. Flow diagram of the selection process

Study characteristics

Table 1 presents the characteristics of the 36 included articles. Except for 3 studies, all were conducted in English speaking countries, of which the United States was the most common (*n* = 26). Other countries of origin were Ireland (*n* = 3), Canada (*n* = 2), Sweden (*n* = 2), Great Britain (*n* = 1), Hong Kong (*n* = 1), and New Zealand (*n* = 1). The majority of articles were published between 1979 and 1999 (*n* = 20) and only a few were published in or after 2010 (*n* = 5). The total number of participants in all 36 studies was 370. Sample sizes greatly differed between studies, ranging from 1 to 57. Nineteen studies (52.8%) had less

than five participants. There were no dropouts during the period in which interventions were provided, but five studies (article #4, 8, 11, 14, 30) reported dropouts at follow-up measurements, ranging from 16.6% to 50% of the initial sample size. The majority of studies had a (multiple) case study design (*n* = 24). Few studies used a randomised controlled trial (*n* = 5), had a no-treatment control group (*n* = 5), or contained more than one training condition (*n* = 7). In case of the latter, the difference between the conditions concerned for example that more BCTs were applied in one group or that one group received in vivo community training versus conventional classroom training in the other group. Twenty-four studies (66.7%) used multiple baseline measures and 23 studies conducted multiples probes during the course of the intervention. Follow-up data were available for 23 studies (63.9%). Period of follow-up was generally a couple of months, however this varied from several days to a few years after training. Data regarding the moments of assessment were often not explicitly reported and moments also greatly varied between studies and even within studies, with sometimes some participants being assessed more often than others, with varying periods of time in between.

Participant characteristics

Data regarding age were not always complete. In some studies only the average age without a standard deviation was provided, in others only the range. Based on the data that were available, the average age was found to vary between 18.2 to 50.3 years. Participants' ages ranged from 18-64 years. On average of 54.5% of participants were female. Most studies included both people with mild and moderate ID (*n* = 16), instead of solely people with mild (*n* = 11) or moderate ID (*n* = 9). It was, however, not always clear how the level of ID was determined. Data regarding recruitment and inclusion and exclusion criteria were also often not fully reported (*n* = 33).

Outcome measures

The specific outcome measures differed per study, but in most cases (*n* = 30; 83.3%) it concerned to what extent the targeted self-management behaviour was performed properly (e.g., number of correctly performed steps). In some studies, previously developed instruments (e.g., questionnaires) were used, but whether these were validated measures was not reported (article #1, 4, 11, 14, 23). Twenty-seven studies (75.0%) assessed participants' behaviour in their real life setting.

Intervention characteristics

The vast majority of interventions had a specific focus on a practical skill, such as teaching people with ID a singular daily living skill within a certain context. Only six studies targeted several daily living skills (article #1, 11, 14, 16, 31, 36). The daily living skills mostly concerned independently managing oneself at home (*n* = 13; e.g., food preparation, doing laundry) or in the community (*n* = 11; e.g., traveling by bus, doing groceries). Interventions focusing on self-determination or rights were scarce (article #4, 6, 8) and only targeted a specific domain or context (e.g., dealing with health right violations). There was only one study that aimed for generalisation of self-management skills across situations (article #16). Interventions were mostly provided on an individual basis, with ten studies using group interventions (range 3-8 participants in a group). Several studies explicitly reported some kind of tailoring within their intervention (e.g., tailoring to individual learning preferences), but it is possible that other interventions were also (partially) tailored, especially those that were provided individually.

Setting and provider

The setting of the interventions varied between studies, with half of the interventions (partially) taking place in the real life setting of the participants (e.g., at home or at work), thereby fostering the transfer of learnt skills to daily life. It widely varied between studies who the provider of the intervention was (e.g., trainer) and it was mostly not specified how this person was instructed to provide the training and what his or her qualifications were.

Length and intensity

The number and duration of training sessions greatly differed between interventions and data about this were often incomplete. For example, the number of sessions varied from one to 180 over a period of 1 day to 18 months and information about this was missing for at least half of the studies. Session length was mostly less than 1 (*n* = 9) or 2 hours (*n* = 8), although for 16 studies no data were available. Three studies provided 'booster' sessions for participants who were lagging behind (article #8, 16, 26) and four studies provided follow-up sessions after the training (article #1, 6, 12, 36).

Table 1 Main study and participant characteristics of the studies included

#	Authors (year) [reference]	Country	Design (Presence of control group or multiple training groups)	Setting	Participants • *n* • Mean (*M*) age (*SD*) • % female • Level of ID	Target behaviour	Time-related aspects • Number of sessions • Length of session • Timespan	Provider	Individual or group training (group size)
1	Crnic et al. (1979) [63]	USA	Unclear (no)	Group home	*n* = 17; *M* = 23.4 (*n/a*), 52.9% female; mild ID	Independent living skills NOS[1]	4-18 months (mean = 12.1)	Support staff	Individual
2	Davies et al. (2003) [64]	USA	Within-subjects (no)	Unknown	*n* = 9; *M* = 25.8 (*n/a*); 44.4% female; mild ID	Withdraw cash from ATM	1 session; 20-45 minutes	Unknown	Individual
3	Davies et al. (2010) [36]	USA	Between-subjects (control group)	Unknown	*n* = 23; *M* = 32.0 (*10.4*); 60.9% female; mild-moderate ID	Navigate a bus route	1 session; 30-60 minutes	Hand-held computer Researcher	Individual
4	Dukes et al. (2009) [65]	IRL	Multiple case study (no)	Unknown	*n* = 4; *M* = 22.5 (*0.6*); 50.0% female; moderate ID	Sexually related decision making	20 sessions; 45 minutes; twice a week for 10 weeks	Unknown	Individual
5	Faloon et al. (2008) [66]	USA	Case study (no)	Human services agency	*n* = 1; age = 19; 0.0% female; mild ID	Use of overt and covert self-rules	3-5 sessions per week; 30-40 minutes	Experimenter	Individual
6	Faw et al. (1996) [67]	USA	Multiple case study (no)	Group homes and simulation home	*n* = 4; *M* = 22.8 (*2.2*); 25.0% female; mild-moderate ID	Self-determination skills in selecting a home	4 sessions; 1 hour	Trainer	Individual
7	Feldman et al. (1999) [68]	CAN	Multiple case study (no)	Home	*n* = 10; *M* = 28 (*n/a*); 100% female; mild ID	Child-care skills	1 session	Manual	Individual
8	Feldman et al. (2012) [69]	CAN	Randomised controlled trial (control group)	Unknown	*n* = 31; *M* = 49.0 (*7.6*); 51.6% female; mild-moderate ID	Recognition and redressing health rights violations	Mean number of sessions = 10.89 (SD = 3.88); 2 hours; twice a week	Trainer	Group (3)
9	Gilson et al. (2016) [70]	USA	Case study (no)	Internship job site	*n* = 1; age = 22; 0.0% female; level of ID unknown	Social interactions and task engagement at work	30 sessions; 4 hours	Job coach	Individual

Table 1 Continued

#	Authors (year) [reference]	Country	Design (Presence of control group or multiple training groups)	Setting	Participants • *n* • Mean (*M*) age (*SD*) • % female • Level of ID	Target behaviour	Time-related aspects • Number of sessions • Length of session • Timespan	Provider	Individual or group training (group size)
10	Goodson et al. (2007) [71]	USA	Multiple case study (no)	Vocational training centre	*n* = 4; *M* = 34.8 (*1.5*); 0.0% female; moderate ID	Setting a table	5-6 sessions for video prompting, 9-13 sessions for video-prompting plus error-correction	Computer Trainer	Individual
11	Hällgren et al. (2005) [72]	SWE	Multiple case study (no)	Unknown	*n* = 6; *M* = n/a (*n/a*); 66.7% female; mild-moderate ID	Activities of Daily Living (ADL)	5 sessions; 3 months	Occupational therapist	Individual
12	Johnson et al. (1981) [73]	USA	Multiple case study (no)	Sheltered workshop	*n* = 4; *M* = 32.4 (*13.7*); 25.0% female; mild-moderate ID	Cooking skills: broiling, baking, boiling	2-12 sessions per subtask (mean = 4-6); 5-40 minutes (mean = 17)	Trainer	Individual
13	Katz et al. (1986) [74]	NZL	Multiple case study (no)	Group home	*n* = 9; *M* = n/a (*n/a*); 55.6% female; mild-moderate ID	Fire-safety skills	20-30 sessions	Student	Individual
14	Kottorp et al. (2003) [75]	SWE	Multiple case study (no)	Disability Services	*n* = 3; *M* = 26.7 (*3.0*); 100% female; moderate ID	Activities of Daily Living (ADL)	6-10 sessions; 4 months	Occupational therapist	Individual
15	LaCampagne et al. (1987) [76]	USA	Multiple case study (no)	Day treatment centre	*n* = 4; *M* = 30.0 (*5.4*); 75.0% female; mild ID	Paying bills	12 sessions; 1 hour; 12 days	Trainer	Group (4)
16	Lovett et al. (1989) [77]	USA	Between-group (group 1: self-recording training, group 2: self-recording, self-evaluation, self-reinforcement training	Home	*n* = 9; *M* = 27.0 (*5.2*); 55.6% female; mild-moderate ID	Activities of Daily Living (ADL)	Unknown	Trainer	Individual

Table 1 Continued

#	Authors (year) [reference]	Country	Design (Presence of control group or multiple training groups)	Setting	Participants • *n* • Mean (*M*) age (*SD*) • % female • Level of ID	Target behaviour	Time-related aspects • Number of sessions • Length of session • Timespan	Provider	Individual or group training (group size)
17	Marchetti et al. (1983) [78]	USA	Randomised controlled trial (group 1: classroom training, group 2: community training)	Classroom or community	*n* = 18; *M* = 41.0 (*n/a*); unknown % female; mild-moderate ID	Pedestrian skills	40 sessions; 1.5 hours; twice a week for 20 weeks	Support staff	Group (3)
18	Martin et al. (1987) [79]	USA	Multiple case study with partial-sequential withdrawal (no)	Home	*n* = 3; *M* = 31.0 (*8.9*); 66.7% female; mild-moderate ID	Preparation of breakfast and dinner	50 meals; maximum of 3.5 months	Support staff	Individual
19	Matson (1981) [80]	USA	Randomised controlled trial (control group)	Outpatient clinic and grocery store	*n* = 20; *M* = 34.0 (*n/a*); 50.0% female; mild ID	Shopping behaviour	20 sessions; 1 hour; 20 weekdays	Trainer	Group (5)
20	Matson (1982) [81]	USA	Randomised controlled trial (control group, group 1: modelling training, group 2: independence training)	Unknown	*n* = 45; *M* = 38.4 (*n/a*); 55.6% female; mild ID	Phone conversational skills	1 hour; three times per week for 2 months	Trainer	Group (7-8)
21	Matson et al. (1986) [82]	USA	Multiple case study (no)	Care institution and grocery stores	*n* = 3; *M* = 41.7 (*10.6*); 0.0% female; mild-moderate ID	Computational and shopping skills	26 sessions; 1.5 hours; twice a week for 13 weeks	Teacher	Group (3)
22	McInerney et al. (1992) [83]	USA	Within-subjects (no)	Shopping malls	*n* = 29; *M* = n/a (*n/a*); 69.0% female; mild-moderate ID	Use of the bus	60-90 minutes; 3-5 times per week (mean = 2.86 sessions per week; *SD* = 1.50) for 6.58 weeks on average (*SD* = 4.19)	Occupational therapist	Group (4-5)

Table 1 Continued

#	Authors (year) [reference]	Country	Design (Presence of control group or multiple training groups)	Setting	Participants • *n* • Mean (*M*) age (*SD*) • % female • Level of ID	Target behaviour	Time-related aspects • Number of sessions • Length of session • Timespan	Provider	Individual or group training (group size)
23	Michie et al. (1998) [84]	GBR	Randomised block design (control group, group 1: classroom training, group 2: in vivo training)	Unknown	*n* = 57; *M* = 36.2 (*12.7*); unknown % female; mild-moderate ID	Community living skills	±180 sessions, twice per week	Unknown	Group (4-6)
24	Neef et al. (1990) [85]	USA	Case study (no)	Day habilitation centre, (group) home, and laundromat	*n* = 1; age = 41; 0% female; mild-moderate ID	Laundry skills (washing and drying)	3-4 times per week; ±3.4 hours for drying and ±36.1 for washing	Trainer	Individual
25	Ores et al. (1984) [86]	USA	Within-subjects design (no)	Unknown	*n* = 10; *M* = n/a (*n/a*); 50.0% female; moderate ID	Make a telephone call	1 session; 48 seconds-5 minutes and 22 seconds demonstration time, 33 seconds-5 minutes practice time	Researcher	Individual
26	Rehfeldt et al. (2003) [87]	USA	Multiple case study (no)	Day treatment	*n* = 1; age = 22; 0.0% female; moderate ID	Making a sandwich	13 sessions	Computer instruction	Individual
27	Richman et al. (1984) [88]	USA	Multiple case study (no)	Home	*n* = 1; age = 34; 100% female; mild-moderate ID	Menstrual care skills	5-15 minutes	Researcher Support staff	Individual
28	Risley et al. (1980) [89]	USA	Multiple case study (no)	Sheltered workshop	*n* = 3; *M* = 37.7 (*13.2*); 33.3% female; mild-moderate ID	Making an emergency call	Mean number of sessions = 6; 8-35 minutes (M = 13); 5 per week	Trainer	Individual
29	Sarber et al. (1983) [90]	USA	Case study (no)	Home and supermarket	*n* = 1; age = 34; 100% female; mild ID	Menu planning and grocery shopping	Unknown	Counsellor	Individual
30	Sigafoos et al. (2005) [5]	USA	Multiple case study (no)	Vocational programme	*n* = 3; *M* = 35.3 (*SD* = 1.2); 0.0% female; moderate ID	Make a bag of microwave popcorn	±25 sessions; 6-8 minutes; twice per week	Computer, Trainer	Individual

Table 1 Continued

#	Authors (year) [reference]	Country	Design (Presence of control group or multiple training groups)	Setting	Participants • *n* • Mean (*M*) age (*SD*) • % female • Level of ID	Target behaviour	Time-related aspects • Number of sessions • Length of session • Timespan	Provider	Individual or group training (group size)
31	Taber-Doughty et al. (2010) [91]	USA	Multiple case study with alternating treatment (group 1: telecare support, group 2: standard care staff)	Home	*n* = 4; *M* = 49.3 (*5.9*); 25.0% female; mild-moderate ID	Household tasks	20 sessions; 5-7 days	Support staff, Telecare staff	Individual
32	Tam et al. (2005) [92]	HKG	Quasi-experimental (group 1: conventional training, group 2: Virtual Reality training)	Vocational skills training centre	*n* = 16; *M* = 18.2 (*2.3*); 50.0% female; moderate ID	Supermarket shopping	Control group: two 30 minute sessions VR group: one 45 minute sessions and one 30 minute session	Trainer	Individual
33	Taylor et al. (1997) [93]	IRL	Multiple case study with multi-element phases (no)	Vocational training centre and supermarkets	*n* = 7; *M* = 28.7 (*5.6*); 50.0% female; mild ID	Shopping	3-4 sessions per week	Trainer	Group (3-4)
34	Taylor et al. (2000) [94]	IRL	Multiple case study (group 1: Stimulus Equivalence training, group 2: Single Instance training, group 3: Multiple Exemplar training)	Vocational training centre and supermarkets	*n* = 6; *M* = 27.2 (*5.9*); 66.7% female; mild ID	Supermarket shopping	±32 sessions; 45 minute (individual session) and 90 minutes (group training); 4 days a week for 2 months	Trainer	Group (6)
35	Wacker et al. (1986) [95]	USA	Case study (no)	School and job site	*n* = 1; age = 19; 100% female; moderate ID	Clerical Tasks	40 sessions; 2 hours	Job coordinator	Individual
36	Wu et al. (2016) [31]	USA	Multiple case study (no)	School	*n* = 2; *M* = 18.5 (*0.7*); 50% female; mild-moderate ID	Daily living skills	13 or 40 sessions; 15-30 minutes	Trainer	Individual

n/a = not available

[1] Not Otherwise Specified

Behavioural Change Techniques

To obtain an overview of the used BCTs that were applied to attain the targeted self-management behaviour, we analysed per study which antecedent BCTs preceded the desired self-management behaviour of participants and which consequent BCTs followed afterwards [Appendix B; 60, 96]. We also made a distinction whether BCTs were applied by the participant or by the provider of the intervention (Table 2).

All interventions aimed to promote self-management by means of the provider of the intervention, who often applied a range of BCTs to help the participants reach the targeted self-management behaviour. A common combination of BCTs preceding the desired self-management behaviour of participants (12/36 studies, 33.3%) concerned the provider modelling the targeted behaviour or skill, giving instructions, and providing prompts (e.g., a visual/auditory cue, least-to-most prompting). These three BCTs were not only provided verbally, but sometimes also visually (e.g., with the use of a pictorial manual, videos, or gestures). In nine studies, the provider encouraged the generalisation of the targeted self-management behaviour to another situation (e.g., a different supermarket; article #6, 8, 17, 22, 24, 28, 33, 36). Less frequently applied antecedent BCTs included chaining (article #15, 22, 23, 27), physical guidance (e.g., holding someone's hand while executing a task; article #12, 13, 28, 34, 36), and role-play (article #6, 8, 9, 23, 32, 34). Consequent BCTs that were applied by the provider that followed the execution of the desired self-management behaviour mostly concerned giving feedback, which could be further distinguished into praise, corrective feedback, or descriptive feedback. Often a combination of these types of feedback was used (16/36 studies, 44.4%). In nine cases, some kind of reinforcement was provided (e.g., a consumable or activity; article #7, 12, 13, 16, 17, 20, 21, 23, 32).

Several studies (n = 13) trained participants to apply BCTs themselves to attain the targeted self-management behaviour. The antecedent BCTs that were taught concerned the use of self-instructions (article #5, 7, 18, 23, 33, 36) or environmental cues (article #3, 22). Consequent BCTs applied by participants regarded some form of self-recording or self-monitoring of the performed self-management behaviour, followed by self-evaluation of the performance and self-reinforcement (article #16, 19, 20, 21), or praise (article #5, 13, 33).

Table 2 Intervention characteristics of the included studies

#	Authors (year) [reference]	Target behaviour	Behaviour Change Techniques applied by participant		Behaviour Change Techniques applied by provider		Main results
			Antecedent	Consequent	Antecedent	Consequent	
1	Crnic et al. (1979) [63]	Independent living skills NOS[1]	Unknown	Unknown	Unknown	Unknown	Outcome: Improved skills in personal maintenance, clothing care, home maintenance, food preparation, time management, social behaviour, community utilisation, communication, and academic functioning. Generalisation to daily life: yes. Follow-up: not measured.
2	Davies et al. (2003) [64]	Withdraw cash from ATM	n/a	n/a	Instruction Modelling Prompts	Feedback (NOS[1])	Outcome: Fewer required help prompts and fewer errors. Generalisation to daily life: yes. Follow-up: not measured.
3	Davies et al. (2010) [36]	Navigate a bus route	Use of cues (pictures and audio messages)	n/a	Instruction Prompts	Feedback (descriptive)	Outcome: Experimental group was more successful at completing a bus route, made less errors and needed less landmarking prompts vs. control group. Generalisation to daily life: yes. Follow-up: not measured.
4	Dukes et al. (2009) [65]	Sexually related decision making	Unknown	Unknown	Unknown	Unknown	Outcome: Improved knowledge of human sexuality and safety practices and improved decision-making capacity. Generalisation to daily life: not measured. Follow up: Maintenance of effects for safety practices, some decay in knowledge.
5	Faloon et al. (2008) [66]	Use of overt and covert self-rules	Self-instruction	Feedback (praise)	Instruction Modelling Prompts	Feedback (corrective, praise)	Outcome: Accuracy improved after overt and covert self-instruction training. Performance decreased during overt and covert blocking sessions. Generalisation to daily life: yes. Follow-up: not measured.

Table 2 Continued

#	Authors (year) [reference]	Target behaviour	Behaviour Change Techniques applied by participant		Behaviour Change Techniques applied by provider		Main results
			Antecedent	Consequent	Antecedent	Consequent	
6	Faw et al. (1996) [67]	Self-determination skills in selecting a home	n/a	n/a	Generalisation Instruction Modelling Prompts Role-play	Feedback (descriptive, instructive, praise)	Outcome: Increase in skills regarding asking preference questions, reporting information, and evaluating homes. Generalisation to daily life: yes. Follow up: Performances were maintained.
7	Feldman et al. (1999) [68]	Child-care skills	Self-instruction	n/a	Instruction	Feedback (NOS[1]), Modelling, Reinforcement (NOS[1])	Outcome: Increased child-care skills to normal levels for most mothers and child-care skills. Higher mean percentage correct after training. Generalisation to daily life: yes. Follow-up: Even higher mean percentage correct, skills were maintained.
8	Feldman et al. (2012) [69]	Recognition and redressing health rights violations	n/a	n/a	Generalisation Instruction Modelling Prompts Role-play	Feedback (praise)	Outcome: Training group had more correct responses to video scenarios showing health rights, respect, or responsibility situations vs. control group. Generalisation to daily life: yes. Follow-up: Improvements were maintained.
9	Gilson et al. (2016) [70]	Social interactions and task engagement at work	n/a	n/a	Instruction Modelling Prompts Role-play	Feedback (corrective, praise)	Outcome: Social interactions increased modestly and high task engagement maintained when job coaches reduced proximity and delivered prompts discretely. Generalisation to daily life: yes. Follow-up: not measured.
10	Goodson et al. (2007) [71]	Setting a table	n/a	n/a	Instruction Modelling	Feedback (corrective)	Outcome: Accuracy in setting the table improved from 0-60% (baseline) to 100% after a video prompting plus error correction procedure. Generalisation to daily life: yes. Follow-up: not measured.

Table 2 Continued

#	Authors (year) [reference]	Target behaviour	Behaviour Change Techniques applied by participant		Behaviour Change Techniques applied by provider		Main results
			Antecedent	Consequent	Antecedent	Consequent	
11	Hällgren et al. (2005) [72]	Activities of Daily Living (ADL)	n/a	n/a	Unknown	Feedback (NOS[1])	Outcome: ADL performance improved in five out of six participants after the intervention, both regarding motor and process skills. Generalisation to daily life: yes. Follow-up: Improvements were maintained.
12	Johnson et al. (1981) [73]	Cooking skills: broiling, baking, boiling	n/a	n/a	Instruction Modelling Physical guidance Prompts	Feedback (descriptive, praise) Reinforcement (reward)	Outcome: Relatively quick acquisition of cooking skills once training initiated. Three out of four participants showed generalisation effects within and between the cooking methods. Generalisation to daily life: not measured. Follow-up: Relatively high maintenance of cooking skills.
13	Katz et al. (1986) [74]	Fire-safety skills	n/a	Feedback (praise)	Instruction Modelling Physical guidance Prompts	Feedback (corrective, descriptive, praise) Reinforcement (reward)	Outcome: For most participants, perfect mastery of fire-safety skills after training and significantly increased knowledge and understanding of fire-safety behaviour. Generalisation to daily life: yes. Follow-up: Most participants maintained perfect mastery.
14	Kottorp et al. (2003) [75]	Activities of Daily Living (ADL)	n/a	n/a	Compensatory techniques (NOS[1]) Environmental restructuring	Feedback (NOS[1])	Outcome: The intervention had different impacts across participants. Generally, ADL process ability improved, but effects on ADL motor ability and awareness of disability were questionable. Generalisation to daily life: yes. Follow-up: Improvements were maintained.
15	LaCampagne et al. (1987) [76]	Paying bills	n/a	n/a	Chaining Instruction Modelling	Feedback (NOS[1])	Outcome: Few errors in paying bills after training, compared to many errors at baseline. Skills generalised to untrained bills. Generalisation to daily life: not measured. Follow-up: Skills were maintained.

Table 2 Continued

#	Authors (year) [reference]	Target behaviour	Behaviour Change Techniques applied by participant		Behaviour Change Techniques applied by provider		Main results
			Antecedent	Consequent	Antecedent	Consequent	
16	Lovett et al. (1989) [77]	Activities of Daily Living (ADL)	n/a	Feedback (NOS[1]) Self-evaluation Self-recording Self-reinforcement	Instruction Modelling	Feedback (NOS[1]) Reinforcement (reward)	Outcome: Improved ADL performance compared to baseline. Group 2 (several BCTs) generally performed better than Group 1 (self-recording only) and performed slightly better during maintenance phase, but received more training. Generalisation to daily life: yes. Follow-up: Higher ADL task completion for all participants during long-term follow-up vs. baseline.
17	Marchetti et al. (1983) [78]	Pedestrian skills	n/a	n/a	Generalisation Prompts	Feedback (praise) Reinforcement (social NOS[1])	Outcome: Community training group significantly improved pedestrian skills. No significant change in the Classroom group. Generalisation to daily life: yes. Follow-up: not measured.
18	Martin et al. (1987) [79]	Preparation of breakfast and dinner	Self-instruction	n/a	Instruction Prompts	Feedback (corrective, praise)	Outcome: Rapid improvement in food preparation skills with the use of picture recipe cards. Generalisation to daily life: yes. Follow-up: Two participants maintained high performance, for the other it was variable, but satisfactory.
19	Matson (1981) [80]	Shopping skills	n/a	Self-evaluation	Instruction Modelling	Feedback (descriptive, praise)	Outcome: Intervention group improved shopping skills, which generalised to another store. The control group did not improve. Generalisation to daily life: yes. Follow-up: Intervention group maintained gains and generalisation effects.

Table 2 Continued

#	Authors (year) [reference]	Target behaviour	Behaviour Change Techniques applied by participant		Behaviour Change Techniques applied by provider		Main results
			Antecedent	Consequent	Antecedent	Consequent	
20	Matson (1982) [81]	Phone conversational skills	n/a	Self-evaluation Self-monitoring	Instruction Modelling Shaping	Feedback (corrective, descriptive, praise) Reinforcement (social NOS[1])	Outcome: Independence training group had better conversational skills than the modelling and the control group. Modelling group performed better than the control group. Generalisation to daily life: not measured. Follow-up: Results were similar to immediate outcomes.
21	Matson et al. (1986) [82]	Computational and shopping skills	n/a	Self-evaluation	Instruction Modelling	Feedback (descriptive, praise) Reinforcement (social and tangible NOS[1])	Outcome: Computational and shopping skills rapidly improved after initiation of intervention. Skills generalised to other stores. Generalisation to daily life: yes. Follow-up: Improvements were maintained.
22	McInerney et al. (1992) [83]	Use of the bus	Use of cues (environmental landmarks)	n/a	Chaining Generalisation	Feedback (corrective, praise)	Outcome: Only follow-up measures were used. Generalisation to daily life: yes. Follow-up: Participants maintained their mobility skills regarding making leisure outings by bus.
23	Michie et al. (1998) [84]	Community living skills	Self-instruction	n/a	Chaining Instruction Modelling Prompts Role-play Shaping	Reinforcement (social NOS[1])	Outcome: In-vivo training group performed better on community living skills and adaptive behaviour vs. the other groups, and scored higher on independent functioning and socialisation vs. the control group. Classroom group only performed better regarding library use vs. the control group. Generalisation to daily life: yes. Follow-up: Results were similar to immediate outcomes.

Table 2 Continued

#	Authors (year) [reference]	Target behaviour	Behaviour Change Techniques applied by participant		Behaviour Change Techniques applied by provider		Main results
			Antecedent	Consequent	Antecedent	Consequent	
24	Neef et al. (1990) [85]	Laundry skills (washing and drying)	n/a	n/a	Generalisation Modelling	Feedback (corrective, praise)	Outcome: Accuracy on the single case machine improved from 70-83% at baseline to 100% at post-training. Performance on general case machines improved from 60-83% to 92-95%. Generalisation to untrained machines only occurred after general case instruction. Generalisation to daily life: yes. Follow-up: not measured.
25	Ores et al. (1984) [86]	Make a telephone call	n/a	n/a	Modelling	n/a	Outcome: Nine out of ten participants were able to dial successfully immediately after training. Generalisation to daily life: not measured. Follow-up: Results were similar to immediate outcomes.
26	Rehfeldt et al. (2003) [87]	Making a sandwich	n/a	n/a	Modelling	Feedback (praise)	Outcome: Rapid mastery of meal preparation skill once training initiated. Skill generalisation across settings. Generalisation to daily life: not measured. Follow-up: Skill was maintained.
27	Richman et al. (1984) [88]	Menstrual care skills	n/a	n/a	Chaining Instruction Prompts	Feedback (corrective, praise)	Outcome: Performance improved substantially after training initiated. 100% correct performance maintained on the validation and maintenance session. Generalisation to daily life: yes. Follow-up: Maintenance of a high level of responding.
28	Risley et al. (1980) [89]	Making an emergency call	n/a	n/a	Generalisation Instruction Modelling Physical guidance	Feedback (corrective, descriptive, praise)	Outcome: Performance improved after training initiated. Skill generalisation to other emergency parties. Generalisation to daily life: not measured, Follow-up: Results were similar to immediate outcomes.

Table 2 Continued

#	Authors (year) [reference]	Target behaviour	Behaviour Change Techniques applied by participant		Behaviour Change Techniques applied by provider		Main results
			Antecedent	Consequent	Antecedent	Consequent	
29	Sarber et al. (1983) [90]	Menu planning and grocery shopping	n/a	n/a	Instruction Modelling Prompt	Feedback (corrective, praise)	Outcome: Improved performance on planning nutritious meals from 0% to 100% after completion of intervention. Grocery shopping skills improved from 25-72.5% to 100% post-intervention. Generalisation to daily life: yes. Follow-up: Meal planning and grocery shopping skills varied from 92.5-100%.
30	Sigafoos et al. (2005) [5]	Make a bag of microwave popcorn	n/a	n/a	Instruction Modelling	n/a	Outcome: Two out of three participants improved from 0-30% at baseline to 100% independence after video prompting started. Generalisation to daily life: no. Follow-up: Independence ranged from 80-100%.
31	Taber-Doughty et al. (2010) [91]	Household tasks	n/a	n/a	Instruction Prompts	n/a	Outcome: Slightly more independent performance when prompted by a telecare provider vs. a standard care provider. Generalisation to daily life: yes. Follow-up: Results were variable.
32	Tam et al. (2005) [92]	Supermarket shopping	n/a	n/a	Instruction Modelling Role-play	Feedback (NOS[1]) Reinforcement (verbal NOS[1])	Outcome: Conventional training and Virtual Reality (VR) group showed a significant and similar improvement in shopping skills. Generalisation to daily life: yes. Follow-up: not measured.

Table 2 Continued

#	Authors (year) [reference]	Target behaviour	Behaviour Change Techniques applied by participant		Behaviour Change Techniques applied by provider		Main results
			Antecedent	Consequent	Antecedent	Consequent	
33	Taylor et al. (1997) [93]	Shopping	Self-instruction	Feedback (descriptive, praise)	Instruction Modelling Prompts	n/a	Outcome: In Phase 1, successful performance of shopping task across training and generalisation stores using overt and covert self-instruction. Blocking of overt and covert self-instruction resulted in reversal to baseline levels. In Phase 2, successful performance of shopping task using self-rules. High levels of task analysis responding corresponded with high levels of self-instruction. Similar results in the generalisation settings. Generalisation to daily life: yes. Follow-up: not measured.
34	Taylor et al. (2000) [94]	Supermarket shopping	n/a	n/a	Generalisation Instruction Modelling Physical guidance Prompts Role-play	Feedback (corrective, praise)	Outcome: All participants reached criterion responding in supermarket training settings with little difference between groups. Stimulus Equivalence training and Multiple Exemplar training were equally effective in promoting generalisation, Single Instance training was the least effective. Generalisation to daily life: yes. Follow-up: not measured.
35	Wacker et al. (1986) [95]	Clerical Tasks	n/a	n/a	Modelling	Feedback (corrective, praise)	Outcome: 90% of sheets were copied correctly. Substantial increase in incidental behaviours, indicating a more appropriate interaction with the work environment. Generalisation to daily life: yes. Follow-up: not measured.
36	Wu et al. (2016) [31]	Daily living skills	Self-instruction	n/a	Generalisation Modelling Physical guidance Prompts	Feedback (corrective)	Outcome: All participants acquired a variety of daily living skills using video prompting. Generalisation to daily life: yes. Follow-up: 100% accuracy was maintained.

n/a = not applicable

[1] Not Otherwise Specified

Intervention effectiveness

All studies reported that the applied interventions were effective, which generally meant that participants were better able to execute the targeted self-management behaviour properly and independently after training. The 23 studies that collected follow-up data generally found that training effects maintained over the follow-up period. The 15 studies (41.7%) that examined generalisation of the trained self-management behaviour to other settings or tasks, all found evidence for such generalisation effects. Studies that included a no-treatment control group all found that participants from the training groups performed better than the control group (article #3, 8, 19, 20, 23), both immediately after training as well as at follow-up (in case follow-up data were available). In studies with several training groups, results were mixed. Two studies only reported a significant improvement in the community or in vivo training group, but not in the classroom group (article #17, 23). Other studies found that training groups improved equally (article #32, 34) or that both training groups improved performance but with one group outperforming the other (article #16, 20, 31). In two of these latter cases, the group with the most improvement received an intervention that used more varied BCTs than the other training group.

Discussion and conclusion

Discussion

This systematic review analysed studies on interventions that aim to promote self-management in daily life for adults with mild to moderate ID. We described the effectiveness of the interventions, as well as the BCTs that were used to attain the desired self-management behaviour. In all the included studies, the self-management interventions were reported to be effective and positive effects generally maintained over time. All studies that measured generalisation effects found that the trained self-management behaviour generalised to other tasks or (daily life) situations. With regard to the applied BCTs, in only a third of interventions were participants with ID trained to apply BCTs themselves, whereas all interventions applied BCTs by means of the provider of the intervention (e.g., trainer). Antecedent BCTs applied by participants included self-instructions and the use of cues, consequent BCTs for example concerned self-monitoring of the execution of the target behaviour and self-reinforcement. Providers often combined several antecedent BCTs, mainly modelling, instructing, and prompting, with several consequent BCTs such as providing feedback or reinforcement. The findings

imply that interventions can promote self-management in people with ID, irrespective of the targeted self-management behaviour and the intervention characteristics.

This review extends previous reviews that only analysed interventions for people with ID that targeted a specific self-management domain [e.g., 12, 34] or BCT [e.g., 24, 59]. In line with previous reviews, the included self-management interventions showed positive results, but it was difficult to determine which factors contributed to the interventions' effectiveness. Previous studies have suggested that a combination of multiple BCTs is most effective in promoting behaviour change [34, 97]. However, it is yet unknown which particular combinations might be especially effective for this population. Our finding that the studied interventions were considered to be effective is promising, as this implies that people with ID can improve their self-management in daily life, regardless of the target behaviour, the specific intervention characteristics, and applied BCTs. It seems that as long as people with ID are provided with a self-management training, they are able to manage their affairs more independently, regardless of the type of affairs or self-management behaviour that is targeted. However, the finding that all interventions were reported to be effective also suggests a possible publication bias [98]. In addition, studies were generally of poor quality, which further suggests a high risk of bias. Sample sizes were often very small, a (multiple) case study design was used in two thirds of studies, and only few studies included a control group. Notably, quantitative data on results was often missing or incomplete. As a result, the interpretation and generalisation of the positive findings must be conducted with great caution and hence no firm conclusions can be drawn.

Regarding the BCTs that were used in the reviewed interventions to attain the targeted self-management behaviour, it was found that in most cases only the provider applied BCTs. This means that most of the times when people with ID were trained to promote their self-management, they were still largely dependent on the provider of the training. One could argue however, that a more effective and efficient way to promote overall self-management in people with ID is to teach them to apply BCTs or strategies themselves, such as self-instructions, self-rules, or general problem solving. This could reduce the need for proximity of a provider [99]. Especially since support staff already feel they cannot provide the quality of care that is needed for people with ID [19], a decreased dependence on the support provider is important to consider in self-management interventions. Furthermore, BCTs used by participants themselves can more easily be

applied to other self-management tasks or situations [66, 99-101], although whether this will occur might depend on the cognitive level of the person with ID.

If generalisation of BCTs is to be achieved, this needs to be targeted in interventions. However, even in the reviewed interventions in which BCTs were applied by participants, they only focused on the application of BCTs for specific behaviours. These behaviours often concerned very specific practical skills necessary at home or in the community, such as making a telephone call or withdrawing cash. Looking at the quality of life domains as proposed by Schalock [102], the focus of self-management interventions for people with ID has mostly been limited to the domains of personal development, material wellbeing, and physical wellbeing. On the contrary, domains as interpersonal relations, self-determination, social inclusion, and rights were hardly addressed in the reviewed interventions. Only three interventions targeted self-determination or rights [65, 67, 69], but these again only focused on a specific domain or context (e.g., making sexuality-related decisions). Therefore, to promote the overall quality of life of people with ID, interventions may need to go beyond the training of singular practical skills.

Limitations

With regard to the limitations of this study, we conducted a systematic review instead of a meta-analysis, because of the heterogeneity in study designs, types of interventions, and outcome measures. In addition, we could not analyse which factors (e.g., participant or study characteristics) contributed to the effectiveness of interventions, how these factors contributed, and to what extent. We also could not analyse whether interventions in which BCTs were applied by participants with ID were more effective than interventions in which providers (mainly) applied the BCTs. Reasons for this were that all interventions were found to be effective, that sometimes only qualitative descriptions of results were reported, and that quantitative data (e.g., effect sizes) were often incomplete. Other important information was also often not reported. This included information regarding age, diagnosis of ID, recruitment of participants, inclusion and exclusion criteria, moments of assessment, whether and how interventions were tailored, the provider, the length and intensity of the intervention, and the applied BCTs. This all hampers the aggregation of data and thus the deduction of factors contributing to interventions' effectiveness, as well as a further examination of the specific groups of people with ID for which interventions are particularly effective. Also, the total sample size of all reviewed studies was relatively small, which limits the generalisability of our findings. The abovementioned limitations are not only commonly present in studies on

self-management interventions, but also in other types of studies in the field of ID, such as studies on lifestyle change interventions [61, 62].

For future studies on self-management interventions it is recommended to provide more detailed information about the results and the participant and intervention characteristics. In addition, given the frequent occurrence of relatively low quality studies in this field, there is a need for studies with a high quality and a low risk of bias (e.g., by means of larger samples and randomisation). Aspects to consider in future interventions concern the wider application of BCTs by people with ID themselves, thereby aiming to promote overall self-management and quality of life, instead of solely targeting a particular practical skill. The transfer and generalisation of the target behaviour to daily life and across settings also needs to be incorporated in the interventions, as well as in the assessment of the intervention outcomes.

Conclusion

In sum, this review described a broad range of interventions for people with mild to moderate ID that aim to promote their self-management in daily life, thereby also evaluating the effectiveness of the interventions and the applied BCTs. Interventions generally targeted a particular skill by using a combination of several BCTs, mainly applied by the provider of the training. Although the results must be interpreted with caution due to the poor methodological quality of most studies and the resulting high risk of bias, the finding that all interventions were reported to be effective suggests that additional training can aid in the promotion of self-management in people with ID, regardless of the specific skill that is trained and the type of intervention that is provided. Further research is necessary to study the interventions' effectiveness more thoroughly, for example by examining what factors contribute to the effects of interventions.

Acknowledgements

We thank Jan Schoones of the Leiden University Medical Center for his help in developing the search strategy.

Appendix A. Search strategy

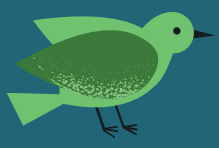
PubMed search strategy

((“Self Care”[majr] OR “self care”[ti] OR “self management”[ti] OR “self reliance”[ti] OR self relian*[ti] OR “Independent Living”[majr] OR “independence”[ti] OR “indepedent”[ti] OR “daily living skills”[ti] OR “daily living skill”[ti] OR “Activities of Daily Living”[majr] OR “adaptive functioning”[ti] OR “Self Efficacy”[majr] OR “self efficacy”[ti] OR “self-efficacy”[ti] OR “selfefficacy”[ti] OR “self efficacies”[ti] OR “self efficacious”[ti] OR “self efficiency”[ti] OR “self efficient”[ti] OR “self efficiently”[ti] OR “self regulation”[ti] OR “self regulated efficacy”[ti] OR “ability to function”[ti] OR “functional capacity”[ti] OR “coping ability”[ti]) AND (”Intellectual Disability”[majr:noexp] OR ”Intellectual Disability”[ti] OR ”Intellectual Disabilities”[ti] OR ”intellectually disabled”[ti] OR ”Mental Retardation”[ti] OR ”Mental Retardations”[ti] OR ”Mental Deficiencies”[ti] OR ”Mental Deficiency”[ti] OR ”mentally disabled”[ti] OR ”mental disability”[ti] OR ”mental disabilities”[ti] OR ”mental handicap”[ti] OR ”mental handicaps”[ti] OR ”mentally handicapped”[ti] OR ”mentally retarded”[ti] OR ”developmental disability”[ti] OR ”developmental disabilities”[ti] OR ”neurodevelopmental disability”[ti] OR ”neurodevelopmental disabilities”[ti] OR ”development disability”[ti] OR ”development disabilities”[ti] OR ”multiple disabilities”[ti] OR ”learning disabilities”[ti] OR ”learning disability”[ti]) AND (“Clinical Study”[Publication Type] OR “Clinical Studies as Topic”[Mesh] OR “trial”[tw] OR intervention*[tw] OR “training”[tw] OR “Evaluation Studies as Topic”[mesh] OR “Evaluation Studies” [Publication Type] OR “Validation Studies” [Publication Type] OR “Validation Studies as Topic”[Mesh]) NOT ((“Adolescent”[mesh] OR “Child”[mesh] OR “Infant”[mesh]) NOT (“Adult”[mesh] OR “Aged”[mesh])))

Appendix B. Description of applied Behavioural Change Techniques

Behavioural Change Technique	Description
Applied by the participant	
Self-instruction	Person instructs himself (aloud or silently) before or during execution of the target behaviour to encourage, support, and maintain action.
Self-recording	'Self-monitoring of behaviour': Person keeps a record of specified behaviour(s) as a method for changing behaviour (Michie ***et al.*** 2011).
Self-monitoring	Similar to self-recording, except that the executed behaviour is not recorded, but merely monitored by the person in relation to the desired outcome.
Self-evaluation	'Review of behavioural goals': A review or analysis of the extent to which previously set outcome goals were achieved (Michie et al. 2011).
Self-reinforcement	'Rewards contingent on effort or progress towards behaviour': The person uses praise or rewards for attempts at achieving a behavioural goal (Michie et al. 2011).
Use of cues	'Use of prompts/cues': Person is taught to identify environmental prompts which can be used to remind him to perform the behaviour (Michie et al. 2011).
Applied by the provider	
Chaining	The target behaviour is broken down into smaller steps ('behaviour chains'). The person gradually learns to perform the target behaviour by subsequently building one step onto the previous learned step(s) in the sequence.
Compensatory techniques	Using new approaches to execute the target behaviour by working around/compensating for the difficulties.
Environmental restructuring	'Environmental restructuring': The environment is altered in ways so that it is more supportive of the target behaviour (Michie et al. 2011).
Feedback	'Provide feedback on performance': Providing the person with data about their behaviour or commenting on a person's behavioural performance (Michie et al. 2011).
Corrective	Providing feedback in which errors are corrected.
Instructive	Providing feedback in which the person is told how the target behaviour should have been performed.
Descriptive	Reviewing the performance of the person, without attaching any value to this.
Praise	Expressing admiration or approval, giving compliments to the person.

Behavioural Change Technique	Description
Applied by the provider	
Generalisation	'Prompting generalisation of a target behaviour': Once a behaviour is performed in a particular situation, the person is encouraged or helped to try it in another situation (Michie et al. 2011).
Instructions	'Provide instruction on how to perform the behaviour': Telling the person how to perform a behaviour or preparatory behaviours, either verbally or in written form (Michie et al. 2011).
Modelling	'Model/demonstrate the behaviour': Showing the person how to perform a behaviour (Michie et al. 2011).
Physical guidance	Performing the target behaviour together with the person, while physically guiding the person through the correct response.
Prompts	Providing the person with a cue to elicit the correct behaviour.
Reinforcement	'Provide rewards contingent on successful behaviour': Reinforcing successful performance of the target behaviour. The reward/ incentive must be explicitly linked to the achievement of the specific target behaviour (Michie et al. 2011).
Roleplay	Rehearsing the target behaviour with the person by acting in a simulated situation.
Shaping	'Shaping': Graded use of contingent rewards over time to encourage the execution of the target behaviour (Michie et al. 2011).



Chapter 3

Promoting independence of people with intellectual disabilities: A focus group study. Perspectives from people with intellectual disabilities, legal representatives, and support staff

Accepted for publication:
Sandjojo, J., Gebhardt, W.A., Zedlitz, A.M.E.E., Hoekman, J., Den Haan, J.A. & Evers, A.W.M. (2018). Promoting independence of people with intellectual disabilities: A focus group study. Perspectives from people with intellectual disabilities, legal representatives, and support staff. *Journal of Policy and Practice in Intellectual Disabilities.* doi: 10.1111/jppi.12265

Abstract

People with intellectual disabilities (ID) commonly struggle with managing their affairs, while they consider it important to be independent. This study aimed to gain insight into the perspectives of people with ID, legal representatives, and support staff on promoting independence in this population. Two focus groups were conducted with people with ID (n = 7), two with legal representatives (n = 13), and three with support staff (n = 17). Topics included the meaning of independence, the current level and needs of people with ID regarding their independence, and what they perceived as barriers and requirements when wanting to promote independence in this group. Possible outcomes of a greater independence of people with ID were also discussed. Verbatim transcripts were analysed qualitatively with a general inductive approach. According to the respondents, people with ID require support from others, but most want to be more independent. Various barriers are experienced when trying to promote independence. These concern barriers at the level of support staff (e.g., lack of time), family (e.g., taking over tasks), and of the persons with ID themselves (e.g., emotional difficulties). When promoting independence in this population, more support and time seem necessary, as well as a clear, step-by-step, tailored approach and good communication between all parties involved. Last, several advantages (e.g., greater self-worth) and risks (e.g., overestimation by others, greater exposure to hazards) were proposed that could result from a greater independence of people with ID. As this study showed that people with ID generally want to become more independent, this stresses the need for the development of interventions, which could benefit from the findings from this study.

Keywords: focus group, independence, intellectual disabilities, self-management, self-reliance.

Background

Most people with intellectual disabilities (ID) struggle with managing their affairs independently [5, 23] and are therefore often at least somewhat dependent on the support from family and care staff [6, 7]. The struggles of people with ID can range from difficulties with personal care and household activities, to trouble with community participation and employment [22-24]. However, being independent is valued by people with ID [3] and a greater level of independence has been related to increased feelings of happiness and satisfaction [2] and higher quality of life [4, 5].

The United Nations [18] have declared that people with ID should be enabled to live as independently as possible. Several countries are urging all their citizens to do as much as possible themselves. For example, in the Netherlands a recent shift has taken place from a 'welfare state', in which the government is primarily responsible for citizens' well-being, to a 'participation society', where people first have to try to take care of themselves and their network, before they can turn towards governmentally provided care. In relation to this, the Dutch mental health care system has experienced many changes, cuts, and savings over the past couple of years, and support staff experience increasing difficulties to meet the care needs of their clients [19]. This all stresses the importance of fostering independence in people with ID.

Independence, just as self-reliance[1], is a term that involves the abilities to take actions to manage one's affairs and to provide for oneself. This entails relying on one's own efforts, resources, judgement, and abilities, without requiring support from others [54]. Both independence and self-reliance can be regarded as a part of self-management, which refers to a variety of activities related to deliberately changing or maintaining behaviours to achieve self-selected outcomes [25]. Self-management thus also includes self-determination, which has been described as the volitional actions that enable one to act as the primary causal agent in one's life, thereby having personal control over one's choices and actions [e.g., 26, 27, 28]. Independence can be seen as a continuum, with total dependence at one end and complete independence at the other extreme [46]. No one is completely independent in all areas, which also goes for people with

1 We used only one Dutch term ('zelfredzaamheid') in our focus groups, which translates into both independence and self-reliance. In this article, we will use the term independence, whereas the term self-reliance could be used as well.

ID. However, one can aim at guiding people with ID towards the most optimal level of independence that is attainable for an individual.

Little research has focused on how to promote the overall level of independence in people with ID. Previous studies mostly focused on teaching specific skills, such as setting the table [103], extinguishing a fire [104], withdrawing cash [64], and grocery shopping [30]. Many of these previous studies had small sample sizes, no control group, and widely varying goals, designs, and outcome measures [12, 23, 57]. This makes it difficult to draw firm conclusions about which intervention elements are critical for effectiveness. Nevertheless, Storey [57] concludes from his review that interventions need to be tailored to the individuals' specific needs and context. This finding is supported by several qualitative studies on self-management of illness and health in people with ID [3, 6, 8]. Several ways of tailoring to people with ID are suggested: providing information visually, using easy-to-understand language, and ensuring sufficient time and repetition. It is also claimed that the promotion of self-management needs to be embedded in an ongoing, lifelong form of education and support [6]. Lastly, it is suggested that it is also important to involve relatives and professional carers who support people with ID in their self-management process [6, 8].

To tailor interventions effectively, insight is needed into the preferences and resources of people with ID, and their individual, interpersonal, and environmental barriers [3, 37]. Although the abovementioned studies [3, 6, 8, 57] provide some important clues, when it comes to promoting the overall level of independence of people with ID still too little is known about these issues. To create a better understanding of how to promote independence in people with ID, 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. The first aim of our study was to explore what these three groups of respondents regarded as independence and what they considered to be the current level and needs of people with ID regarding this domain. Second, the aim was to gain insight into which barriers respondents experienced when wanting to promote independence and what they perceived as requirements for increasing the level of independence amongst people with ID. Lastly, we aimed to examine what respondents thought could be possible advantageous and disadvantageous outcomes of people with ID having a greater level of independence.

Method

This study was the first to obtain the perspectives of people with ID, their legal representatives, and support staff on various topics that concern the promotion of independence in people with ID. These three different viewpoints of the most relevant stakeholders were included to create a broad perspective on the theme of 'independence'. Perspectives were collected by conducting focus groups, which were held separately for the three different groups of respondents to ensure everyone felt free to speak their minds, without having to worry what respondents from the other groups might think.

Ethical issues

The Medical Ethics Committee of the Leiden University Medical Center evaluated the study protocol and declared that neither formal medical ethical approval, nor written informed consent was required (registration number P15.037, P15.300, P16.268).

Recruitment of participants

Three different participant groups were approached: people with ID and legal representatives and support staff of people with ID. All participants were recruited at Raamwerk, a care organisation for people with ID in Noordwijkerhout, the Netherlands. The participants with ID were living in one of the community-based residential facilities of Raamwerk, received day care at Raamwerk, or both. They were previously diagnosed with an ID, based on the criteria from the fourth edition of the Diagnostic and Statistical Manual of mental disorders [105].

For the recruitment of people with ID, support staff helped to select adults who had sufficient language abilities and who did not have severe behavioural or emotional problems that would make participation too demanding for them. Fourteen people with ID were eligible, who were all informed about the study by their personal tutor. Nine agreed to participate. If they had a legal representative, this person was informed and asked for verbal informed consent as well by phone. Representatives were also sent an information letter in which the purpose and the procedure of the focus group were explained again. Participants with ID received a similar, but more accessible letter with shorter sentences containing easy-to-understand information. Textual information was supported by pictograms and in addition, photos were displayed to introduce the moderator and the primary researcher who would attend the focus group. Providing accessible information was previously reported as a good practice method for inclusive

research with people with ID [106]. For the focus groups with legal representatives and support staff, we contacted all people who were representing or supporting a person with ID who participated in an earlier study [54]. Legal representatives were approached by phone and support staff were informed during team meetings. Both staff from group homes as well as from day care services were approached and asked to participate on a voluntary basis, which they were allowed to do during work hours.

Participants

Although nine people with ID agreed to participate, one was unable to attend due to illness and another person forgot the appointment. Thus in total, seven people with ID participated. One participant lived in a group home and the other six lived semi-independently in their own apartment with ambulatory support. Information about their level of ID was obtained from their electronic client records. Two participants had borderline ID, the other five had mild ID.

The 13 participating legal representatives all supported adults with ID. Almost all were relatives of the person they were representing, except for one professional mentor who was appointed by the court. Based on the electronic client records it was found that one participant represented a person with borderline ID, nine represented persons with mild ID, two represented persons with moderate ID, and one represented a person with moderate to severe ID. Four legal representatives were relatives of participants with ID who also took part in this study.

The 17 participating support staff members all worked with adults with ID, either in group homes or in day care services that were intended for people with borderline to moderate ID, with the majority of clients being previously diagnosed with mild ID. Eleven staff members supported someone with ID who also participated in this study. All staff members worked several days per week with people with ID. Their years of work experience with people with ID varied from 5 to 33 years (M = 15.13; SD = 9.28).

Data collection

As this study was conducted in collaboration with Raamwerk, data collection took place at this location. Two focus groups were held separately for people with ID, two for legal representatives, and three for support staff. Participants were distributed based on their availability and with the group size in mind [107]. All focus groups lasted about two hours. They were chaired by an independent moderator with ample experience in the field

of ID who was not acquainted with the participants (JH or TJ). The primary researcher (JS) observed all meetings, but did not actively participate. Prior to all focus groups, participants were informed that the discussion would be audio-recorded and that the data would be handled anonymously and confidentially. Verbal informed consent was obtained from all participants. No incentive was given for participation. Each focus group started with an introduction round. The moderator then continued with a semi-structured discussion with open-ended questions and participants were encouraged to actively share their opinions and to respectfully respond to each other. The focus group topics were selected by a group of experts, including researchers and employees of Raamwerk, during several earlier discussions. Topics were chosen based on questions we would like to have answered that would aid the design of interventions that promote independence in people with ID. The discussion topics included the definition of independence, the current level and needs of people with ID regarding their independence, experienced barriers and requirements when promoting independence in this population, and possible advantageous and disadvantageous outcomes of a greater independence. More details about the discussed topics can be found in Appendix A.

The focus groups with participants with ID were slightly adapted, based on good practice methods for inclusive research [106]. Accessible language was used and questions were printed in a booklet, in which also pictograms, illustrations, and photos were used to visually represent the questions. For example, a pictogram of a tape recorder was used to explain that the focus group would be recorded and an image of a wall that blocked someone's way was used to illustrate the topic of barriers. This adapted method was first piloted with two people with ID, who did not take part in the focus groups. This pilot indicated that no further adaptations were necessary. During the focus group discussions with participants with ID, responses were written on a flipchart and were repeated and summarised from time to time.

Data analysis

All focus groups were transcribed verbatim. Data analysis was facilitated by ATLAS.ti 7.5.6 software. The separate topics of the focus group discussions served as a framework for the analysis (Appendix B). Two coders (JS together with AvR or MG) independently listened to the recordings, while reading and coding the transcripts. For everything that was said, coders evaluated to which topic this was related, what the essence of the quote was, and what code would fit best. For example, the quote "I think that when you're more independent, you feel more confident about yourself" related to the topic of 'advantages',

concerned the theme 'feelings', and was assigned the code 'self-confidence'. After coding all focus groups, discrepancies between codes were discussed until consensus was reached. The discussion entailed that both coders gave arguments as to why they assigned a certain code. In case disagreement remained, a senior researcher (WG) was asked to participate in the discussion and to make a final decision. The definitive codes of all focus groups were analysed with a general inductive approach [108] where main themes were inductively derived from the data by looking at how extensively they were discussed. For some themes, subthemes emerged. For example, the quote "We have the feeling support staff have too few opportunities to support us" belonged to the main theme of 'barriers at the level of support staff' and more specifically to the subtheme 'lack of time'. To compare the results from the three different groups of participants, we analysed what the extensively reported (sub)themes were for each of the groups and whether these differed from those reported by the other groups. To ensure the robustness of our analysis, we also crosschecked for each (sub)theme that emerged by which group of participants this was put forward.

Results

Participants

The characteristics of the composition of the seven focus groups are presented in Table 1.

Table 1 Characteristics of the focus groups

	Group size, n *(n male)*	**Age in years, range (*M; SD*)**
People with ID no. 1	4 (*3*)	26.6 – 64.1 (*40.4; 16.9*)
People with ID no. 2	3 (*3*)	27.9 – 29.9 (*29.1; 1.1*)
Legal representatives no. 1	8 (*4*)	51.1 – 85.1 (*66.0; 10.8*)
Legal representatives no. 2	5 (*3*)	51.7 – 64.8 (*57.4; 5.1*)
Support staff group homes no. 1	4 (*0*)	24.2 – 53.1 (*37.1; 12.4*)
Support staff group homes no. 2	8 (*2*)	24.1 – 51.4 (*37.7; 11.5*)
Support staff day care	5 (*3*)	25.4 – 50.2 (*34.0; 10.5*)

Results of the focus groups

The results are discussed per topic and for the entire sample as a whole, as there were few differences between the perspectives of the three different groups of respondents. The emerged themes that were most extensively discussed by all three groups of

respondents are described first. Wherever applicable, it is specified when only one or two groups of respondents put forward a particular theme. The topics that were addressed concerned the conceptualisation of the term independence, the current level of independence of people with ID, the needs of people with ID regarding their independence, the experienced barriers and the requirements when wanting to promote independence in this population, and the advantageous and disadvantageous outcomes of people with ID having a greater level of independence. The derived themes and subthemes can be found in Appendix B. In Appendix C, several illustrative quotes are listed per topic.

Concept of independence

The first topic concerned what participants understood as 'independence'. All three groups of respondents expressed that independence is a broad concept, covering various aspects. It encompasses knowledge about how to do things, the abilities to perform actions, and taking care of oneself. Many participants stated that independence means doing things yourself. However, some viewed that being independent also means asking for help if you cannot do something yourself. Several participants with ID also talked about managing one's time and appointments. Legal representatives furthermore considered that independence means drawing boundaries regarding what you want and do not want, and what you can and cannot handle.

Level of independence

The level of independence of people with ID was reported to be highly variable. Some need help with basic Activities of Daily Living (ADL), whereas others can live independently with only some ambulatory support. It was agreed by all groups of participants that all people with ID need at least some support. However, various skills were described as well, for example concerning household activities, personal hygiene, and grocery shopping. In addition, legal representatives and support staff stated that the level of independence of the people they were supporting was already increasing and that they constantly notice a development in skills. They also felt that there was still a lot of room for growth for people with ID to develop many skills.

Independence-related desires

Participants with ID, legal representatives, and support staff agreed that most people with ID have the desire to become more independent. When asked what they would want to learn, various things were proposed. In general, it was said that people with ID

just want to lead the 'normal' life of other people their age and that they want to live independently. Several specific needs, such as obtaining a driver's license were also described. Some participants with ID considered in addition that they would like to learn to better deal with their emotions and to obtain a regular employment, where they can work independently. On the contrary, support staff indicated that a few of their clients do not feel the need to become more independent as they like being taken care of.

Barriers and requirements

Amongst all participants, a lack of time for support staff was one of the most frequently discussed barriers that hinder people with ID from becoming more independent. If staff members do not have sufficient time, they are more easily inclined to take over tasks from people with ID, because they can do it faster themselves. However, if they have more time they could use this to teach people with ID new skills. Legal representatives put forward another barrier concerning support staff, which is that staff sometimes lack the knowledge and skills on how to properly guide people with ID. Representatives also expressed that the high turnover of staff is a barrier. Additional barriers mentioned by staff members are fear amongst staff that things could go wrong if people with ID do more independently and staff having the tendency to take over tasks from clients.

Barriers at the level of the family were also identified, mostly by support staff. Family members can be controlling and also tend take over things that people with ID could learn to do themselves. At the level of the person with ID, barriers mostly concern difficulties in emotional and cognitive functioning. For example, anxiety, sadness, or a lack of concentration can make it more difficult for someone with ID to become more independent. Lastly, the situation a person with ID is currently in and whether there are already many changes going on might also hamper someone from becoming more independent as such a situation might already be too overwhelming.

Several requirements for promoting the level of independence of people with ID were identified. The necessity of more time and support (staff) was put forward by all three groups of respondents, as this would create more opportunities to guide people with ID towards a greater level of independence. A clear, univocal approach and adequate communication were almost exclusively put forward by legal representatives and support staff. They stated that all staff and family members must be in line with each other on how to support a person with ID in becoming more independent, which requires good communication, also with the person with ID. Moreover, legal representatives and support

staff claimed that a tailored, individualised, step-by-step plan is required. This means, amongst others, adapting to an individual's level of functioning, interests, learning goals, and speed of learning, and taking small steps to reach a personal goal. Staff furthermore need to possess proper knowledge and skills, for which training would be necessary.

Advantageous and disadvantageous outcomes

Being more independent would have several advantages for people with ID. All three groups of respondents mentioned a greater self-confidence, self-worth, and sense of pride as an advantageous outcome, additional to a better mood. Although some participants with ID said not much would change if they would be more independent, others stressed that they would have increased opportunities to make their own decisions. Support staff moreover felt that the type of support that people with ID receive would change if they would be more independent. They explained that staff would have to spend less time on providing practical support and would have more time for personal contact.

Only a few disadvantages of a greater independence were mentioned, mostly by participants with ID, who expressed that they would then be all on their own, leading to loneliness and having to solve everything themselves. Legal representatives and support staff mainly described several risks. If people with ID would be more independent, they might get more freedom to go out into the community by themselves, thereby becoming exposed to all kinds of hazardous situations, such as exposure to drugs. Another risk concerned overestimating people with ID. If a person with ID is more independent, others might assume that this person is capable of even more, as a result of which they might place demands on this person that are too high. Representatives and staff indicated that this could in turn possibly lead to emotional disturbances such as anger and aggression, and even a relapse in functioning.

Discussion

The aim of this study was to obtain insight into the perspectives of people with ID, their legal representatives, and support staff on various topics concerning independence of people with ID. By combining these three perspectives we were able to create a more comprehensive understanding of these topics. In sum, it was found that all people with ID need at least some support, but that most would like to become more independent. Several barriers are experienced when trying to promote their independence. Barriers

include that support staff do not have enough time to guide people with ID, might not know how to promote independence, or are afraid things might go wrong if people with ID handle things more independently. Both staff and family members furthermore have a tendency to take over tasks from people with ID, which limits the opportunities for them to learn to do things themselves. To promote independence it was reported that more time and support are required, as well as a clear, individualised, and stepwise approach, and adequate communication between all parties involved. Although a greater level of independence could have some negative outcomes, such as an increased risk of overestimation and exposure to hazards, several advantages for people with ID were also proposed, such as feeling more confident and proud.

Overall, independence was regarded as a broad concept by the respondents, involving the knowledge and abilities to take care of your affairs yourself. This closely resembles our aforementioned definition, in which we stated that independence concerns: "the abilities and actions to manage your own affairs and to provide for yourself, without requiring support from others". In this study however, some respondents also stated that independence includes asking help from others if you cannot handle something yourself.

The level of independence of people with ID was experienced to vary greatly, especially by staff. Although various skills were described, everyone agreed that all people with ID require at least some support from others. This is congruent with previous studies [6, 7]. Even though staff reported that a small minority of their clients might not feel the need to become more independent, staff and legal representatives expressed that most people with ID would have both the desire and the ability to become more independent. This desire was also expressed by participants with ID. Generally, it was said that most people with ID just want to lead a 'normal' life, in which they can live, work, and travel independently, just as people without ID. This is in line with previous qualitative studies, in which people with ID stated that doing daily living activities independently is important to them and that they wish for a greater independence in the future, by learning skills such as cooking and travelling [1-3].

Obtaining a greater level of independence can be hindered by several barriers in practice. A frequently reported barrier concerned the lack of time for support staff to guide people with ID towards a greater independence. This is congruent with a study by Hermsen et al. [19], in which support staff also described a shortage of time and difficulties to meet the needs of their clients. However, quantity does not equal quality. It might not always

be about a lack of time, staff, or resources, but more about *how* resources are being used, *what* staff members do and *how* they do it [109]. Staff might lack the knowledge and skills to guide people with ID towards more independence, which was expressed as a barrier in our study by legal representatives. Another reported barrier concerned fear amongst staff, and family members being overprotective. Supporting people with ID concerns walking a fine line in promoting their autonomy, while protecting them from possible risks [42]. Regulations that exist because of these perceived risks and the tendency of staff and family to take over limit the opportunities for people with ID to develop independent skills [43-46], which may in turn actually foster dependence, as well as passivity and learned helplessness [5].

Barriers were said to exist at the level of the persons with ID themselves as well. These mostly concerned difficulties in cognitive and emotional functioning, and in handling more demanding situations. The global intellectual deficits of people with ID [9], as well as emotional difficulties, stress, and stressful situations [45] can negatively affect their functioning and make it more difficult for them to become more independent. These emotional difficulties could include fear to do things independently or difficulties with handling the consequences and responsibilities belonging to a newly acquired skill. Especially in an already demanding or stressful situation, people with ID were said to have even more difficulties with handling things independently, as these situations are already too overwhelming for them cope with.

When asked what would be necessary to overcome these barriers and to increase the level of independence of people with ID, several things were proposed. Requirements for promoting independence in people with ID, included a clear, univocal approach, and adequate communication between all people involved, including the person with ID. If everyone is united on how to guide a person with ID, it is also clear to everyone what to do and what to expect, which could benefit the promotion of independence. Another reported requirement, convergent with previous studies [3, 6, 8, 42], is a tailored, individualised approach, next to a step-by-step plan. This can be achieved by adapting to an individual's level, goals, and speed of learning. In addition, respondents from all three groups proposed that more time and support (staff) would be required. This could help staff who now lack time to guide people with ID towards more independence, which was earlier defined as one of the main barriers. Support from others was also expressed as an important factor for self-management in some previous studies [6, 8]. Although an initial investment in more time and staff might be necessary, in the long

term it could actually save time and money, once people with ID have learnt to do more themselves. A final requirement that was considered was that staff must possess the right knowledge and skills for promoting independence in people with ID. This could be achieved through proper training. Such a training should not only consist of an in-service classroom training, but also of coaching-on-the-job and verbal feedback [110].

Lastly, it was explored what the outcomes would be if people with ID would be more independent. Several advantages were listed, amongst which a greater self-confidence, self-worth, sense of pride, and a better mood. In addition, some participants with ID thought of more opportunities to make their own decisions. This individual autonomy, which includes the freedom to make one's own choices, is not only valued by people with ID [44], but is also one of the leading principles of the United Nations' Convention on the Rights of Persons with Disabilities [18]. Almost no disadvantages were identified, apart from the notion that people with ID might become more solitary. Possible risks were however frequently described, mainly by legal representatives and support staff. They were concerned that too high demands would be placed on more independent people with ID (due to overestimation by others) and that they would be more exposed to risky aspects of life and of society. Especially those who are living by themselves or who are afforded more community independence are more vulnerable and susceptible to abuse, theft, and assault [1, 111, 112]. This is because they are often unaware of the risks in vulnerable situations or because they are unable to deal with them effectively [111, 112]. Therefore, this should be watched closely when promoting independence in people with ID.

This study is the first to combine the views of both people with ID, legal representatives, and support staff on promoting independence. By considering these three perspectives a valuable contribution is offered to the understanding of how independence can be promoted in this population. Nevertheless, this study also has some limitations. The sample was small and only included people affiliated to one care organisation. Furthermore, although our aim was to assemble a heterogeneous group of people with ID, mostly men with borderline to mild ID participated who were already relatively independent. Thus, this study did not include the views of people with more severe levels of ID or with difficulties in communication and group interaction. Altogether, this means that our findings cannot be generalised to the entire population of people with ID. This calls for a broader study with a larger sample, involving several care organisations across countries, thereby also including people with more severe levels of ID and with communication

and social difficulties. Another suggestion for future research concerns interventions that aim to promote independence in this population. These interventions do not only have to be targeted at people with ID, but could also be directed at support staff and family members. It seems that interventions need to take several barriers and risks into account. Furthermore, adequate communication is required between all parties involved, just as a univocal, tailored, and stepwise approach. As this study showed that most people with ID wish to become more independent and that a greater level of independence could have several advantageous outcomes, this stresses the need for the development and evaluation of these types of interventions, which could benefit from the assorted insights acquired in this study.

Acknowledgements

We thank all the participants of our focus groups, moderator Trudy Janson, research assistants Arthur van Rhijn and Marlou Gosman, and Rebecca Schaefer for their contribution to the study.

Appendix A. Focus group questions

Topic	Question for people with ID	Question for legal representatives and support staff
Concept of independence	What do you think independence means? What is independence?	What do you mean by independence?
Level of independence	How independent are you? What can you do yourself? With what things do you still need help from others?	How independent are the people you are representing/supporting?
Independence-related desires	Would you want to become more independent? If so, what would you want to learn?	Would the people you are representing/supporting want to become more independent? If so, what would they want to learn?
Barriers	Is there something that causes you to not be as independent as you would want? Is there something in the way?	What are current barriers that hinder people with ID from becoming more independent?
Requirements	What is necessary to become more independent? How can you be helped to achieve this? What needs to be done?	What is required in order to increase the level of independence of people with ID?
Advantages	What would be the advantages of more independence? Why would it be a good thing if you can do more yourself?	What would be the advantages of a greater level of independence?
Disadvantages	What would be the disadvantages of more independence? Are there also downsides if you can do more yourself?	What would be the disadvantages of a greater level of independence?

Appendix B. Derived themes and subthemes from the focus groups per topic

Topic	Theme	Subtheme
Concept of independence	Abilities and skills	Doing the housekeeping
		Grocery shopping
		Handling money
		Performing actions
		Planning your activities
	Acceptance	Accepting yourself
		Accepting criticism
		Accepting help
	Alone, by yourself	
	Asking for help	
	Behaving yourself	
	Broad concept	
	Different for each person	
	Drawing boundaries	
	Emotion regulation	
	Knowledge	About what you need
		About what to do (at work)
		About whom to ask for help
	Living by yourself	
	Making and keeping appointments	
	Social interaction	
	Taking care of yourself	
	Taking initiative	
Level of independence	Abilities and skills	Asking for help
		Cognitive abilities (e.g., telling time)
		Communication
		Cooking
		Coping
		Drawing boundaries
		Emotion regulation
		Filling in leisure time
		Getting dressed
		Grocery shopping
		Handling money
		Housekeeping, work in and around the house
		Living independently
		Making coffee
		Managing medication
		Perseverance
		Personal hygiene
		Planning
		Regular employment

Appendix B. Continued

Topic	Theme	Subtheme
		Social interaction
		Taking care of chickens
		Using public transportation
		Using own transportation (car, bicycle, motor scooter)
		Using the internet
		Waiting one's turn
		Withdrawing cash
	Already increasing	
	Need for support	Social interaction
	Room for growth	
	Variable	
Independence-related desires	Discipline	
	Doing the housekeeping	
	Emotion regulation	
	Making decisions	
	Managing medication	
	No desire	
	Normal life	Having a family
		Living independently
	Outdoor activities	
	Planning	Making appointments
	Reading and writing	
	Regular employment	
	Self-determination	
	Social contact	Listening to others
	Travelling/transportation	Driver's licence
Barriers	Current situation	
	Disagreement between staff and family members	
	External influences	Changes in the environment
		Group dynamics
	Family	Difficulties letting go
		Overprotective
		Taking over
	Lack of resources	Facilities
		Financial resources
	Limited transfer to daily life	
	Management team	
	More complex society	
	Person with ID	Age
		Autism spectrum disorder
		Busy schedule
		Cognitive disabilities

Appendix B. Continued

Topic	Theme	Subtheme
		Difficulties handling emotions
		Difficulties handling pressure
		Focus on hobbies
		Laziness
		Limited insight
		Limited motivation
		Limited self-confidence
		Losing patience
		(Performance) anxiety
		Personal history
		Social-emotional developmental level
	Restrictions of freedom	
	Support staff	Different ways of providing support
		Fear
		High turnover
		'Institutionalising' clients
		Lack of knowledge and skills
		Lack of time
		Own norms and values
		Taking over
		Working 'on autopilot'
	Taking too far steps	
Requirements	Attainable goal	
	Clear, univocal support	
	Communication	Being clear
		With family members
		With the person with ID
	Encouragement	Compliments
	Experiencing success	
	Family	Involvement
		Shared responsibility
	Patience	
	Perseverance	
	Person with ID	Insight
		Less focus on hobbies
		Less worrying
		Self-confidence
		Training
	Plan	Step-by-step plan
	Resources	Facilities
		Financial resources
	Setting the right example	

Appendix B. Continued

Topic	Theme	Subtheme
	Support staff	Advice and training
		Attitude
		Exchanging experiences
		Flexibility
		More staff
		One-on-one support
		Skills
	Tailoring to the individual	
	Taking risks	
	Time	
	Understanding the person with ID	Taking the person with ID's perspective
Advantages	Attaining goals	
	Health	
	Less behavioural problems	More mature behaviour
	Living independently	
	Making your own decisions	
	Mood	Happiness
		Less frustration
		Satisfaction
	Motivation	Wanting to learn more
	Participation in society	
	Peaceful life	
	Pride, self-worth	
	Self-confidence	
	Social interaction	Having a partner/family
	Taking care of yourself	
	Type of support	Less support needed
		Time for other types of support
	Work	
Disadvantages	Less support	Being on your own
		Loneliness
	Feeling unsafe	
	Mood	Tension
	No disadvantages	
	Risk	Difficulties defending oneself
		Drug abuse
		Emotional disturbance
		Psychosis
		Relapse in functioning
		Too high demands

Appendix C. Illustrative quotes from the focus groups

Topic	Theme *(Subtheme)*	Reported by*	Quote
Concept of independence	Broad concept	PID#1	Independence is something general. Something very broad. Living, working, leisure, learning.
		LR#12	That you can take care of yourself, mentally, physically, and socially.
		SM#1	That someone knows what to do to be able to do something.
	Asking for help	PID#4	Independence also means asking for help when cleaning the bathroom … That you ask for support yourself.
		LR#10	… that they [people with ID] know themselves, "This is beyond my limits, so I need to ask for help."
Level of independence	Highly variable	PID#4	There are all kinds of different degrees … One person can do this, but not that.
		SM#7	Some [people with ID] really won't manage. They can't even dress or undress themselves. Another person only partly needs help, how to make a shopping list, but that person is able to go to the store himself. Whereas for another [person], you need to accompany him to the store.
	Need for support	PID#6	In general, it all just goes really well, but I do need help with everything.
		SM#12	They [people with ID] can actually do a lot themselves, but everything is created by us to such an extent that they are able do it. As soon as we would withdraw, everything would relapse.
	Abilities and skills	PID#7	Washing, ironing, my household, cooking, grocery shopping … Even, um, that's going somewhat okay, I do still need some help with money.
	Room for growth	LR#10	She is very teachable, so you could teach her a lot.
		SM#4	A while ago we got a question from someone who wanted to manage his own medication … We started training and now it goes really well. So in fact, you're always working on teaching things … and that promotes independence.
Independence-related desires	'Normal' life	PID#6	My hobby, my work, and living. Those are the three things I would just like to do independently.
		SM#6	They want their own house, a family, to get married, possibly children … They actually want everything I have in my life … because that's just how it's supposed to be.
	No needs	SM#2	There are a couple, but then I'm talking about clients who have been pampered a lot at home, who are fine with sitting comfortably, while things are being arranged [for them].

Appendix C. Continued

Topic	Theme *(Subtheme)*	Reported by*	Quote
Barriers	Support staff		
	Lack of time	PID#4	There's not enough time. And too little staff, and therefore, too little time. As a result of which, they can't guide us enough.
		LR#7	Independence also has to do with having time for it. They are cutting back [on staff] more and more.
		SM#4	I would like to have a whole day to think about what I would want to achieve with a client, but I don't have time for that.
		SM#10	Literally, time of course also plays a role. No time is no independence … If you don't have time, then often independence is taken over to reach a goal. And that's not always in favour of the client.
	Fear	SM#12	… a lot of fear to let things go. When I come with a client and I say: "I would like to let him work outside of the institution." Then I get all these counter-arguments [from colleagues], because he might ruin the job for the next [client], if it doesn't go well.
	Taking over	SM#17	So many things were done for her in the past that she could've learnt and now still could learn, that she now I think just refuses to do. Because it was done for her all those years.
		SM#7	I am like, "Well, they're finished eating, put your plate on the kitchen counter." Then colleagues are like, "No, support staff takes care of that. We always clear the table." And I am like, "You can pick up your plate, you can walk, you can come to the kitchen counter, so bring it to the counter yourself. Preferably in the dishwasher as well." So as far as this is concerned, there's also a difference between staff members.
	Family	LR#9	You can be impeding or facilitating. For example, you may not want to let go of your control.
	Taking over	SM#3	We have one client, whose aunt is 'putting her claws' into everything. And everything we suggest or want to try out with him is immediately rejected: "He can't do that, that won't work." … We're now teaching him to do his laundry himself. And then you discover that his laundry was snatched away by his aunt.
	Person with ID		
	Emotional difficulties	PID#7	My angry moods. I then send people away, whereas I should actually let them in. As in, "Guys, I can't manage it anymore."
		LR#9	My son doesn't start with things, because he's afraid to fail. So that's his barrier.
		LR#12	You could teach her a lot, but deep down she's a little girl.
	Cognitive difficulties	LR#10	…that she's quickly fed up with it, because she has to think about it, concentrate.
	Current situation	PID#1	That so many things are going on, that you can't see the wood for the trees.
		SM#2	Let's say a client is going to change jobs in the meantime. Then with all due respect, we're not going to overload a client with 20 independence-things they could also learn.

Appendix C. Continued

Topic	Theme *(Subtheme)*	Reported by*	Quote
Requirements	More time and support	SM#7	Don't expect that something is already picked up within a month. Just give people the time to learn something.
		LR#7	Independence comes down to more time for the client and more money.
		SM#7	Availability. By that I mean, if you want to teach someone to go to the store, you will have to go the store with that person a couple of times, which means you can't be with the rest of the group at that moment … Then you need to have an extra staff member to take over the other three clients, so you have time to go with that person.
	Communication and clear approach	SM#7	If you have a plan to reach a goal, then you all have to work in the same way with a client. Because I can't, for example, when doing groceries, say: "Well, I will make a shopping list, if you make sure you have money and a shopping bag." And that someone else comes the next day and says: "I will take care of the bag and you make the list."
		LR#6	The only advice I can think of now is [to] keep communicating with clients' representatives, with support staff, with managers. Keep each other posted and exchange information … so it becomes clear what it should be like and how we can achieve that.
	Tailored, step-by-step plan	SM#13	It's indeed important to look at an individual, at your own client, and to listen well. What are the wishes and interests? Once you have identified that, you can anticipate much better on independence.
		SM#13	We're training, but that goes in very small steps. I mean, you do groceries at a store. First always at one store, then you extend it to two stores, to three stores, until that is routine. You build it up step by step and then you expand.
	Staff training	SM#12	I think that you also need clues as to how you will go about it, how you are going to teach clients to be more independent, by means of the right attitude and tools to teach someone something. Because it's not that easy.

Appendix C. Continued

Topic	Theme *(Subtheme)*	Reported by*	Quote
Advantages	Feelings	PID#1	Satisfied. Because then I have achieved what I wanted.
		LR#12	It's much more fun to do groceries by herself, than when someone goes with her. Because then she gets just a little of that self-confidence. As in, "Hey, look at me, I just did some groceries!"
		SM#2	Some [clients] become enormously happy when they do something themselves, they are literally cheering.
	Decision making	PID#7	Personally, an advantage is, I think, that you can just decide for yourself when you're going to do what. If you, so to speak, want to sit on your balcony, but you know staff are coming by to help with vacuuming, mopping, just to name a few, then you're tied to that. And then you're free, you can think, well the floor looks fine, I'll do it next week.
	Received support	SM#7	Once someone is more independent, you have less to do as staff … You're not supporting the ADL … You're teaching things, thinking of a step-by-step plan, you then have more time for that. You can shower Dick in half an hour or you can sit with Harry half an hour and look at grocery shopping, what do you need, this and that.
Disadvantages		PID#1	If you live independently, you don't have someone you can talk to or who gives you clever advice every day.
	Risks	LR#9	They wanted to make him [a client] more independent, but that went all wrong because they gave him too much freedom. Then he got all confused, because there were too little boundaries.
	Exposure to hazards	PID#1	You're exposed to all joys of life. You have to say no more quickly … Drugs, alcohol, cocaine, heroin, all that shit.
		SM#1	If they will do more things themselves, that involves all kinds of other things… In society, things could happen to them.
	Overestimation	SM#14	He is also a client you easily overestimate … Then he doesn't understand it at all, and then, well, he starts showing undesirable behaviour.
		SM#16	Then you ask too much from him, and then he relapses and then you have to heal those wounds.
		LR#10	We have literally experienced that she then was no longer able to handle, then she becomes aggressive, angry and cranky.
		PID#4	No, that's not good, not for me. I can relapse. If I relapse, then you can't go back that easily. That's also the problem. Because if it's not going well with me at that moment, because it was too big of a step, then try to get back.

*PID = Person with ID, LR = Legal representative, SM = Staff member

Chapter 4

Training staff to promote self-management in people with intellectual disabilities

Published as:
Sandjojo, J., Zedlitz, A.M.E.E., Gebhardt, W.A., Hoekman, J., Dusseldorp, E., Den Haan, J.A. & Evers, A.W.M. (2018). Training staff to promote self-management in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*, 840-850. doi: 10.1111/jar.12440

Abstract

Background: People with intellectual disabilities have increasing difficulties managing their daily affairs. This study examined the effectiveness of a staff training, which teaches staff to promote self-management in people with intellectual disabilities.
Method: Effectiveness was assessed with questionnaires addressing clients' (n = 26) independence and self-reliance, support needs, and challenging behaviour, using a pre-posttest control group design. Additionally, focus groups were conducted with trained staff members 6 months after the training.
Results: In the long term, the intervention group showed a significant increase in independence and self-reliance, in contrast to the comparison group. No effect was found on support needs and challenging behaviour. Trained staff members reported limited benefits of the training, but had noticed changes in their attitude and method of working afterwards.
Conclusions: Further self-management research is required to investigate how independence and self-reliance can be promoted more effectively in this population. Future trainings should carefully consider their content, format, and implementation.

Keywords: independence, intellectual disabilities, self-management, self-reliance, staff training, support need.

Introduction

People with intellectual disabilities (ID) commonly have difficulties managing their own affairs [5, 52]. This can pertain to many aspects of daily living, from taking care of their personal hygiene and their household, to dealing with social interactions and employment [22, 24, 52]. Therefore, people with ID often have to rely on others [6, 7]. This does not only pose everyday challenges for these individuals, but also for their families and health care providers.

While there is a growing view that people with ID should participate as fully as other members of society [11, 18, 113], our society is also becoming more complex. Social developments, such as higher demands at work and the digitalisation of our society, are considered a main explanation for the increasing difficulty of people with ID to function independently [11]. Partially as a result of these developments, the demand for care for people with ID has grown considerably over the past few years in several north western European countries [11]. Possibly related to this, the costs for the care for people with ID have greatly increased as well [20] and support staff experience increasing difficulties to meet the care needs of their clients [19]. As different countries have different, and sometimes restricted, budgets and care systems, this could mean that people with ID do not always have sufficient access to the increasing amount of care they need. Altogether, this requires support staff to focus on promoting self-management in people with ID, in order to make them more independent and self-reliant [11, 114].

Broadly, self-management refers to a variety of activities that are related to deliberately changing or maintaining behaviours in order to achieve self-selected outcomes [25]. It can be seen as an overarching term, related to concepts such as self-determination, autonomy, independence, and self-reliance. Self-determination and autonomy are centred around 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., 28, 115]. Independence and self-reliance involve abilities to take actions to manage one's own 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.

Previous research on self-management in people with ID has focused mainly on specific behaviours or domains. For instance, various studies have concentrated on health behaviour [e.g., 6, 8, 13, 33], work-related activities [56, 57], challenging behaviour [e.g., 116, 117-119], self-instruction [e.g., 24, 99], and the use of technology [23, 39]. What is valuable for people with ID in terms of self-management is that they learn to do more by themselves, thereby becoming more independent and self-reliant. This is important, as this could enhance their overall quality of life and their participation and inclusion as equal and valued co-citizens [4, 5], which could lead to reductions in behavioural problems [53]. Furthermore, it could decrease their demand for professional care and the burden that is experienced by family members [7, 50].

So far, little self-management research has been directed at improving overall independence and self-reliance in people with ID. However, several studies have focused on teaching individual skills to people with ID that would lead to improvements in these domains, such as teaching safety skills [104, 120, 121], food preparation [122, 123], and setting the table [71, 103]. A few intervention studies from the field of occupational therapy have also been conducted, which focused on (instrumental) activities of daily living [72, 83, 124]. Although they showed some promising results, limitations such as a small sample size and a limited number of trained activities impede the generalisability of the findings. Whether these approaches would also be effective and applicable to promoting overall independence and self-reliance has not been investigated.

There is also a lack of research focusing on how support staff can be trained to improve their clients' level of independence and self-reliance. If support staff stimulate clients to do things themselves, instead of taking over, this could reduce clients' dependency, passivity, and 'learned helplessness' [5], regardless of whether someone has a mild or severe ID [23]. Several studies have investigated person-centred active support, an approach directed at active engagement and participation in meaningful activities [e.g., 125, 126, 127]. Although this approach could enhance the ability of people with ID to manage (parts of) tasks independently, it is not its primary aim. What staff can do to effectively target overall independence and self-reliance has not been studied. In general, research on staff training in the field of ID has put forward the importance of practice leadership. Good practice leadership can lead to better implementation of a staff training, as a practice leader enables, encourages, coaches, and reviews staff in order to ensure good support [128]. Coaching was also found to be important in a meta-analysis by Van Oorsouw et al. [110]. They 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. 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]. Whether practice leadership and coaching-on-the-job are also essential for training staff to promote self-management is yet unknown.

The current study is the first to evaluate the effectiveness of a staff training aimed at promoting overall self-management of people with ID. The methodology of the training is called 'On Your Own Two Feet' [130] and is based on the method of Feuerstein [131] and the 'Own Initiative Model' [132]. Inspired by Seligman's positive psychology [133], staff are taught to focus on clients' abilities, instead of disabilities, and on expanding these abilities. By letting clients perform tasks that are within their zone of proximal development, staff facilitate their learning process [134]. According to the methodology, staff need to encourage clients to think and handle things themselves. This approach thus targets clients' general problem solving skills by teaching them to find the answers to their own questions, which could also help them become more independent and self-reliant [99, 101]. The idea is that teaching such a pivotal skill as general problem solving is more efficient than teaching someone a specific skill, since it could generalise more easily to untrained skills [24].

The primary aim of the current study was to investigate whether the staff training 'On Your Own Two Feet' [130], which promotes self-management, was effective in increasing the level of independence and self-reliance of people with ID and whether it would decrease the amount of required support. It was also hypothesised that the training would reduce the occurrence of behavioural problems. The secondary aim of the study was to explore the opinions of trained staff members regarding the effectiveness of the training.

Method

Procedure

The Medical Ethics Committee of the Leiden University Medical Center evaluated the study protocol and declared that no formal medical ethical approval nor written informed consent was required, because the study did not fall under the Medical Research Involving Human Subjects Act. All participating people with ID, their legal representatives and support staff were informed about the study beforehand. People with ID and their legal

representatives were informed by letter and were invited to an information meeting. Staff were informed during team meetings. They were notified that all data would be handled confidentially and anonymously for the purpose of a scientific study and publication. They were given the opportunity to ask questions for further clarification. People with ID or their legal representatives could decline participation. If someone would have objected to participation, the person in question would have been excluded from the study. However, no one declined. As this study was conducted in collaboration with Raamwerk, a health care organisation in Noordwijkerhout, the Netherlands, data collection took place at this location. Preceding the training sessions (T0), questionnaires about the participating people with ID were filled in. This was repeated 3 (T1) and 6 months (T2) after the training.

In addition, 6 months after the training, focus groups were held with trained staff members to evaluate the training and to see whether they had experienced any changes in the past half year. Trained staff members were informed about the focus groups during their team meeting and were asked to participate on a voluntary basis. They were told beforehand that the data from the focus groups would be handled confidentially and anonymously, and that it would be used for the publication of a scientific study. Participation occurred during work hours.

Staff training

In total, 28 staff members (11 men and 17 women) received the training in promoting self-management. They worked either as support staff in group homes (n = 17) or day care services (n = 10), or as a remedial educationalist (n = 1). Their ages ranged from 23.24 to 59.24 years (mean [M] age = 33.26; standard deviation [SD] = 9.47), the years of work experience with people with ID varied from 2 to 20 years (M = 9.45; SD = 4.29). They were divided into three groups that received the training on three different occasions. The training was provided by professional trainers who were instructed by the developers of the training and who all had experience in the field of ID.

The training that was provided is called 'On Your Own Two Feet' ('Op Eigen Benen' in Dutch) and is developed and described in greater detail by Scholten and Schuurman (2008). During the 2 consecutive days of the classroom training, lasting about 12 hours in total, staff are provided with a theoretical framework of the methodology and participate in exercises and role-play to practice different techniques. They start with evaluating and discussing their current attitudes and ways of providing support when working with

people with ID, by means of a self-report questionnaire. Next, the philosophy behind the methodology is explained, which is based on the method of Feuerstein [131], the 'Own Initiative Model' [132], positive psychology [133], and the zone of proximal development [134]. The ideology concerns looking at people with ID as unique individuals and having a positive attitude towards them by focusing on each person's strengths, capacities, abilities to learn, and way of learning. This is illustrated by an exercise to show that each individual has his or her own talents and that an individual approach is therefore necessary. In another exercise, staff are trained to rephrase difficult behaviours in a positive way.

The role of staff also forms an important part of the training. Staff are taught to adopt the role of a coach or a mediator, who encourages people with ID to think, find out, and do things for themselves, instead of taking over or telling them what to do. It is explained how they can promote self-management in their clients, which is practised with a role-playing exercise on coaching people towards the proper execution of a task by asking them questions, while not giving away the answers. Staff are also taught to build on an individual's existing strengths, interests, knowledge, and abilities to stimulate learning and development. This can be achieved by letting clients perform tasks for which they still need some assistance and letting them discover themselves how to execute something. This is also practised with various exercises that teach staff how to connect to another person's knowledge, skills, and style of learning in order to adapt their way of coaching. Attention is also paid to the importance of fostering self-worth and building an equal, trusting, and respectful relationship with clients. Toward the end of the training, the changes in the attitude and role of staff throughout various phases of learning are also addressed. Where providing safety and trust are important in the initial stage of learning, as clients progress, it becomes more important for staff to step back and provide room for their clients to experiment. Finally, it is discussed that it is important to support the transfer of learnt skills to daily life and to include the social network of clients.

Primary research question

Participants

Raamwerk selected three group homes for people with ID whose support staff would receive the training in promoting self-management. The participants of the intervention group were thus selected by means of purposive sampling. This intervention group

consisted of 15 people with ID. Between T1 and T2, three of these people moved away and therefore dropped out of the study. The comparison group was put together by two remedial educationalists of Raamwerk, who selected people with ID that were as comparable as possible to the intervention group with respect to the level of the ID, age, and gender. This group consisted of 11 people with ID, living in four different group homes whose support staff were not trained. Descriptive statistics of the participants are presented in Table 1. Diagnostic information was obtained from their electronic client records.

Table 1 Descriptive statistics of participant groups

	Intervention group (*n* = 15)	**Comparison group (*n* = 11)**
Male, *n (%)*	8 (*53.3*)	8 (*72.7*)
Age in years, *M (SD)*	31.1 (*9.9*)	35.8 (*11.1*)
Level of ID, *n*		
Borderline	1	2
Mild	11	6
Moderate	2	3
Severe	1	
Full Scale IQ, *M (SD)*	61.3 (*8.5*)	61.6 (*11.3*)
Psychiatric comorbidity, *n*		
Autism spectrum disorder	6	2
Other	6	5

Measurements

Independence and self-reliance

The Social Functioning Scale for the Mentally Retarded [SFSMR; 135] was used, which consists of 31 items addressing several components of independent functioning and self-reliance at home and in social situations (e.g., getting dressed, setting the table, cleaning up, language expression). Items can be rated on four levels, objectively reflecting what a participant currently does by himself, with higher scores indicating better functioning. The raw total scores were used for the analyses, which could range from 0 to 124. The questionnaire was filled in by the client's personal tutor, together with either the remedial educationalist or another staff member who frequently worked with the participant at home or at day care. The questionnaire is widely used in Dutch health care organisations

for people with ID. The psychometric properties of the questionnaire regarding both the reliability and construct and criterion validity have been found to be good [136].

Support needs

To evaluate the support needs of the participating people with ID, the Dutch version of the Supports Intensity Scale [SIS; 137] was used. The SIS was only filled in at T0 and T2, since we only expected an effect on support needs in the long term. The SIS is a semi-structured interview that assesses the intensity of support that an individual with ID requires to successfully perform several activities. Section 1 of the SIS includes 49 activities that are grouped into six domains; home living, community living, lifelong learning, employment, health and safety, and social activities. Section 2 consists of eight items that address protection and advocacy. For the analyses, the sum of the raw total score of Sections 1 and 2 was used, which could range from 0 to 655. The SIS was administered by a trained interviewer who obtained the required information from two respondents who knew the person with ID well. This always included the client's personal tutor, together with either the remedial educationalist or another staff member who frequently worked with the client at home or at day care. Respondents had to answer whether their client would require support when having to successfully perform a certain activity, and if so, how frequent, how long, and what kind of support would be needed. The more support is needed, the higher the score on the SIS. Several studies have demonstrated the reliability and validity of the SIS [138].

Behavioural problems

The Dutch version of the Developmental Behaviour Checklist [DBC; 139] was filled in by the client's personal tutor to assess the occurrence of emotional and behavioural problems. These concerned disruptive/antisocial, self-absorbed, communication, anxiety, and social problems. In this questionnaire, 95 items are rated on a 3-point scale, indicating the frequency of occurrence of a particular type of behaviour (0 = not at all, 1 = a little or sometimes, and 2 = clearly, often). The raw total score was used for the analyses, with higher scores reflecting more behavioural problems. This score could range from 0 to 190. Although the questionnaire is aimed at minors with ID, it has been used in previous research on adults with ID [140]. Both the reliability and construct validity of the questionnaire were rated as satisfactory [141-143].

Statistical analysis

A pre-test/post-test follow-up control group design was used to study whether the staff training in promoting self-management had an effect on the level of independence and self-reliance, the support needs, and the occurrence of behavioural problems of people with ID. The data was analysed with IBM Statistical Package for the Social Sciences version 23.0. Descriptive statistics were used to summarise the characteristics of the groups at baseline. The groups were compared by means of an independent samples *t*-test and Chi-squared tests. The total scores of the questionnaires used for the analyses were normally distributed (z-scores of skewness and kurtosis |<3.0|) per measurement per group, except for the scores of the comparison group on the DBC at T0 and for the scores of the intervention group on the DBC at T2. There was one outlier (> 3 SD) in the data of the DBC. Analyses were performed with and without this outlier.

Longitudinal multilevel analyses were conducted to examine the differences between the groups in the scores on the three different questionnaires. This type of analysis accounts for missing data. We included a random intercept and the fixed factor of group. In addition, for the analysis of the SFSMR and the DBC, two dummy variables for time were created (Time 1 and Time 2), representing the short term (T1 versus T0) and long term (T2 versus T0), respectively. Only for these two questionnaires, to analyse the short- and long-term effects of the staff training, the interaction terms (i.e., cross-products) between group and each of the two dummy variables for time were included. For the SIS, only one post-test was available, therefore the two dummy variables for time were not used, but merely the fixed factor of time and the interaction between group and time.

Given the small sample size, non-parametric Mann-Whitney tests were conducted as well on the difference scores between T1 and T0 (only for the SFSMR and DBC) and T2 and T0, in order to check whether the results from the longitudinal multilevel analyses could be confirmed.

Secondary research question

Focus groups

To further evaluate the staff training in promoting self-management, two focus groups were held with trained staff members of Raamwerk 6 months after the training. Unlike individual interviews and surveys, focus groups use group interaction to generate a better

understanding of not only *what* people think, but also *how* they think and *why* they think that way. It is a particularly useful method for exploring people's knowledge, attitude, and experiences, and for gaining insight into behaviour, organisational issues, and needs [107, 144]. One focus group was with support staff working in the group homes that were part of the training (*n* = 6; 1 man and 5 women; *M* age = 36.29 ± 12.51 *SD*). The other focus group was held with trained staff members working in day care services (*n* = 7; 5 men and 2 women; *M* age = 33.60 ± 9.33 *SD*). The addressed topics included what they had learnt from the training and whether they had noticed any changes afterwards in knowledge, attitude, skills, and method of working of themselves and their team members. If so, they were asked what might have caused these changes. Moreover, they were asked whether they missed anything within the training. The focus groups were chaired by an independent moderator with experience in the field of ID. The primary researcher (first author) observed both meetings and took notes, but did not actively participate in the discussions. The focus groups were audio-recorded with the participants' consent and were transcribed verbatim.

Qualitative analysis

For the secondary research question, a qualitative analysis was performed to study the opinions of trained staff members regarding the effectiveness of the staff training in promoting self-management. Analysis of the data took a general inductive approach [108], using ATLAS.ti 7.5.6 software. The four questions addressed in the focus groups served as a framework for the analysis. Two coders independently listened to the recordings, while reading and coding the transcripts. Discrepancies between coding were discussed until consensus was reached. In case of a remaining disagreement, a senior researcher was asked to make a final decision. The definitive codes were analysed and categories were inductively identified based on how extensively codes were discussed.

Results

Baseline characteristics

The intervention group and the comparison group had a similar gender balance and did not differ in age. The level of severity of the ID, IQ, and the presence of comorbid psychiatric diagnoses also did not differ significantly between the groups. Baseline scores on all three questionnaires were not significantly different either. Overall descriptive statistics for both groups per questionnaire per measurement point are presented in Table 2.

Table 2 Descriptive statistics for total raw scores on the questionnaires for participant groups

	Intervention group			Comparison group		
	T0 (*n* = 15)	T1 (*n* = 15)	T2 (*n* = 12)	T0 (*n* = 11)	T1 (*n* = 11)	T2 (*n* = 11)
SFSMR[1], *M (SD)*	105.7 (11.6)	109.1 (9.3)	108.5 (10.1)	112.1 (9.9)	111.9 (11.1)	111.0 (11.9)
SIS[2] Section 1+2, *M (SD)*	284.9 (82.9)		295.2 (63.8)	303.7 (96.7)	-	291.9 (95.2)
DBC[3], *M (SD)*	33.2 (15.6)	34.3 (9.5)	33.0 (11.8)	33.3 (27.0)	35.9 (27.4)	36.8 (24.0)

[1]Social Functioning Scale for the Mentally Retarded
[2]Supports Intensity Scale
[3]Developmental Behaviour Checklist

Effect of the training on independence and self-reliance

Table 3 presents the results of the longitudinal multilevel analysis. There was a significant interaction effect of Group by Time 2. In the long term (T2 versus T0), the intervention group showed a significant increase in the score on the SFSMR, in contrast to the comparison group.

Table 3 Results of the longitudinal multilevel analysis of the Social Functioning Scale for the Mentally Retarded

	Coefficient (b)	SE	*t*	*F*	*p*-Value	95% Confidence interval	
Intercept	112.09	3.13	35.84	1284.61	.00	105.73	118.46
Group	-6.42	4.12	-1.56	2.43	.13	-14.81	1.96
Time 1 (short-term versus baseline)	-0.18	1.86	-0.10	0.01	.92	-3.91	3.55
Time 2 (long-term versus baseline)	-1.09	1.86	-0.59	0.35	.56	-4.82	2.64
Group * Time 1	3.58	2.44	1.47	2.15	.15	-1.33	8.49
Group * Time 2	6.74	2.54	2.66	7.08	.01*	1.65	11.84

* $p < .05$

Effect of the training on support needs

The results of the longitudinal multilevel analysis of the SIS indicated that there was no Group by Time effect, indicating that the support needs of the intervention group did not significantly differ (from T0 to T2) compared to the comparison group (Table 4).

Table 4 Results of the longitudinal multilevel analysis of the Supports Intensity Scale

	Coefficient (b)	SE	*t*	*F*	*p*-Value	95% Confidence interval	
Intercept	303.73	25.33	11.99	143.74	.00	252.00	355.45
Group	-18.86	33.35	-0.57	0.32	.58	-86.96	49.24
Time	-11.82	15.91	-0.74	0.55	.47	-44.79	21.16
Group * Time	-1.27	21.92	-0.06	0.00	.95	-46.66	44.12

Effect of the training on behavioural problems

The longitudinal multilevel analysis of the DBC did not show a Group by Time effect, which means that there were no significant differences in the occurrence of behavioural problems, neither in the short nor in the long term. The results that are reported (Table 5) are from the analysis with the outlier included, since there were no differences in terms of statistical significance between the outcomes of the analyses with and without the outlier.

Table 5 Results of the longitudinal multilevel analysis of the Developmental Behaviour Checklist

	Coefficient (b)	SE	*t*	*F*	*p*-Value	95% Confidence interval	
Intercept	33.34	5.70	5.85	34.18	.00	21.88	44.79
Group	-0.10	7.51	-0.01	0.00	.99	-15.19	14.98
Time 1 (short-term versus baseline)	2.53	5.56	0.46	0.21	.65	-8.65	13.71
Time 2 (long-term versus baseline)	3.43	5.56	0.62	0.38	.54	-7.76	14.61
Group * Time 1	-1.45	7.33	-0.20	0.04	.84	-16.17	13.27
Group * Time 2	-6.33	7.58	-0.84	0.70	.41	-21.56	8.90

Non-parametric tests

In addition to the longitudinal multilevel analyses, non-parametric Mann-Whitney tests were performed to see whether the abovementioned results could be confirmed. Again, only the difference score on the SFSMR between T2 and T0 differed significantly between the groups, $U = 9.00$, $p < .01$. The difference scores on the DBC, the SIS, and the SFSMR between T1 and T0 were not significantly different between the groups (all p-values > .05).

Focus groups

The content of the focus group discussions was mostly comparable between the focus group with staff working in group homes and the focus group with staff working in day

care services. Table 6 summarises the identified categories and lists several illustrative quotes. Overall, according to the trained staff members, the training provided them with little new information. What they had learnt however was (how) to ask their clients more questions. Although the various teams did not make any new agreements on how to guide their clients after the training, they had noticed several changes since then, especially within the group homes. Some staff members attributed these changes to the training, whereas others did not. Changes included a difference in their attitude towards clients and an increased awareness that they should not take over from them but instead focus on what their clients are able to do themselves. Furthermore, many noticed an alteration in their method of working. They listened more carefully to their clients, instead of (automatically) thinking on their behalf. They did not take over tasks from them as much as they used to and they more often dared to let go and let the clients take charge. When asked whether they missed anything within the staff training, additional coaching-on-the-job was mentioned, next to learning new techniques and learning how to apply the training to their own daily practice at work, for example by discussing and practising with their own case studies.

Table 6 Overview of categories and illustrative quotes from the focus groups

What have you learnt from the training?		
Category	**Subcategory**	**Quotes**
Not much new	Little new knowledge	*There was little new knowledge obtained.*
	Confirmation	*To me it was more a confirmation. What was said in the training, yes, that is how we work as well.*
Skills	General	*Yes, skills have grown, in my opinion.*
	Asking questions	*With regard to skills, we have learnt questioning techniques.*
Have you noticed any changes after the training in knowledge, attitude, skills, method of working?		
Category	**Subcategory**	**Quotes**
Awareness	General	*I tend to take things over a lot from clients, but I am now more aware that I should do that less frequently.* *We are now more aware that clients can do much more themselves.*
Attitude	Focus on abilities	*I now focus more on clients' possibilities to develop, which makes my job more fun.*

Table 6 Continued

Have you noticed any changes after the training in knowledge, attitude, skills, method of working?		
Category	**Subcategory**	**Quotes**
Method of working	Client in control	*In our group home, we should sit with our feet up more often, give some guidance, and do nothing more. Just follow them with your hands behind your back. If I look back 6 to 12 months to see whether this has happened, then, yes. Now you can, so to speak, really sit with your feet up on the table and say "Go ahead, what would you do?"* *We let the client take control more often than before. We dare to let go more often.*
Method of working	Client in control	*Less automatic thinking, but listening more to the client, what he wants.*
	Taking over	*More letting go, letting them think for themselves more, letting them do things themselves more.*
Little changes	General	*We already did a lot of those things.*
	Team agreements	*In our group home, little changed. After the training, there was no meeting on how to implement this within the team and in our way of guiding clients.*
What might have caused these changes?		
Category	**Subcategory**	**Quotes**
Training	Training effect	*The awareness has increased because of the training.*
	No training effect	*I do not think these changes are caused by the training.*
Have you missed anything within the training?		
Category	**Subcategory**	**Quotes**
Application	Daily practice	*Putting it into practice was not discussed that much.*
Own case studies	General	*It [the training] was more with the use of pictures and case studies, but it is different when you focus on your own client: "I am running into these difficulties with this client, how can we approach that?" … Everyone from the other group homes can learn from that as well. That is an easier way to help each other and give each other advice than with a picture.*
Coaching-on-the-job	General	*Shadow me for a day, a couple of hours, and observe how I am doing within my group home.*
Techniques	Communication	*Yes, conversational techniques. How are you going to motivate clients that find it difficult to devise themselves how to do something, to still find this out themselves?*

Discussion

The aim of this study was to evaluate a training for support staff, which teaches them how to promote self-management in people with ID. Apart from improvements in independence and self-reliance, it was hypothesised that the staff training would lead to reductions in support needs and behavioural problems of people with ID. The main

finding of this study was that even though no differences between the intervention and comparison group were found in support needs and behavioural problems, the intervention group showed more improvement in independence and self-reliance in the long term. However, this latter effect was small and thus overall, it can be concluded that the results only provide limited evidence for the effectiveness of the staff training. Although various previous studies have found more convincing evidence for the effectiveness of self-management interventions, caution is still in order, for example because of their even smaller sample sizes and the lack of a comparison group [57, 103, 104]. The heterogeneity of the studies' specific goals, designs, and outcome measures also impedes a proper comparison of the interventions and their impact [12]. However, important factors for an effective intervention seem to be that it can be adapted to the individual user and the specific context [6, 8, 57], and that not only people with ID are involved, but also those who care for them [6, 8, 33]. Although both were the case in the intervention that we evaluated, its effect was still small.

In the focus groups, trained staff members also reported that the staff training had limited benefits. It mainly confirmed their knowledge and method of working. Nevertheless, after the training, some staff members had noticed positive alterations in their attitude towards clients and in their method of working. However, these were possibly too subtle to induce significant changes in their clients' level of functioning. Concerning the content of the training, support staff stated that they would have liked to learn more about things they did not know yet and could therefore develop during the training, such as new techniques for guiding their clients. They also would have liked to focus more on the application of the training's methodology to their own daily practice.

The above-mentioned findings from the focus groups could suggest that the training did not yet sufficiently clarify how the staff members could have promoted self-management in their own clients. This might explain why afterwards, none of the teams made new agreements on how to guide their clients based on the methodology that was taught. It seems that the actual implementation of good support staff practices in the field of ID is a difficult task, as was also seen in previous research [128]. A barrier to the implementation also possibly concerns insufficient encouragement from within the organisation to practice the methodology [38]. If a practice leader would have been appointed, this person could have organised, encouraged, supervised, and coached the trained staff to put the methodology of the training into practice. This could have improved the implementation

of the training, the quality of staff practice, and therefore the outcomes for the people with ID who were supported by the trained staff members [128].

Apart from an inadequate implementation, the format of the training also shows room for improvement. Because our study took place in a naturalistic setting, at the time, it was only feasible to provide a classroom training, whereas previous research has found that coaching is an important addition to this. This was confirmed by several staff members who stated in the focus groups that they would have liked additional coaching. Classroom training therefore seems to be insufficient for teaching staff to guide their clients towards greater self-management.

Apart from aspects related to the training, another explanation for the limited effects could pertain to the fact that people with ID need more time to develop their self-management skills, given their overall learning deficit [9]. Therefore, it may well take more than 6 months before significant improvements in independence and self-reliance, support needs, and behaviour can be observed. Furthermore, the questionnaires that were used in this study might not be sensitive enough to measure change in our population. On the DBC [139], participants showed relatively low scores overall. As was mentioned, this questionnaire is aimed at minors with ID, which may explain why many of the behaviours that were addressed were uncommon in our adult participants. Conversely, there was a ceiling effect on the SFSMR [135], already at baseline. Therefore, for many participants, there was little room for improvement in scores, whereas in real life much progress in independence and self-reliance was possible. It should also be noted that the significant difference between the groups on this outcome measure could also be related to the fact that the scores of the comparison group slightly decreased over time, especially in the long term. Therefore, this significant result should be interpreted with caution. Furthermore, contrary to what would be expected, the intervention group had higher support needs in the long term, whereas the comparison group showed a decrease in support needs. These results were, however, not significantly different.

Besides the use of questionnaires that seem inadequate for our population, other limitations of the study include the small sample size and the fact that our follow-up measurements only lasted until 6 months after the training. In addition, quality of life was not assessed in this study, although this would have been a valuable outcome measure, as people can experience a higher quality of life when self-management is promoted [4]. Furthermore, there was a non-random allocation of the homes to either

the intervention or comparison group and participants could not be matched, given the diversity and complexity of their problems. Although there were no significant differences between the groups on several background characteristics, slight differences between the groups may still have influenced the results. Also, while there were no dropouts in the comparison group, there were three in the intervention group, who were all relatively well functioning people with ID.

Despite its limitations, this study could still offer a valuable contribution to the field of ID. Apart from being a mixed-methods study, it is to our best knowledge also the first to evaluate the effectiveness of a staff training aimed at promoting overall self-management in people with ID. Thus, the study could serve as a starting point for the further development and evaluation of similar kind of trainings. When designing these trainings, the content and setup should be carefully considered, as well as the implementation and application into daily practice. Organising good practice leadership and coaching-on-the-job appear to be important factors to consider in this context. In future research, it would also be of interest to study the effects on different subgroups of people with ID, as well as the cost-effectiveness. Apart from selecting measurement instruments that are more appropriate for this population, such as the SFSMR for a higher level [145], or the Adult Behavior Checklist [146], it is also worthwhile to consider self-reports. This could be achieved by including people with ID when filling in questionnaires or by interviewing them to hear their perspectives and experiences. Studying whether any improvements in quality of life occur, would be of interest as well. Furthermore, to avoid bias of trained staff members, investigating (changes in) client and staff behaviour by using a more direct and objective measure (e.g., through observations) would be a valuable addition to the more subjective experiences as collected through questionnaires and focus groups.

In conclusion, this study found limited evidence for the effectiveness of a staff training that promotes self-management in people with ID. Further research is required on how this can be achieved more effectively. Although the limitations should be kept in mind, this study could serve as a basis for the further development and evaluation of similar kind of trainings. In order to be more effective, the training's content, format, and implementation should be carefully considered, for example by paying more attention to its application into daily practice and including coaching-on-the-job.

Acknowledgements
We thank all staff members of Raamwerk and Leiden University who contributed to the study.

Chapter 5

Development of the Leiden Independence Questionnaire for Support Staff: A measure of staff behaviour regarding promoting independence of people with intellectual disabilities

Accepted for publication:
Sandjojo, J., Gebhardt, W.A., Zedlitz, A.M.E.E., Hoekman, J., Dusseldorp, E., Den Haan, J.A., & Evers, A.W.M. (2018). Development of the Leiden Independence Questionnaire for Support Staff: A measure of staff behaviour regarding promoting independence of people with intellectual disabilities.
Journal of Intellectual Disability Research. doi: 10.1111/jir.12574

Abstract

Background: Support staff of adults with intellectual disabilities (ID) play an important role in promoting independence in home and community settings. However, little is known about the types of behaviours staff should use to promote independence and instruments that assess such behaviour do not yet exist. The aim of this study was therefore to develop and initially validate a reliable questionnaire that measures the degree to which support staff display behaviours that promote independence in people with ID.
Method: The Leiden Independence Questionnaire for Support Staff (LIQSS) was constructed to measure the extent to which support staff promote independence in people with ID. The LIQSS was completed by 142 staff members working with people with ID. For the psychometric evaluation of the LIQSS, a Principal Component Analysis (PCA) was performed with an oblique rotation in all items. Next, the PCA was performed with a forced three-component extraction and three subscales were computed. To assess internal consistency, Cronbach's alpha was calculated for each of the subscales.
Results: The LIQSS was found to consist of three internally consistent (Cronbach's α was respectively .92, .79, and .76) and meaningful components: (1) Communication, Agreements, and Coordination; (2) Positive Encouragement and Tailoring; and (3) Supporting Independent Performance. The final 22 items had factor loadings between .44 and .91 on their corresponding component and a minimal difference in loading to the other factors of .20.
Conclusions: The LIQSS appears to be an instrument with positive face validity and reliability (internal consistency) that assesses the degree to which support staff promote independence in people with ID. To increase the instrument's value for both scientific research and clinical practice, studies should focus on the further validation of the LIQSS.

Keywords: independence, intellectual disabilities, self-management, support staff, questionnaire.

Background

There is international consensus that people with intellectual disabilities (ID) should live as independently as possible [18]. However, as our Western society is becoming more complex, being independent has become increasingly challenging for people with ID, leading to a growing demand for care [11]. People with ID often struggle with managing their personal care, household, community or work activities [22, 24, 52], and therefore are often dependent on others for support [6, 7, 102, 147]. Being independent, however, is important for people with ID [3] and has been related to greater happiness, satisfaction [1, 2], and quality of life [4, 5]. Therefore, to enhance the quality of life of people with ID, it is important to promote their overall self-management and independence in particular. Support staff could play an important role in this regard. However, clear indications are lacking on what type of staff behaviours promote independence in people with ID and valid and reliable instruments that target these behaviours are missing.

Independence, just as self-reliance, can be defined as the ability to take action to manage one's affairs and to provide for oneself, thereby solely relying on one's own efforts, resources, judgement, and abilities, without requiring help or support from others [54]. Someone's level of independence can be placed on a continuum, with complete dependence at one extreme and complete independence at the other [46]. Although no one is completely independent in all areas, the goal for people with ID is to be as independent as possible. The concept of independence is part of the overarching term 'self-management'. Self-management has been defined and described in various ways [25, 100, 114]. Taking these studies together, self-management can be defined as the set of actions and cognitions that a person deliberately undertakes to change or maintain his or her behaviour in order to achieve self-selected outcomes. As self-management thus involves the capacity to manage one's behaviour, it includes the concept of independence. Additionally, related terms include self-determination and autonomy, which are centred on making self-selected choices. Self-determination and autonomy are separate constructs 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].

Traditionally, within residential care settings for people with ID, there may be less emphasis on promoting aspects of self-management [148]. A way to improve self-management in

people with ID could be through focusing on support staff to help promote independence. Changing the way support staff behave can have a positive impact on client outcomes [149]. For example, if staff encourage clients to handle things themselves, instead of taking over from them, this could increase clients' independence and reduce passivity and 'learned helplessness' [5]. Although there are only a few studies that directly targeted staff behaviour with regard to promoting self-management in this population [e.g., 54, 150], staff often play a role in self-management interventions that target people with ID directly. In a recent systematic literature review on interventions that aimed to promote self-management in daily life of people with ID [151], it was found that it was always the provider of the intervention (e.g., support staff member) who applied behavioural change techniques to promote self-management. Mostly a combination of techniques was used, such as modelling, instructing, prompting, and providing feedback, which all seemed to be effective. However, when it comes to promoting independence in particular in people with ID, no studies have been conducted to date on the specific types of staff behaviours that are necessary.

Furthermore, instruments that assess independence-promoting behaviour of staff do not yet exist. In the few previous studies that focused on staff behaviour in relation to promoting self-management in people with ID, various types of measures were used. For example, in one study an observer made detailed records of staff's skills and behaviours while they were working (e.g., interaction with clients, providing opportunities for involvement and choice-making) [125]. Other studies conducted interviews with trained staff to evaluate how a training affected their behaviour [38], attitude, knowledge, and skills [54]. Wong and Wong [150] constructed their own scale to assess staff's attitude, knowledge, and skills, with a specific focus on facilitating self-determination of people with ID. Their instrument mostly contained statements, but they also used vignettes to assess staff's responses. Based on these four studies, it seems that it is generally important that support staff closely involve people with ID in activities and decision-making. However, it is not yet clear which staff behaviours are specifically important for promoting independence in people with ID, as this was not specifically addressed in these studies. Furthermore, there are concerns about the reliability and validity of measures that evaluate staff behaviour and the effect of staff trainings, especially measures that can be easily completed. This implies the need for the development of validated measures to assess staff practice [47].

In the current study, we developed and initially validated a reliable questionnaire that assesses the degree to which support staff promote independence in people with ID.

Methods

Participants

For the development of the questionnaire we approached 174 support staff members of Raamwerk and 's Heeren Loo who worked in residential homes or day care services with adults with moderate to mild ID without significant physical impairments. There were 142 staff members who participated, 109 from Raamwerk and 33 from 's Heeren Loo. The response rate was 81.6%. The descriptive statistics of the whole sample are displayed in Table 1. In general, there were more female than male participants and most participants completed intermediate secondary vocational education and training. The majority of the participants worked as a regular staff member, as opposed to working as a personal tutor, and most participants worked within a residential setting.

Table 1 Descriptive statistics of participating staff members

	Whole sample (*n* = 142)
Gender, *n (%)*	
Male	49 (34.5)
Female	93 (65.5)
Age in years, *M (SD)*	37.9 (12.5)
Level of education, *n (%)*	
Lower secondary vocational	3 (2.1)
Intermediate secondary vocational	89 (62.7)
Higher professional	31 (21.8)
Unknown	19 (13.4)
Work experience in years, *M (SD)*	13.4 (9.5)
Work setting, *n (%)*	
Homes	104 (73.2)
Day services	38 (26.8)
Role, *n (%)*	
Personal tutor	42 (29.6)
Regular staff	97 (68.3)
Unknown	3 (2.1)

Note. Independent samples *t*-tests were conducted for numeric variables and Chi-squared tests for categorical variables.

Instrumentation

To construct our questionnaire, the Leiden Independence Questionnaire for Support Staff (LIQSS), we based our method on the Intervention Mapping approach by Bartholomew et al. [37], who devised a protocol for developing effective behaviour change interventions.

One of the Intervention Mapping steps concerns making an overview of performance objectives, which in our case concerned staff behaviours that are important when wanting to promote independence in people with ID. This was done by having discussions with the first author and members from our expert group, in which we brainstormed about all the behaviours that support staff should display to promote independence in people with ID. Based on these discussions, the list of performance objectives was revised and complemented several times until consensus and saturation was reached. Based on this list, we clustered the performance objectives into several domains (i.e., setting goals, motivating people with ID, supporting the learning process, and coordinating with others). The list was then converted into a questionnaire, in which no explicit reference was made to these domains. For example, the performance objective 'Support staff give clients room to make mistakes' was converted into the questionnaire item "I give clients room to make mistakes". The final version of the questionnaire that was used for the psychometric evaluation contained 32 items reflecting the extent to which staff expressed behaviours that promote independence (Appendix A). Participants were instructed to carefully read the items and to indicate to what extent these items were applicable to them in the past two weeks on a scale from 1 (not at all/never) to 7 (completely/always). By having our group of experts review the appropriateness, relevance, and completeness of the final scale, we could ensure its face validity.

Procedure

The study protocol was evaluated by the Medical Ethics Committee of the Leiden University Medical Center. It was declared that neither formal medical ethical approval nor written informed consent was required and that there were no objections to conducting the study. The LIQSS was developed by a group of experts (n = 12), including researchers, psychologists, and support staff and managers of two care organisations (i.e., Raamwerk and the Academy of Independence). Their years of work experience in the field of ID ranged from 2 to 22 years. The first version on the questionnaire was piloted with four support staff members in a think aloud study [152]. While filling in the questionnaire, staff expressed all their thoughts out loud and afterwards they were asked how they evaluated the questionnaire (e.g., whether anything was unclear, whether it fit our purpose, and whether it addressed all of the relevant behaviours). Based on the results of this think aloud study, some adaptations were made such as clarifying an item with an example, rephrasing three items, and slightly adapting the instructions. Data collection was carried out in collaboration with the organisations Raamwerk and 's Heeren Loo, both care organisations for people with ID in the Netherlands. All participating staff were informed

about the study beforehand by e-mail or by the psychologist or remedial educationalist of their team. All staff members were asked to participate on a voluntarily basis, which they could do during work hours.

Data analyses and statistics

The data were analysed with IBM Statistical Package for the Social Sciences (SPSS) version 23.0. Descriptive statistics were used to summarise the characteristics of the participants. To evaluate the LIQSS, a Principal Component Analysis (PCA) was performed with an oblique rotation (direct oblimin) on all items. The Kaiser-Meyer-Olkin (KMO) measure was used to verify the sampling adequacy and Bartlett's test of sphericity was used to test whether the correlations between items were sufficiently large for a PCA [153]. A scree plot inspection was used to aid decision on the number of components, after which a PCA was performed with a forced three-component extraction. Based on the PCA solution, three subscales were computed by computing the unweighted sum of the items with a loading of > .40 on one component. Cronbach's alpha was calculated to assess the reliability (internal consistency) of each of the subscales.

Results

In the PCA, the KMO measure of sampling adequacy was .86, which indicates that a PCA is suitable for the data [153]. Bartlett's test of sphericity χ^2 (496) = 2459.84, p <.001 showed that the correlations between items were sufficiently large for a PCA. The initial results of the PCA showed that seven components had eigenvalues over Kaiser's criterion 1 and in combination they explained 65.66% of the variance. Based on the scree plot, there were three to five components that could be derived from the LIQSS. Further inspection of the item loadings on the components revealed that three components fitted the data best, using the guideline that an item loading should be > .30 on one component, with a minimal difference in loading of .20 on the other components. Therefore, a PCA was performed with a forced three-component extraction (Appendix A). The items that have a high loading (i.e., > .40) on the same component (Table 2) suggest that component 1 represents communication, making agreements, and coordinating on something with others (e.g., "*Together with my team, I make clear agreements about the way to guide our clients*", "*I keep all those involved up to date about the progress the client has made*"); component 2 corresponds to staff's positive approach and their ability to provide tailored support (e.g., "*I compliment clients while they are learning something, as well as afterwards*",

"*While clients are learning, I build on what they already know and are able to do*"); and component 3 concerns supporting independent performance of clients (e.g., "*I let clients carry out tasks that they can do themselves*", "*If clients do not know how to proceed, I ask (mediating) questions, so they come up with the solution themselves*"). Ten items were removed from the questionnaire because they did not load highly (i.e., > .40) on one component, did not correspond to any of the components, or because the difference in loadings between two or three components was smaller than .20. The final version of the LIQSS consisted of 22 items, which had factor loadings between .44 and .91 on their corresponding component and a minimal difference in loading to the other factors of .20 (Table 2). The PCA of these 22 items with the three components extracted showed that together they explained 55.31% of the variance. The inter-component correlation coefficients were small to medium (between .20 and .36). In terms of reliability, all subscales (derived from the components) were found to be internally consistent (Cronbach's alpha was .92, .79, and .76, respectively). The correlation coefficients between the subscales were also small to medium (between .29 and .44).

Discussion

The objective of this study was to develop a questionnaire that assesses the degree to which support staff promote independence in people with ID. The questionnaire had three meaningful, reliable (internally consistent) components of staff behaviours that are important for promoting independence in people with ID. Based on the results of our initial validation, its face validity appears to be strong.

Three distinct and reliable components of staff behaviour regarding promoting independence were identified with the LIQSS. The first component, or subscale, of the LIQSS was termed 'Communication, Agreements, and Coordination' and concerned communicating and coordinating on something with others and making agreements about the way to guide people with ID towards their learning goals. Involving other people does not only mean the person with ID or other staff members. It is also important to include the social support network when promoting independence [6, 8, 51]. The second component, 'Positive Encouragement and Tailoring', pertained to staff's behaviour towards people with ID during the learning process. These behaviours concern positive encouragement and adapting the provided support to the existing knowledge, skills, and preferred way of learning of an individual. The importance of tailoring self-management support to

Table 2 Principal Component Analysis (PCA) results for the Leiden Independence Questionnaire for Support Staff (LIQSS) with the final 22 items included (n = 142)

		Pattern Matrix factor loadings			
		Component 1: Communication, Agreements, and Coordination	**Component 2: Positive Encouragement and Tailoring**	**Component 3: Supporting Independent Performance**	**Communalities (Variance accounted for per variable)**
Mean component score (*SD*)		4.94 (*1.19*)	5.94 (*0.71*)	5.81 (*0.62*)	
Cronbach's alpha (internal consistency)		.92	.79	.76	
Item					
1	I keep my team members up to date about the learning goals of clients and how they will be worked on (*32*)	**.91**	-.01	-.20	.74
2	I make clear agreements with all those involved (psychologist, personal tutors, legal representatives) about the learning goals and how they will be worked on (*31*)	**.90**	.01	-.15	.74
3	I keep all those involved up to date about the progress the client has made (*25*)	**.83**	-.02	-.04	.65
4	I make agreements with clients about how they could achieve their learning goals (*30*)	**.82**	.01	.05	.71
5	Together with my clients, I formulate their learning goals in a 'SMART' way (Specific, Measurable, Acceptable, Realistic, Time-bound) (*29*)	**.77**	-.06	-.02	.57
6	I give other people involved (e.g., psychologist, personal tutors, legal representatives) feedback on their way of guiding clients (*24*)	**.76**	-.03	.08	.32
7	Together with clients, I evaluate their progress with regard to their learning goals (*18*)	**.71**	.14	.09	.63
8	I stimulate all those involved to practise together with clients what they have learnt, and to put this into practice (*26*)	**.70**	.20	-.07	.55
9	I ask clients to determine their own learning goals (*28*)	**.63**	-.07	.24	.54

Table 2 Continued

		Pattern Matrix factor loadings			
		Component 1: Communication, Agreements, and Coordination	**Component 2: Positive Encouragement and Tailoring**	**Component 3: Supporting Independent Performance**	**Communalities (Variance accounted for per variable)**
10	I give my team members feedback on their way of guiding clients (*23*)	**.57**	.04	.11	.39
11	Together with my team, I make clear agreements about the way to guide our clients (*21*)	**.45**	-.13	.23	.31
12	I motivate and encourage clients while they are learning something (*3*)	-.02	**.88**	-.12	.74
13	I compliment clients while they are learning something, as well as afterwards (*4*)	-.00	**.86**	-.10	.71
14	While clients are learning, I build on what they already know and are able to do (*10*)	-.01	**.71**	-.02	.51
15	While clients are learning, I make use of to their preferred method of learning (*11*)	.13	**.57**	.34	.60
16	I express my confidence towards clients about them reaching their learning goals (*2*)	.02	**.53**	.27	.43
17	I let clients themselves think about how they should solve or deal with something (*8*)	-.15	-.05	**.79**	.54
18	If clients do not know how to proceed, I ask (mediating) questions, so they come up with the solution themselves (*15*)	.21	-.06	**.75**	.71
19	I give clients room to make mistakes (*16*)	-.04	.07	**.69**	.49
20	I believe that clients should think and do as much as possible themselves (*27*)	.07	-.00	**.64**	.45
21	I let clients carry out tasks that they can do themselves (*9*)	.03	.03	**.45**	.22
22	I take care that not too much is asked of clients (that they have to do more or try to do more than they can handle) (*17*)	.16	.16	**.44**	.33

Note. For each item, the highest loading on a certain component is presented in bold, which corresponds to component they were assigned to. The original item numbers are presented between parentheses.

individuals' needs has been proposed in previous studies as well [3, 6, 8, 42, 154]. The third component, 'Supporting Independent Performance', related to supporting independent performance by letting people with ID handle things themselves as much as possible, as this could benefit the level of independence of people with ID [5]. The structure and the domains that we found based on the results of the PCA, largely match the domains that were assumed to underlie the structure of the questionnaire, based on the list of performance objectives we discerned before designing the questionnaire. Our initial domains of 'setting goals' and 'coordinating with others' can be clustered into the first component 'Communication, Agreements, and Coordination'. The initial domain of 'motivating people with ID' corresponds with the second component, 'Positive Encouragement and Tailoring'. The third component, 'Supporting Independent Performance' is almost similar to our initial domain 'supporting the learning process'.

There are some limitations to this study. First, we used self-reports as an outcome measure, which could have led to subjective and socially desirable answers. Staff might not have enough self-reflection into their own behaviour towards people with ID and might overestimate the degree to which they are promoting the level of independence of their clients. The relatively high scores on the LIQSS, especially on component 2 and 3 (4.9, 5.9, and 5.8, respectively), seem to support this. Further fine-tuning could therefore be considered, for example by including a 'social desirability scale' that can detect and control for responses that may be influenced by social desirability [155] or by assessing staff responses to vignette scenarios [150]. Related to the relatively high scores, was the finding that few responses were distributed amongst the lowest three answering categories of the seven point scale, showing that these were less discriminative than the higher categories. Perhaps a five point Likert scale fits better, as this was found to yield data of higher quality than a seven point scale. Having a higher number of answering categories increases the possibilities of differences in interpretation, therefore a five point scale may be preferred over a seven point scale [156]. For future research a larger-scale study with more participants working within various care organisations is recommended. Furthermore, research is necessary on the final version of the LIQSS with 22 items, to replicate the factor structure found in this study and to examine other aspects of the LIQSS's reliability and validity (e.g., inter-rater reliability or construct validity), as well as its sensitivity to change.

In this study, we describe and initially validate the first questionnaire that assesses the degree to which support staff promote independence in people with ID. Although the

questionnaire could profit from further validation and fine-tuning to minimise socially desirable answers [155, 157], it has a high potential and promise for use in both scientific research and clinical practice. For example, studies could use the LIQSS to examine which factors influence staff's behaviour in relation to promoting independence and to evaluate staff trainings that target these types of behaviour. Care organisations could use the LIQSS as an assessment instrument to evaluate staff, for example for training purposes. An independent coach could observe staff and give feedback with the help of the LIQSS. The LIQSS could also be used as a self-reflection instrument, to create awareness amongst staff about which behaviours contribute to the promotion of independence in people with ID, thereby possibly contributing to behavioural change. These efforts could all contribute to improvements in the support provided by staff and thereby enhance the lives of people with ID.

Appendix A. Principal Component Analysis (PCA) results for the Leiden Independence Questionnaire for Support Staff (LIQSS) with all 32 items included

Item (with original item number)		Pattern Matrix factor loadings		
		Component 1: Communication, Agreements, and Coordination	Component 2: Positive Encouragement and Tailoring	Component 3: Supporting Independent Performance of Clients
2	I express my confidence towards clients about them reaching their learning goals	.02	.51	-.22
3	I motivate and encourage clients while they are learning something	-.05	.89	.17
4	I compliment clients while they are learning something, as well as afterwards	-.03	.86	.15
8	I let clients themselves think about how they should solve or deal with something	-.14	-.11	-.77
9	I let clients carry out tasks that they can do themselves	.07	.01	-.38
10	While clients are learning, I build on what they already know and are able to do	-.02	.71	.04
11	While clients are learning, I make use of to their preferred method of learning	.13	.57	-.30
15	If clients do not know how to proceed, I ask (mediating) questions, so they come up with the solution themselves	.25	-.12	-.74
16	I give clients room to make mistakes	-.01	.01	-.67
17	I take care that not too much is asked of clients (that they have to do more or try to do more than they can handle)	.17	.14	-.43
18	Together with clients, I evaluate their progress with regard to their learning goals	.71	.16	-.09
21	Together with my team, I make clear agreements about the way to guide our clients	.48	-.16	-.26
23	I give my team members feedback on their way of guiding clients	.58	.04	-.11

Appendix A. Continued

Item (with original item number)		Pattern Matrix factor loadings		
		Component 1: Communication, Agreements, and Coordination	Component 2: Positive Encouragement and Tailoring	Component 3: Supporting Independent Performance of Clients
24	I give other people involved (e.g., psychologist, personal tutors, legal representatives, …) feedback on their way of guiding clients	.77	-.03	-.04
25	I keep all those involved up to date about the progress the client has made	.82	-.01	.05
26	I stimulate all those involved to practise together with clients what they have learnt and to put this into practice	.69	.20	.09
27	I believe that clients should think and do as much as possible themselves	.10	-.09	-.61
28	I ask clients to determine their own learning goals	.64	-.08	-.20
29	Together with my clients, I formulate their learning goals in a 'SMART' way (Specific, Measurable, Acceptable, Realistic, Time-bound)	.80	-.07	.08
30	I make agreements with clients about how they could achieve their learning goals	.83	.01	-.01
31	I make clear agreements with all those involved (psychologist, personal tutors, legal representatives) about the learning goals and how they will be worked on	.88	.04	.17
32	I keep my team members up to date about the learning goals of clients and how they will be worked on	.92	-.01	.25
	Deleted items			
1	I express my confidence towards clients about their possibilities/abilities (what they are able to do)	-.02	.25	-.35
5	I remain patient and 'affectively neutral' (i.e., not angry or irritated) during setbacks and/or in the absence of success	-.15	.10	-.43

Appendix A. Continued

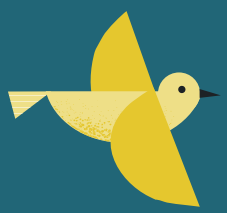
Item (with original item number)		Pattern Matrix factor loadings		
		Component 1: Communication, Agreements, and Coordination	Component 2: Positive Encouragement and Tailoring	Component 3: Supporting Independent Performance of Clients
6	After setbacks and/or in the absence of success, I evaluate the situation with clients (for example regarding what went wrong or how it could be/could have been done better).	.17	.44	-.36
7	I give constructive feedback after a setback and/or in the absence of success	.04	.44	-.45
12	I make sure that clients work towards their goal in small steps	.33	.33	-.34
13	I explain to clients why they are learning something, so they see the importance of it	.36	.16	-.51
14	I change my teaching method/approach if clients get stuck	.36	.46	-.20
19	I tell clients how they should solve or deal with something	-.24	-.08	.30
20	I stimulate clients to keep practising and keep putting what they have learnt into practice	.25	.30	-.23
22	I am on the same page as my team, regarding the way to guide our clients	.18	-.02	-.06

Note. Participants were instructed to carefully read the items and to indicate to what extent these items were applicable to them in the past two weeks on a scale from 1 (not at all/never) to 7 (completely/always)

Chapter 6

Effects of a self-management training for people with intellectual disabilities

Accepted for publication:
Sandjojo, J., Zedlitz, A.M.E.E., Gebhardt, W.A., Hoekman, J., Den Haan, J.A. & Evers, A.W.M. (2019).
Effects of a self-management training for people with intellectual disabilities.
Journal of Applied Research in Intellectual Disabilities, 32, 390-400. doi: 10.1111/jar.12536



Abstract

Background: To help people with intellectual disabilities (ID) lead a more independent life, it is important to promote their self-management. This study evaluated the effectiveness of a self-management training for people with ID directed at independent functioning in daily life.

Method: In the training, 17 people with ID worked on personal self-management goals covering a wide range of everyday affairs. Primary outcome measures focused on goal attainment, independence, and support needs. Moreover, outcomes regarding psychopathological behaviour and quality of life were explored. Data were collected before and at the start of the training, and 3, 6, 9, and 12 months later.

Results: The training contributed to the attainment of self-management goals and to the reduction of support needs ($p < .01$). There were no changes in independence, psychopathological behaviour, and quality of life.

Conclusions: Results indicate that the training supports people with ID to self-manage their daily affairs.

Keywords: daily living skills; independence; intellectual disabilities; personal goal attainment; self-management; training

Introduction

Intellectual disabilities (ID) are commonly operationalised as deficits in intellectual and adaptive functioning, as measured by standardised tests (e.g., IQ score < 70). The disabilities have an onset during the developmental period (e.g., < 18 years) and lead to limitations in daily life for which ongoing support is needed. These deficits not only affect independent functioning at home, but also participation in social, community, academic, or occupational activities [9, 10]. The United Nations [18] have declared that people with ID should be enabled to live as independently as possible, which is also desired by many individuals with ID [1-3]. Increasing their abilities to independently manage their affairs could enhance their quality of life and community participation [4, 5]. Furthermore, it could reduce behavioural problems [53] and the need for support from professionals and family members who now often feel overburdened [7, 19, 50]. Therefore, interventions are required that promote self-management of people with ID.

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 thus includes the autonomy to self-determine one's choices to lead one's life according to one's own preferences [28, 55, 115]. Furthermore, self-management involves independence and self-reliance, which encompass 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 [54].

Various studies on promoting self-management in people with ID have been conducted. However, most of these studies have included only a very small sample and have investigated only one type of approach (e.g., self-instruction) or a singular domain (e.g., grocery shopping). To our best knowledge, none of the investigated interventions were generalised to a wider range of people with ID with different self-management goals. Previous research focused, for example, on prompting [4, 30, 31], the use of technology [23, 39, 48, 103, 158], employment [34, 35], or health behaviour [13, 33]. Most studies presented promising results, but drawing firm conclusions about the effects of self-management interventions is difficult due to studies' narrow focus and methodological limitations. However, previous studies emphasised that overall, it is important that interventions are (1) tailored to the needs and personal situations of people with ID [3, 6, 8, 39, 40], (2) that their support network is involved [6, 8], and (3) that attention is paid to the transfer of learnt skills to daily life [34, 40].

In this study, for the first time the Academy of Independence (AoI) was evaluated, which is a self-management training for people with ID that incorporates the abovementioned three important elements. This training is tailored to an individual's personal self-management goal (PSMG) and to their preferences regarding how they would like to work on this PSMG and is not limited to a singular domain, or a specific strategy or approach. Participants determine themselves which goal(s) within the domain of self-management they would like to work on, which can concern a daily living skill, but also for example dealing with emotions or social situations. This intrinsic motivation can benefit their personal growth [159]. The training also takes individuals' abilities and disabilities into account, actively involves the support network, and fosters the transfer to daily life. The primary purpose of this study was to investigate whether this self-management training would support people with ID to reach their PSMGs and whether it would increase their independence and reduce their support needs. Furthermore, we explored whether the training would reduce psychopathological behaviour and enhance quality of life.

Method

Procedure

The Medical Ethics Committee of the Leiden University Medical Center declared that neither formal medical ethical approval, nor written informed consent was necessary. Participants were recruited at Raamwerk, a care organisation that provides housing and day care services to people with ID in Noordwijkerhout, the Netherlands. Staff of Raamwerk asked their clients if they wanted to take part in the self-management training. If a client and his or her legal representative agreed on taking part, they received a letter which explained the study and informed them that data would be handled anonymously. If someone would have objected to participation in the study, that participant would have been excluded from the data collection, but not from the training. However, this did not occur. Data were collected 6 months before the start of the training (T0), at the start of the training (T1), and 3, 6, 9, and 12 months later (T2-T5). Before the start of the training (i.e., in the 6 months between T0 and T1) participants received care as usual.

Participants

Participants had to be adults (≥18 years) diagnosed with ID and they at least had to be able to focus on the instructions and exercises during the training. The latter was based on the clinical judgement of someone's support staff. If someone's personal situation would significantly interfere with following the training (e.g., due to severe psychiatric

problems) that person was not eligible for participation. There was no minimal level of cognitive functioning required (e.g., regarding language skills or intelligence level). Seventeen people with ID enrolled in the training. Between T1 and T2, one participant moved away and therefore dropped out of the study. Personal information regarding age, gender, and type of housing was collected. All participants lived within the compound of Raamwerk in Noordwijkerhout, most participants lived in a group home, but some lived semi-independently in their own apartment, receiving only ambulatory support. Diagnostic information was obtained from their electronic client records. Comorbid conditions as classified in the Diagnostic and Statistical Manual of mental disorders [9] were common (e.g., autism spectrum disorders and attention-deficit hyperactivity disorder). Descriptive statistics of the participants are presented in Table 1.

Table 1 Descriptive statistics of the participants

	Intervention group (*n* = 17)
Male, *n (%)*	12 (*70.6*)
Age in years, *M (SD)*	35.9 (*13.9*)
Level of ID, *n*	
Borderline	2
Mild	12
Moderate	3
Full Scale IQ, *M (SD)*	61.1 (*9.6*)
Neuropsychiatric comorbidity, *n*	
Autism spectrum disorder	6
Other	5
Housing	
Group home	13
Semi-independent	4

Training

The self-management training is developed and described in greater detail by the AoI [160]. The aim of the AoI is to promote independent functioning of people with ID and to enable their equal participation in society. Its approach is founded on the methodology 'On Your Own Two Feet' [54, 130]. The AoI's core values encompass a positive and respectful approach, effective learning, nourishment of self-worth, and creating a sense of responsibility in its trainees. The AoI specifically focuses on the abilities and talents of people with ID, instead of their disabilities. AoI trainers encourage and coach people with ID to think and handle things themselves, instead of taking over from them, thereby facilitating their development and fostering a sense of responsibility.

The training was implemented within day care services. Experienced support staff received a 3-day training to become AoI trainers. On average, there were two trainers guiding four participants. At the start of each participant's training, trainers used Motivational Interviewing techniques [161] to discover the PSMGs. Participants were free to choose the number of PSMGs they wanted to work on targeting a skill needed at home, at work, or in their leisure time. Goals had to be specific, measurable, achievable, and relevant. Examples of our participants' PSMGs included cleaning the bathroom, cycling to work, and using the internet. Participants were trained for about half a day per week per PSMG. Training modules took a step-by-step approach and used easy-to-understand language and many photographs and pictograms. Trainers ensured that each participant's training was tailored to their abilities, disabilities, and preferences regarding how they would like to attain their PSMGs, by continuously consulting them about how they would like to be trained. For example, if a participant was unable to read, the training was presented more orally or visually, for example with demonstrations, role-play, or video material. Another example of this tailored approach is that when a participant would report to have difficulties with remembering the steps of a certain task, the trainer would ask what could help him or her, which could be making a personalised checklist together with self-selected instructions, photographs, and pictograms. Other behaviour change techniques [60] that were used by the trainer included prompting, instructions, modelling, and giving feedback (praise, corrective and descriptive feedback). Which behaviour change techniques were applied was based on the goals, needs, and preferences of a participant at a certain moment, in close consultation with the participant. At the start of each training day, trainers talked with participants about what they had done during the previous training and what they had done the rest of the week with regard to their PSMGs. Participants were also asked how they would like to work on their PSMG that training day. In case participants reported or showed to have difficulties with what was previously trained, instructions and exercises were repeated until the participant was ready for a more advanced step. Then, together with the trainer, the participant worked on acquiring further knowledge and skills necessary for obtaining the PSMG. At the end of a training day, trainers provided participants with a self-evaluation form on which they could reflect what they had done and learnt that day and also to look ahead at what they would practice outside of the training during the rest of the week and what they would like to do in the following training session. Some participants were able to do this independently, but if a participant could not read or write or reported to have difficulties with this reflection, the trainer helped the participant to fill in the form. In both cases, this self-evaluation was discussed with the trainer, who also provided feedback. To foster the transfer of learnt skills to daily life, trainers also practised with participants

at their home or work locations or in the community. Participants also took their training material home so they could practise in their everyday environment. Trainers also held close contact with involved family members and support staff to ensure that the support network also knew what they could practice with them. Once a participant reached a PSMG and finished the training module, he or she received a certificate and was given the option to start with a new PSMG directed at a different skill or to leave the training.

Data collection and outcome measures

Primary outcome measures regarded the assessment of goal attainment, independence, and support needs. Secondary measures concerned psychopathological behaviour and quality of life. The questionnaires INVRA-Home (*INventarisatie Van RedzaamheidsAspecten*; Inventory of Independence Aspects), INVRA-Work, and the Supports Intensity Scale (SIS) are more time-consuming. Therefore, these were only collected at T0, T1, T3, and T5. All other questionnaires were filled in at all six measurement points (T0-T5). To limit the burden on participants, they were only involved in the questionnaire on quality of life. For all other measures, the personal tutors from the residential facility and from day care services provided the relevant information.

Attainment of personal self-management goals (PSMGs)

To evaluate the extent to which participants reached their PSMGs, Goal Attainment Scaling (GAS) was used [162-164]. GAS can be flexibly applied to different individuals and goals, also in people with ID [165]. For each PSMG a five-point scale was constructed together with the input of the participant and the AoI trainer. Each level of the GAS had to be specific and measurable. The level of the participant before working on a goal was set at -2 (e.g., Participant does not know the value of any of the euro coins and bills). The desired PSMG was set at level 0 (e.g., Participant knows the value of all euro coins and bills). If the participant had already made progress, but not enough to reach the PSMG, the level was scored as -1 (e.g., Participant knows the value of some, but not all euro coins and bills). A score of +1 or +2 could be obtained if (much) more than the expected goal was achieved (e.g., level +1: Participant knows the value of all the euro coins and bills and can put together amounts up to €5; level +2: Participant knows the value of all the euro coins and bills and can put together amounts up to €10). The GAS was scored every 3 months (T1-T5) by evaluating with AoI trainers, participants, and sometimes support staff from group homes and day care which GAS level was attained by the participant at that point in time. As the levels were specified beforehand, this could be done easily and objectively.

Participants could start with a new PSMG once they attained their previous PSMG (with a GAS score of 0 or higher). The mean raw GAS score was used for the statistical analyses. In addition, learning curves were analysed visually.

Independence in general

The Social Functioning Scale for the Mentally Retarded-Plus [SFSMR-P; 145] consists of 63 items addressing several components of independent functioning at home, at work, and in social situations. The personal tutors filled in whether a participant currently performed these activities independently (score of 1) or not (score of 0). The mean item score was used for the analyses. The SFSMR-P is widely used in Dutch care organisations for people with ID and both the reliability and construct and criterion validity were found to be good [166].

Independence at home and in the community

The level of independence at home and in the community was assessed with INVRA-Home [167]. This questionnaire is developed for the field of ID and lists 114 abilities and skills belonging to several aspects of independence: Personal care and health, Household competence, Cognitive competence, Societal competence, and Social interaction. The personal tutor from the residential facility scored whether the participant performed the activities: a) independently, b) on his or her own initiative, c) for the most part, and d) in an acceptable manner. Per item a score from 0-4 could be obtained. The sum of all item scores was used for the analyses. The inter-rater reliability was found to be substantial and the internal consistency is high [167].

Independence at work

The INVRA-Work questionnaire [168] is developed for people with ID to assess independence at work. It contains 38 items covering three domains: Performance at work, Motor competence, and Attitude at work. For each item a score from 0-3 could be given which reflects to what extent something was performed independently, on the participant's own initiative, and in an acceptable manner. The sum of the three scales was used for the analyses. INVRA-Work has a moderate inter-rater reliability and a high internal consistency [168].

Support needs

To evaluate participants' support needs, the SIS [137] was used. The SIS is a semi-structured interview developed by the American Association of Intellectual and Developmental

Disabilities to assess the intensity of support someone requires to successfully perform several activities. Section 1 includes 49 activities grouped into six domains: Home living, Community living, Lifelong learning, Employment, Health and safety, and Social activities. Section 2 consists of 8 items addressing protection and advocacy. A trained interviewer collected the information from participant's personal tutors. They had to answer whether the participant would require support when having to successfully perform a certain activity and if so, how frequent, how long, and what kind of support would be needed. For the analyses, the total score of section 1 and 2 was used, ranging from 0 to 655. Higher scores mean greater support needs. The reliability and validity were found to be sufficient to excellent [138, 169].

Psychopathological behaviour

The Adult Behavior Checklist [ABCL; 146] was filled in by the participant's personal tutors to assess the occurrence of emotional and behavioural problems. In this questionnaire, 118 items are rated on a 3-point scale, indicating the frequency of occurrence of a particular type of behaviour (0 = not at all, 1 = a little or sometimes, 2 = clearly or often). Items can be divided into eight syndrome scales: Anxious/Depressed, Withdrawn, Somatic complaints, Thought problems, Attention Problems, Aggressive Behaviour, Rule-breaking behaviour, and Intrusive behaviour. The first three syndrome scales form the Internalising Scale, the latter three comprise the Externalising Scale. The Total Problem Score consists of the sum of all 118 items. The mean scores for all scales were used for the analyses. The ABCL has shown to be a reliable and valid instrument to assess psychopathology in people with ID [170].

Quality of life

Participants reported about their quality of life through five items from the World Health Organization Quality of Life Assessment-5 [WHOQOL-5; 171-172]. The items encompass overall quality of life and satisfaction with health, daily activities, relationships, and living conditions. The validity and reliability of the WHOQOL-5 were rated as acceptable to high, respectively [173]. Questions were adapted to people with ID based on the WHOQOL for Disabilities [WHOQOL-DIS; 174]. Questions could be answered on a scale from 1 to 4, with smiley faces (ranging from very unhappy to very happy) representing different levels of satisfaction. The total score was used for the analyses.

Statistical analyses

All data were analysed with IBM Statistical Package for the Social Sciences version 23.0. Descriptive statistics were used to summarise the scores of the participants on the various questionnaires. The scores of the questionnaires used for the analyses were normally distributed (z-scores of skewness and kurtosis |<3.0|). No outliers (> 3 SD) were found.

For the questionnaires, multilevel analyses were conducted to examine possible changes in participants' functioning over time. In the first model, only a random intercept was included, then the overall effect of time on the outcome measures was added as a linear effect. Next, in the final multilevel model, we again used a random intercept and the separate measurement points were added as fixed factors. In this model, T1 (the start of participants' AoI training) was used as a reference point, with which the scores on T0 and T2-5 were compared. This enabled the analyses of whether any changes in functioning already occurred before the start of the training, as well as whether scores improved over time once the training had started. By using multilevel analyses and by collecting data at six different measurement points for each participant, the statistical analyses were less vulnerable to the limitations of a small sample size.

Results

For all outcome measures, descriptive statistics per measurement point are presented in Table 2.

Attainment of personal self-management goals

Figure 1 presents to what extent participants attained their PSMGs over time (except for the participant who dropped out). On average, participants worked on 3.4 PSMGs (range: 1-6 goals) during the 12 months we followed them. Visual analysis of Figure 1 shows that all participants made progress in reaching one or more of their PSMGs, i.e., for at least one PSMG they went from level -2 to level -1 or higher. Once a PSMG was attained (level 0), most participants kept working on other PSMGs, except for the person who dropped out and for another person who left the training after obtaining his certificate after 10 months. Improvements regarding the attainment of PSMGs were mostly already made within the first 3 months. Initial achievements were generally maintained and additional improvements were continued to be made over time, both regarding the initial PSMGs and in some cases also regarding new PSMGs. Of the 52 PSMGs that were set in total,

Table 2 Descriptive statistics for the scores on the questionnaires per measurement point (*n* = 17)

	T0	T1	T2	T3	T4	T5
Independence						
SFSMR-P[1]	0.50	0.54	0.52	0.55	0.53	0.57
mean item score, *M (SD)*	*(0.17)*	*(0.14)*	*(0.11)*	*(0.12)*	*(0.12)*	*(0.11)*
INVRA-Home[2]	251.20	277.65	-	266.19	-	285.13
total score, *M (SD)*	*(53.08)*	*(59.64)*		*(55.99)*		*(46.71)*
INVRA-Work[3]	63.83	62.25	-	61.94	-	64.06
total score, *M (SD)*	*(19.80)*	*(15.72)*		*(18.08)*		*(14.15)*
Support needs						
SIS[4] Section 1+2	283.53	278.06	-	246.50	-	247.94
total score, *M (SD)*	*(56.68)*	*(51.70)*		*(69.27)*		*(45.33)*
Psychopathological behaviour						
ABCL[5] Internalising Scale	0.52	0.48	0.49	0.61	0.46	0.43
mean item score, *M (SD)*	*(0.31)*	*(0.31)*	*(0.22)*	*(0.35)*	*(0.24)*	*(0.21)*
ABCL[5] Externalising Scale	0.42	0.48	0.54	0.51	0.45	0.45
mean item score, *M (SD)*	*(0.33)*	*(0.32)*	*(0.38)*	*(0.33)*	*(0.28)*	*(0.25)*
ABCL[5] Total Problems Scale	0.41	0.48	0.51	0.54	0.46	0.45
mean item score, *M (SD)*	*(0.17)*	*(0.27)*	*(0.25)*	*(0.28)*	*(0.22)*	*(0.22)*
Quality of life						
WHOQOL-5-DIS[6]	15.29	15.65	15.53	15.20	16.50	15.63
total score, *M (SD)*	*(2.95)*	*(2.62)*	*(2.49)*	*(3.16)*	*(3.06)*	*(2.83)*

[1] Social Functioning Scale for the Mentally Retarded-Plus (range: 0–1)
[2] Inventory of Independence Aspects-Home (range: 0–464)
[3] Inventory of Independence Aspects-Work (range: 0–114)
[4] Supports Intensity Scale (range 0–655)
[5] Adult Behavior Checklist (range: 0–1)
[6] World Health Organization Quality of Life Assessment-5 for Disabilities (range: 5–20)

26 PSMGs (50%) were attained by 13 participants taken together (level 0). For 13 of these 26 attained PSMGs (25% of the total), participants even exceeded the goal they had set (level +1 or +2). Regarding the 26 PSMGs that were not attained by 13 of the participants, mostly small improvements were nevertheless made (level -1). Only for four PSMGs no improvement occurred (level -2). However, in these cases the four corresponding participants attained at least one other PSMG. Furthermore, in three of these cases, participants started with this PSMG at a later stage (around T2, T3, or T4). One participant relapsed in a previously attained PSMG, although in the meantime she progressed in three other PSMGs.

Questionnaires

In the multilevel analyses of the various questionnaires, effects of age and gender were also explored, but no interaction effects were found with the various measurement points on any of the questionnaires (all *p*-values > .05).

Independence

The analysis of the SFSMR-P data showed that there was no difference in the level of independence between T0 and T1. Furthermore, there were no differences between T2-T5 compared to T1 (all *p*-values > .05), indicating that the level of independence did not change once participants started with the training. Similar results were found for INVRA-Home and INVRA-Work.

Support needs

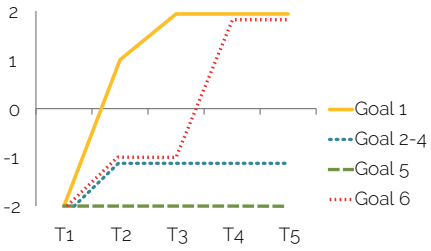
Participants' support needs did not differ between T0 and T1. However, participants had significantly lower support needs at the following measurement points of the SIS, i.e., T3 ($p < .01$, $d = 0.57$) and T5 ($p < .01$, $d = 0.55$) compared to T1 (Table 3).

Table 3 Results of the longitudinal multilevel analysis of SIS scores with T1 as the reference point

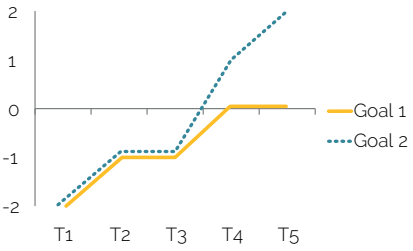
	Coefficient (b)	SE	t	F	*P*-value	95% Confidence interval	
Intercept	278.06	13.20	21.07	443.99	.00	251.08	305.04
T0	5.47	10.87	0.50	0.25	.62	-16.37	27.31
T3	-33.24	11.10	-2.99	8.97	.00*	-55.55	-10.94
T5	-31.80	11.10	-2.87	8.21	.01*	-54.11	-9.50

* *P* <.01

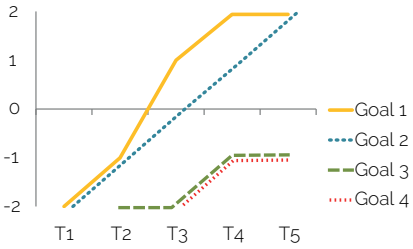
SIS, Supports Intensity Scale



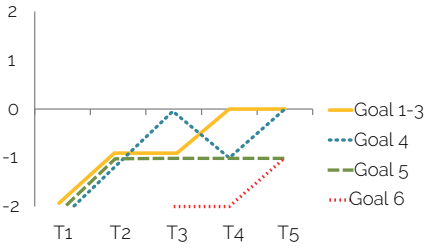
Participant 1



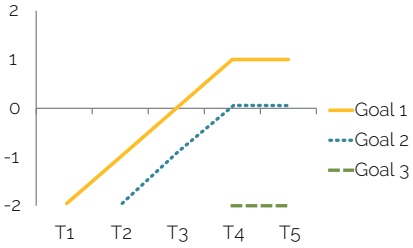
Participant 2



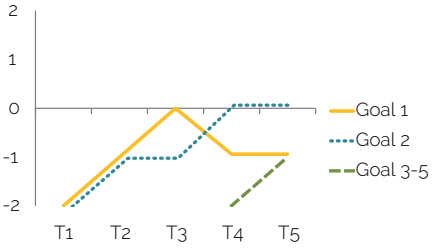
Participant 3



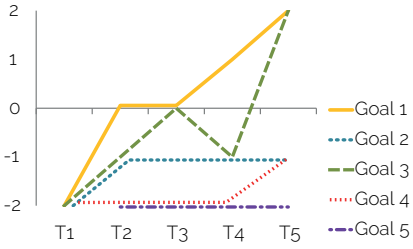
Participant 4



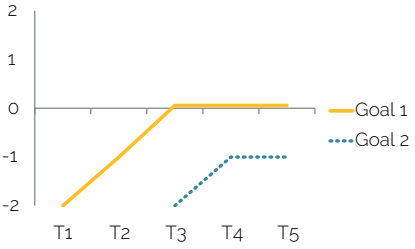
Participant 5



Participant 6

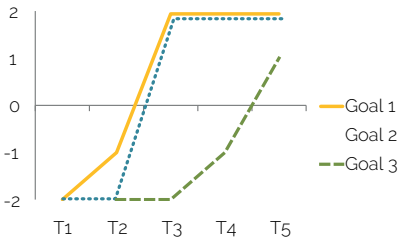


Participant 7

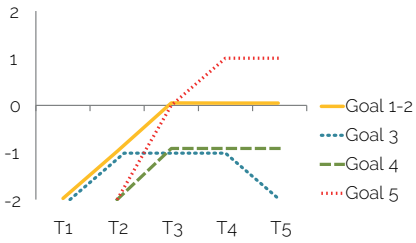


Participant 8

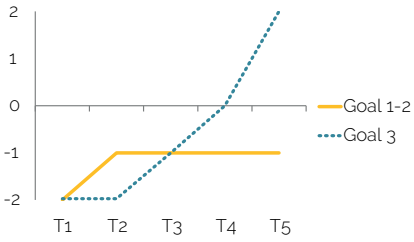
Figure 1. Goal Attainment Scaling (GAS) scores for each personal self-management goal (PSMG) per measurement point (T1-T5)
Level 2: Participant has attained much more than the PSMG
Level 1: Participant has attained more than the PSMG
Level 0: Participant has attained the PSMG
Level -1: Participant has made progress, but not enough to attain the PSMG
Level -2: Participant's initial level before working on the PSMG



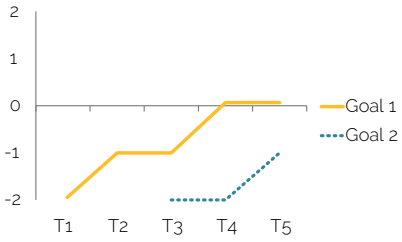
Participant 9



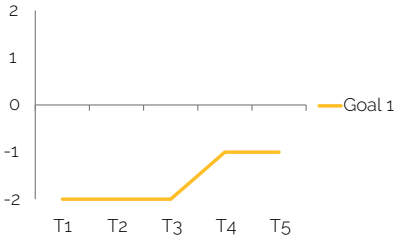
Participant 10



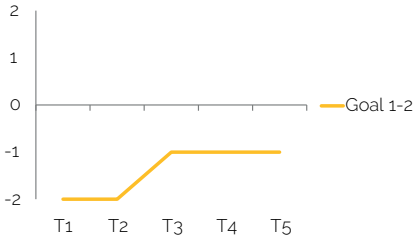
Participant 11



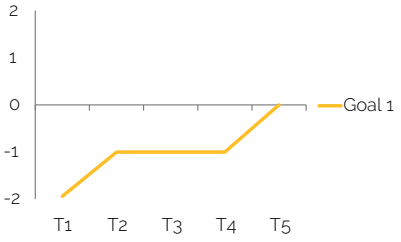
Participant 12



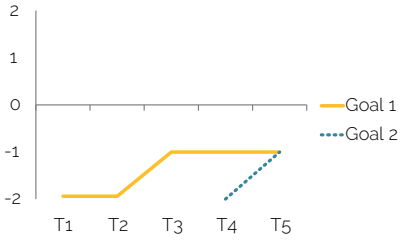
Participant 13



Participant 14



Participant 15



Participant 16

Figure 1. Continued

Psychopathological behaviour

The analysis of the ABCL Total Problems Scale revealed no significant differences in the occurrence of psychopathological behaviour when T0 was compared to T1, as well as when T2-T5 were compared to T1 (all *p*-values > .05). Similar results were found when the Internalising and Externalising Scale were analysed separately.

Quality of life

There were no changes in quality of life, as measured by the WHOQOL-5-DIS. When comparing the scores at T0 to those at T1 and when comparing T2-T5 to T1 no significant differences were found (all *p*-values > .05).

Discussion

This study evaluated a self-management training for people with ID that aims to enhance independent functioning in daily life and that can be tailored to individuals' PSMGs, abilities, and preferences regarding how they would like to work on these PSMGs. Results of the follow-up measurements after the start of the training indicate that the training contributed to the attainment of PSMGs, while also decreasing participants' support needs. The level of independence was not affected, nor was the occurrence of psychopathological behaviour and quality of life.

Principal findings

This study's findings support a lifelong learning for people with ID. Significant improvements were observed in the attainment of PSMGs already within the first 3 months after the start of the training and more improvements were continued to be made during the following months. All participants made improvements in attaining their PSMGs. Half of all PSMGs were attained and for a quarter of these attained PSMGs, participants even exceeded the goal they had set. Regarding the unattained PSMGs, smaller improvements were nonetheless made. Although the PSMGs were often very specific, reaching these goals can be of great personal significance to an individual. Learning to cycle to work or learning to use the internet, as was the case for some of our participants, can greatly contribute to one's community participation [e.g., 121, 175]. The training's effectivity was further supported by the finding that participants' support needs significantly decreased once they started with the training. Elements of the training's approach, i.e., tailoring to the individual, involving the support network, and assisting the transfer of learnt skills to

daily life seem to benefit people with ID. This has already been suggested in previous research [3, 6, 8, 34, 39, 40, 48], however our study for the first time evaluated a self-management training in which all these elements were combined and which showed that this is a promising approach.

The finding that the level of independence did not change might be explained by the fact that participants only worked on specific PSMGs. Although these were aimed at promoting independence, it is plausible that attaining only some specific PSMGs does not significantly improve overall independence. The used outcome measures may also not be sensitive enough to detect these small improvements. Furthermore, not all participants' PSMGs were included in the independence questionnaires, so the successful attainment of a PSMG was not necessarily reflected in these questionnaires' scores. In addition, given the overall learning deficit of people with ID [9], significant improvements in independence are perhaps also not to be expected within 12 months' time. Future studies have to focus on more long-term effects of these types of self-management trainings on independence. Another finding was that the occurrence of psychopathological behaviour and quality of life did not change. As the training did not directly target these domains, improvements in these domains might only occur over longer periods of assessments and if more PSMGs are attained and the level of independence increases [4, 53]. Regarding quality of life, it must also be noted that we used a brief questionnaire to minimise the burden on participants. Therefore, not all aspects of quality of life [102, 176] could be included and the questionnaire might not have been sensitive enough to detect changes over time.

Limitations and future research

An important limitation of the study concerns the relatively small sample size which mostly consisted of people with mild ID. Whether the results can be generalised to all levels of ID is therefore unknown. Another limitation is that we were unable to conduct a randomised controlled trial, as the problems of people with ID can be so diverse and complex that forming an adequate control group is challenging. Furthermore, 8 months after the AoI was implemented, almost all participants moved to a different apartment or group home within the organisation's compound. For several months, participants were unsure of the house in which they were going to live, whom their fellow residents would be, and which staff members would be working in their homes. As this was very stressful to them, this might have negatively affected participants' functioning, thereby potentially having confounded our results. Last, the support network was perhaps

not always optimally involved. Although we did not conduct a process evaluation, the support staff from other locations were possibly not always sufficiently aware of what participants were training at the AoI and how to support their development at home or at day care. This might have limited the transfer to daily life and the effects of the training. Such a process evaluation would have been of additional value to this study, just as the inclusion of interviews or focus groups with participants, trainers, support staff, and family members about how they evaluated the training. This could have increased the insight into effects of the training that cannot be easily measured through questionnaires. Regarding the latter, the use of direct observations of participants' level of self-management, independence, support needs, and behaviour would also have contributed to a more complete view of the training's effects.

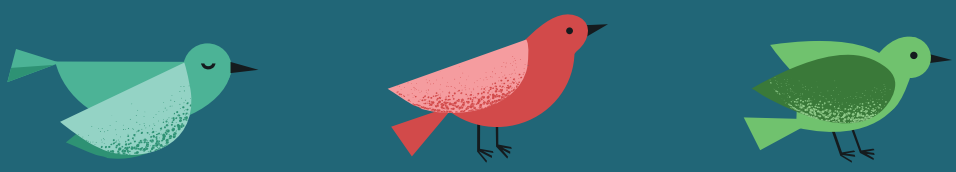
These limitations call for a further study with a larger sample, including people with various levels of ID. In addition to the inclusion of qualitative and observational measures, the use of validated self-reports regarding the measured domains should be considered, to further investigate the perspectives of participants themselves. Extra attention to the transfer of learnt skills to daily life should also be facilitated, by ensuring that family and support staff are actively involved.

Conclusions

To our best knowledge, this is the first study to report on a self-management training for people with ID that is broadly applicable and adaptable to people's different goals, abilities, and preferences regarding their way of training for their goals. The training was found to contribute to the attainment of PSMGs and to the reduction of support needs once participants started the training. This promising result justifies continued research on its implementation and further evaluation of the training's effects on specific subgroups of people ID to study who benefits most from the training. Further research and implementation may not only positively influence the lives of people with ID by helping them manage their affairs more independently, but may also reduce the burden on family and support staff because of participants' decreased support needs.

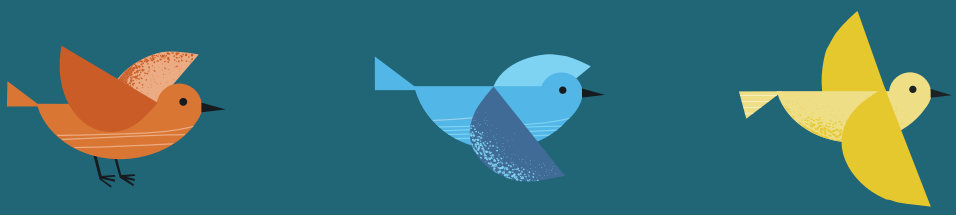
Acknowledgements

We thank all study participants and staff members of Raamwerk and the Academy of Independence who contributed to the study, research assistants Arthur van Rhijn and Marlou Gosman, and Mathilde Verdam for her contribution to the statistical analyses.



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

Intellectual disabilities (ID) are commonly defined as significant deficits in intellectual and adaptive functioning that originate in the developmental period (i.e., < 18 years). The deficits lead to various limitations in daily life for which ongoing support is needed. While there is a growing view that people with ID should participate as fully as other members of society, our society is also becoming more complex. Seemingly as a result of this, people with ID have been experiencing increasing difficulties with functioning independently. The difficulties in self-managing everyday affairs do not only apply to the home situation, but also to academic, occupational, social, recreational, and community settings. As a consequence, people with ID are mostly at least to some extent dependent on others. However, people with ID generally find it important to manage their activities themselves and obtaining a greater level of independence could positively contribute to their quality of life. In addition, it could benefit their support network, as family members and support staff commonly experience difficulties with meeting the demand for care of people with ID. Taken together, increasing the abilities of people with ID to self-manage their affairs deserves further attention. The aim of this dissertation was therefore to obtain a greater understanding of how self-management can be promoted in people with ID.

Self-management can be seen as an overarching term involving all cognitions and actions of persons that deliberately influence their behaviour in order to realise self-selected outcomes. Self-management relates to concepts as self-determination, autonomy, independence, and self-reliance. Self-determination and autonomy are separate concepts that both concern making self-selected choices. Independence and self-reliance are similar concepts that involve the abilities to take actions to manage one's own affairs and to provide for oneself, without requiring help and support from others. For the purpose of this dissertation, a literature review was conducted that focused on self-management interventions for people with ID. In addition, the perspectives of various stakeholders on promoting independence in people with ID were gathered. Furthermore, a questionnaire was developed that assesses the degree to which support staff display behaviours that promote independence. To conclude, self-management interventions were evaluated for both support staff and people with ID.

Chapter 2 presents a systematic literature review in which a broad range of self-management interventions for people with ID were described and evaluated, with a specific focus on the effectiveness of the interventions and the applied behavioural change

techniques (BCTs). Self-management interventions for people with ID generally targeted a singular practical skill within a certain context, such as at home (e.g., meal preparation) or in the community (e.g., grocery shopping). All interventions targeted the desired self-management behaviour through the application of BCTs by the intervention provider. Providers often combined several antecedent BCTs, mainly modelling, instructing, and prompting, with several consequent BCTs, such as providing feedback or reinforcement. In only a third of interventions, participants with ID themselves were trained to apply BCTs. These mostly concerned antecedent BCTs, such as self-instructions and the use of cues, and consequent BCTs, including self-recording, self-monitoring, self-evaluation, and self-reinforcement. All reviewed self-management interventions were reported to be effective and, wherever investigated, positive effects generally maintained over time. In addition, the targeted self-management behaviour often generalised to other tasks or situations. These findings should, however, be interpreted with caution due to a high risk of bias. Sample sizes were often very small, a (multiple) case study design was used in two thirds of studies, and only few studies included a control group. Nonetheless, it seems promising that potentially effective interventions are available that can promote self-management in people with ID.

In **Chapter 3** perspectives were obtained on the promotion of independence, by conducting focus groups with people with ID, their legal representatives, and support staff. The respondents of our focus groups regarded independence as a broad concept that includes knowledge about how to do things, the abilities to perform activities, and taking care of yourself. The level of independence of people with ID was reported to widely vary, with some people requiring help with performing the basic Activities of Daily Living (ADL), while others are able to live almost independently. Regardless of the level of independence, respondents agreed that all people with ID need at least some support from others. In addition, it was said that most people with ID have the ability and the desire to become more independent. They generally want to lead a 'normal' life in which they can live, work, and travel independently. Various other learning goals were expressed in addition, such as dealing with one's emotions. When trying to promote independence, respondents reported to experience several barriers. These concern barriers at the level of support staff (e.g., lack of time or skills), of the family (e.g., taking over tasks), and of the persons with ID themselves (e.g., cognitive and emotional difficulties). In order to overcome these barriers and promote independence in this population, more support and time seem necessary, as well as a clear, step-by-step, and tailored approach. To get all family and support staff members to concur on how to guide a person with ID

towards a greater level of independence, good communication between all involved parties was reported to be essential. Possible advantageous outcomes of a greater level of independence included an enhanced self-confidence, self-worth, and sense of pride, in addition to a better mood. One of the few disadvantages that was mentioned concerned that more independent people with ID would be more on their own, leading to loneliness and having to solve everything themselves. In addition, several risks were described, which concerned a greater exposure to hazardous situations and being overestimated by others. The latter could lead to too high demands and consequentially to emotional disturbances and a relapse in functioning.

Chapter 4 describes the implementation and evaluation of a staff training, in which staff are taught how to promote self-management in people with ID. Staff learn to adopt a positive attitude towards people with ID, by focusing on their clients' abilities, strengths, and possibilities, and how to stimulate their development in the domain of self-management. In this regard, staff are taught to encourage people with ID to handle things themselves, instead of taking over from them. This study adopted a mixed-methods approach, by evaluating the staff training quantitatively through the use of questionnaires and qualitatively by conducting focus groups with trained staff members. The questionnaires were filled in by support staff and concerned the level of independence and self-reliance of their clients with ID, as well as their support needs and the occurrence of behavioural problems. It was found that in the long term, people with ID whose staff were trained (intervention group) showed a small, but significant increase in their level of independence and self-reliance, whereas people with ID from the comparison group did not. No effect of the training was found on the level of support needs and the occurrence of behavioural problems. The limited effects of the training were confirmed by the trained staff members who participated in the focus groups. According to these respondents, they did not learn many new things from the training, apart from asking their clients more questions. However, still some changes within the teams were noticed. For instance, staff reported an increased awareness that it is better if they do not take over so much from people with ID and that they should focus on what people with ID are able to handle themselves. Furthermore, it was said that after the training, staff listened more carefully to their clients, instead of thinking on their behalf. It was also expressed that staff did not take over as much anymore and that they more often dared to let go and let the clients take charge.

In **Chapter 5** the role of support staff in guiding people with ID was examined in greater detail, with a specific focus on how staff contribute to a greater level of independence. As no suitable instruments were yet available that assess independence-promoting behaviour of staff, we developed and initially validated a self-report questionnaire for support staff that measures the degree to which staff display behaviours that promote independence in people with ID. To this end, we made an inventory of performance objectives for support staff that concerned behaviours that are important for promoting independence in people with ID. This list was converted into a questionnaire (Leiden Independence Questionnaire for Support Staff; LIQSS), which was reviewed by a group of experts to ensure its face validity. The final version of the 22-item questionnaire was found to consist of three meaningful subscales. The first subscale was termed 'Communication, Agreements, and Coordination' and pertains to communicating and coordinating on something with others and making agreements about the way to guide people with ID towards their learning goals. The second subscale, 'Positive Encouragement and Tailoring', concerns staff's behaviour towards people with ID during the learning process. These behaviours concern positive encouragement and adapting the provided support to the existing knowledge, skills, and preferred way of learning of an individual. The third subscale, 'Supporting Independent Performance', relates to supporting independent performance by letting people with ID handle things themselves as much as possible. The questionnaire was found to be a reliable psychometric instrument, as all subscales showed to have a high internal consistency. Although further validation of the questionnaire and fine-tuning of the questions and answering categories is required to minimise socially desirable answers, the questionnaire has a high potential and promise for use in both scientific research and clinical practice.

Chapter 6 reports on the implementation and evaluation of a self-management training for people with ID themselves, the so-called Academy of Independence. In this weekly training, participants with ID worked on self-selected self-management goals covering a wide range of everyday affairs. The training was tailored to their goals, abilities, disabilities, and preferred ways of learning and took a stepwise approach. Attention was also paid to involving the support network and to the transfer of learnt skills to daily life, by practising with participants in their home or work situation or in the community. The findings indicated that the training positively contributed to the attainment of self-management goals and to the reduction of support needs. All participants made progress in reaching one or more of their self-management goals, mostly already within the first 3 months of the training. Achievements generally maintained over time and additional

improvements were continued to be made. The overall level of independence, the occurrence of psychopathological behaviour, and quality of life remained unchanged. The latter findings might be explained by the fact that participants worked on very specific goals. Although improvements in such particular goals do not seem to affect the overall level of independence or quality of life, they can still be of great personal relevance to an individual, which justifies continued research and implementation of this self-management training.

In sum, this dissertation underlines the importance of promoting self-management in people with ID. Whereas previous self-management interventions mostly focused on singular practical skills, we aimed to target the promotion of overall self-management. We concluded from our focus group study that people with ID generally have the desire to become more independent, but that they are hindered by several barriers, such as a lack of time for support staff to guide them, and staff and family members taking over, partially as a result of fear or overprotectiveness. When promoting independence in this population, more support and time seem necessary, as well as a clear, step-by-step, and tailored approach, and good communication between all parties involved. Support staff play an important role in this regard. Therefore, we implemented and evaluated a staff training. In this training, staff were taught to adopt a positive approach towards their clients with ID and to stimulate their self-management, by encouraging clients to handle things themselves instead of taking over from them. Although the effects of the training were limited, this study did give direction to the further development, implementation, and evaluation of similar kind of staff trainings. In addition to the evaluation of this staff training, we also developed a self-report questionnaire for support staff, that assesses to what extent support staff promote independence in their clients with ID. In this study, a number of staff behaviours were found to be important for promoting independence in people with ID. This concerns good communication and coordination between all people involved, a tailored approach, positive encouragement of people with ID during the learning process, and letting them handle things as much as possible themselves. The lessons learnt from the abovementioned studies were embedded in our final study, in which we implemented and evaluated a self-management training for people with ID where they worked on a wide range of self-selected self-management goals. In this tailored training, attention was also paid to the transfer to daily life and to the involvement of the support network. It was found that this training positively contributed to the attainment of self-management goals and to the reduction of support needs, although the overall level of independence, the occurrence of psychopathological behaviour, and quality

of life were unaffected. Future research may build upon the findings of this dissertation to further increase our understanding of how self-management can be promoted even more effectively in people with ID.

Nederlandse samenvatting

Verstandelijke beperkingen (VB) worden gekenmerkt door significante tekorten in het intellectuele en adaptieve functioneren die al in de ontwikkelingsperiode (< 18 jaar) hun oorsprong hebben. Deze tekorten leiden tot allerlei beperkingen in het dagelijks leven, waardoor mensen met VB vaak ondersteuning nodig hebben van anderen. Terwijl in toenemende mate de overtuiging groeit dat mensen met VB net zo volwaardig moeten kunnen deelnemen aan de samenleving als ieder ander, wordt onze samenleving tegelijkertijd steeds complexer. Mogelijk als een gevolg van hiervan, ervaren mensen met VB steeds meer moeite zelfstandig te functioneren. De moeilijkheden waar ze in het dagelijks leven tegenaan lopen betreffen niet alleen de thuissituatie, maar ook school, werk, en sociale, recreatieve en maatschappelijke situaties. Mensen met VB zijn hierdoor vaak tot op zekere hoogte afhankelijk van anderen. Zij vinden het doorgaans echter belangrijk hun activiteiten zelf te managen en het behalen van een grotere mate van zelfstandigheid zou dan ook positief kunnen bijdragen aan hun kwaliteit van leven. Ook voor het steunnetwerk zou het gunstig kunnen zijn wanneer mensen met VB zelfstandiger zouden zijn, aangezien het voor familieleden en begeleiders vaak een uitdaging is te voldoen aan de zorgvraag van mensen met VB. Al met al is er meer aandacht nodig voor het vergroten van de vaardigheden van mensen met VB om hun dagelijkse zaken zelf te regelen. Het doel van dit proefschrift was daarom meer inzicht te verkrijgen in hoe zelfmanagement bevorderd kan worden bij mensen met VB.

Zelfmanagement kan worden beschouwd als een overkoepelende term, die alle cognities en handelingen omvat die betrekking hebben op het doelbewust beïnvloeden van het gedrag om zelfgekozen uitkomsten na te streven. Zelfmanagement is gerelateerd aan concepten als zelfdeterminatie, autonomie, zelfstandigheid en zelfredzaamheid. Zelfdeterminatie en autonomie zijn afzonderlijke concepten gericht op het maken van zelfgeselecteerde keuzes. Zelfstandigheid en zelfredzaamheid zijn vergelijkbare concepten die de vaardigheden omvatten zelf actie te ondernemen om diens eigen zaken te regelen en voor zichzelf te zorgen, zonder daarbij hulp en ondersteuning nodig te hebben van anderen. Ten behoeve van dit proefschrift is een literatuuroverzicht gemaakt van studies naar zelfmanagementinterventies voor mensen met VB. Tevens zijn de perspectieven van diverse betrokken partijen verzameld die betrekking hebben op het bevorderen van de zelfstandigheid van mensen met VB. Daarnaast is een zelfrapportagevragenlijst ontwikkeld die meet in welke mate begeleiders de zelfstandigheid van mensen met VB

helpen bevorderen. Tot slot is zowel een zelfmanagementinterventie voor begeleiders geëvalueerd als een zelfmanagementinterventie voor mensen met VB.

Hoofdstuk 2 omvat een systematische literatuurreview waarbij een breed scala aan zelfmanagementinterventies voor mensen met VB werd beschreven en geëvalueerd. In deze studie lag de focus met name op de effectiviteit van de interventies en de toegepaste gedragsveranderingstechnieken (GVT). Zelfmanagementinterventies voor mensen met VB richtten zich over het algemeen op een enkele praktische vaardigheid in een bepaalde context, bijvoorbeeld binnen de thuissituatie (zoals maaltijdbereiding) of in de maatschappij (zoals boodschappen doen). Alle interventies werkten aan het beoogde zelfmanagementgedrag door GVT toe te passen via de aanbieder van de interventie (zoals een trainer of begeleider). De aanbieders combineerden vaak meerdere antecedente GVT (met name het voordoen van het gedrag en het geven van instructies en aanwijzingen) met meerdere consequente GVT (zoals het geven van feedback of een beloning). Slechts in een derde van de interventies werden deelnemers met VB getraind zelf GVT toe te passen. Wanneer dit het geval was, betroffen dit meestal antecedente GVT zoals zelfinstructies en het gebruik van aanwijzingen, en consequente GVT, waaronder zelfregistratie, zelfmonitoring, zelfevaluatie en zelfbeloning. Over alle bestudeerde zelfmanagementinterventies werd gerapporteerd dat deze effectief waren en, voor zover dit was onderzocht, dat de positieve effecten aanhielden over de tijd. Daarnaast generaliseerde het beoogde zelfmanagementgedrag vaak naar andere taken of situaties. De bevindingen moeten echter met voorzichtigheid worden geïnterpreteerd gezien het hoge risico op *bias*. De steekproefomvang was doorgaans zeer klein, in twee derde van de studies was er sprake van een *case study design* waarbij slechts één of enkele participanten waren geïncludeerd en slechts enkele studies hadden een controlegroep. Desalniettemin lijkt het veelbelovend dat er interventies beschikbaar zijn die mogelijk effectief zijn voor het bevorderen van zelfmanagement bij mensen met VB.

In **Hoofdstuk 3** zijn verschillende visies verzameld ten aanzien van het bevorderen van de zelfstandigheid van mensen met VB, door middel van focusgroepen met mensen met VB en hun wettelijk vertegenwoordigers en begeleiders. De respondenten van onze focusgroepen beschouwden zelfstandigheid als een breed begrip. Het omvat volgens hen kennis over hoe men dingen doet, het bezitten van vaardigheden om activiteiten uit te voeren en het voor zichzelf kunnen zorgen. Over de mate van zelfstandigheid van mensen met VB werd gezegd dat deze sterk verschilt van persoon tot persoon, waarbij sommige mensen met VB hulp nodig hebben bij het uitvoeren van basale

Algemene Dagelijkse Levensverrichtingen (ADL), terwijl anderen in staat zijn bijna geheel zelfstandig te wonen. Ongeacht de mate van zelfstandigheid, waren de respondenten het erover eens dat alle mensen met VB op zijn minst enige ondersteuning nodig hebben van anderen. Daarnaast werd aangeven dat de meeste mensen met VB het vermogen en de wens hebben zelfstandiger te worden. Over het algemeen willen ze een 'normaal' leven kunnen leiden waarin ze zelfstandig kunnen wonen, werken en reizen. Daarnaast werden ook nog andere doelen genoemd, zoals het kunnen omgaan met emoties. Respondenten gaven aan diverse belemmeringen te ervaren bij het bevorderen van de zelfstandigheid van mensen met VB. Deze betroffen belemmeringen ten aanzien van begeleiders (zoals een gebrek aan tijd of vaardigheden), familieleden (zoals het overnemen van taken) en mensen met VB zelf (zoals cognitieve of emotionele problemen). Om deze obstakels te overwinnen en de zelfstandigheid in deze populatie te bevorderen lijken vooral meer tijd en ondersteuning noodzakelijk, net als een eenduidige, stapsgewijze en geïndividualiseerde aanpak. Volgens de respondenten was verder goede communicatie tussen alle betrokken partijen essentieel om onder alle familieleden en begeleiders overeenstemming te krijgen over *hoe* iemand met VB te begeleiden naar meer zelfstandigheid. Mogelijke voordelen van een grotere mate van zelfstandigheid betroffen verbeteringen in het zelfvertrouwen, de eigenwaarde en het gevoel van trots, naast een verbeterde stemming. Een van de weinig nadelen die werd genoemd was dat een hogere mate van zelfstandigheid gepaard zou kunnen gaan met er ook meer alleen voor staan, wat ertoe zou kunnen leiden dat men vereenzaamt en dingen veelal zelf moet zien op te lossen. Ook werden enkele risico's benoemd van een grotere mate van zelfstandigheid. Deze risico's hebben betrekking op een verhoogde blootstelling aan potentieel gevaarlijke situaties en het overschat worden door anderen. Dit laatste zou kunnen leiden tot overvraging, met emotionele problemen en een achteruitgang in functioneren als gevolg.

Hoofdstuk 4 beschrijft de implementatie en evaluatie van een training voor begeleiders waarbij begeleiders werd geleerd hoe ze zelfmanagement kunnen bevorderen bij mensen met VB. Begeleiders leerden een positieve houding aan te nemen ten aanzien van mensen met VB, door zich te richten op de vermogens, sterktes en mogelijkheden van hun cliënten. Begeleiders leerden ook hoe ze de ontwikkeling van cliënten op het gebied van zelfmanagement konden stimuleren. De studie had een *mixed-methods* aanpak door de training zowel kwantitatief te evalueren door middel van vragenlijsten als ook kwalitatief door middel van focusgroepen met getrainde begeleiders. De vragenlijsten gingen over de mate van zelfredzaamheid van cliënten met VB, hun

ondersteuningsbehoeften en gedragsproblemen. Deze vragenlijsten werden ingevuld door begeleiders. Uit de resultaten bleek dat mensen met VB wiens begeleiders waren getraind (de interventiegroep) op de langere termijn een kleine, maar significante toename lieten zien in de mate van zelfredzaamheid, terwijl dat niet het geval was bij de mensen met VB uit de vergelijkingsgroep. Er werd geen trainingseffect gevonden op de mate van ondersteuningsbehoeften en het voorkomen van gedragsproblemen. De beperkte effecten van de training werden bevestigd door de bevindingen van de focusgroepen met getrainde begeleiders. Volgens hen hadden ze niet veel nieuwe dingen geleerd in de training, behalve het stellen van meer vragen aan hun cliënten. Desondanks werden er enkele veranderingen bemerkt binnen de teams. Begeleiders rapporteerden bijvoorbeeld een verhoogd besef dat het beter is als zij minder overnemen van mensen met VB en dat ze zich meer zouden moeten richten op wat mensen met VB zelf kunnen doen. Er werd ook gezegd dat begeleiders na afloop van de training beter luisterden naar hun cliënten, in plaats van dingen voor hen in te vullen. Er werd ook benoemd dat begeleiders minder overnamen dan voorheen en dat ze vaker hun cliënten los durfden te laten en hen meer de regie gaven.

In **Hoofdstuk 5** werd nader bestudeerd hoe begeleiders bijdragen aan een grotere mate van zelfstandigheid. Aangezien er nog geen geschikte instrumenten beschikbaar waren om zelfstandigheid-bevorderend gedrag onder begeleiders te meten, hebben wij een zelfrapportagevragenlijst voor begeleiders ontwikkeld en gevalideerd. Deze vragenlijst meet in welke mate begeleiders gedrag vertonen dat de zelfstandigheid van mensen met VB bevordert. Wij hebben hiervoor een lijst opgesteld met de beoogde gedragingen (*performance objectives*) van begeleiders die van belang zijn bij het bevorderen van de zelfstandigheid van mensen met VB. Deze lijst werd omgezet naar een vragenlijst (Leidse Zelfredzaamheidsvragenlijst voor Begeleiders; *Leiden Independence Questionnaire for Support Staff; LIQSS*) die door een groep van experts werd beoordeeld op de indruksvaliditeit (*face validity*). De uiteindelijke versie van de vragenlijst bestaat uit 22 items verdeeld over drie betekenisvolle subschalen. De eerste subschaal werd 'Communicatie, Afspraken en Afstemmen' genoemd en heeft betrekking op het communiceren, afstemmen en het maken van afspraken met anderen over hoe mensen met VB begeleid worden ten aanzien van hun leerdoelen. De tweede subschaal, 'Positieve Aanmoediging en Aanpassen', gaat over het gedrag van begeleiders ten aanzien van mensen met VB tijdens het leerproces. Dit gedrag betreft positieve aanmoediging en het aanpassen van de ondersteuning aan de reeds aanwezige kennis en vaardigheden van een individu en diens leerstijl. De derde subschaal,

'Ondersteunen van Zelfstandige Uitvoering', is gerelateerd aan het ondersteunen van de zelfstandige uitvoering van activiteiten door mensen met VB. De vragenlijst bleek een betrouwbaar psychometrisch instrument te zijn, aangezien alle subschalen een hoge interne consistentie lieten zien. Hoewel verdere validatie van de vragenlijst en verfijning van de vragen en antwoordcategorieën noodzakelijk is om sociaal wenselijke antwoorden tot een minimum te beperken, is de vragenlijst veelbelovend voor gebruik in zowel wetenschappelijk onderzoek als de klinische praktijk.

Hoofdstuk 6 beschrijft de implementatie en evaluatie van een zelfmanagementtraining voor mensen met VB, de zogenaamde academie voor Zelfstandigheid. In deze wekelijkse training werkten deelnemers met VB aan zelfgekozen zelfmanagementdoelen die een breed scala van alledaagse zaken omvatten. De stapsgewijze training werd aangepast aan de doelen, vermogens, beperkingen en leerstijlen van een individu. Er werd ook aandacht besteed aan het betrekken van het steunnetwerk en de *transfer* van het geleerde naar het dagelijks leven. Dit laatste werd bereikt door met deelnemers ook te oefenen in hun woon- of werksituatie of in de maatschappij. De resultaten gaven aan dat de training positief bijdraagt aan het behalen van zelfmanagementdoelen en aan het verminderen van de ondersteuningsbehoeften. Alle deelnemers boekten vooruitgang in het behalen van een of meerdere van hun zelfmanagementdoelen, doorgaans al binnen de eerste drie maanden van de training. De behaalde prestaties werden doorgaans behouden en veelal werd daarna nog verdere vooruitgang geboekt. De algehele mate van zelfstandigheid, het voorkomen van problemen in emotie en gedrag, en de kwaliteit van leven bleven evenwel onveranderd. Deze laatstgenoemde bevindingen zouden verklaard kunnen worden door het feit dat deelnemers aan hele specifieke doelen werkten. Hoewel vooruitgang in enkele van zulke specifieke doelen niet de algehele mate van zelfstandigheid of kwaliteit van leven lijkt te beïnvloeden, kan de geboekte vooruitgang voor een individu wel van groot persoonlijk belang zijn, wat verder onderzoek en implementatie van deze zelfmanagementtraining rechtvaardigt.

Samengevat, dit proefschrift benadrukt het belang van het bevorderen van zelfmanagement bij mensen met VB. Waar vorige zelfmanagementinterventies zich voornamelijk richtten op een enkele praktische deelvaardigheid, richtten wij ons op het bevorderen van zelfmanagement in het algemeen. Naar aanleiding van ons focusgroeponderzoek concludeerden wij dat mensen met VB doorgaans de wens hebben zelfstandiger te worden, maar dat ze belemmerd worden door diverse obstakels, zoals een gebrek aan tijd voor begeleiders hen te begeleiden, maar ook het overnemen van taken door

begeleiders en familieleden uit angst of (over)bescherming. Bij het bevorderen van de zelfstandigheid in deze populatie lijkt het van belang dat er meer tijd en ondersteuning beschikbaar is, naast een eenduidige, stapsgewijze en geïndividualiseerde aanpak en goede communicatie tussen alle betrokken partijen. Begeleiders spelen hierbij een belangrijke rol. Om die reden hebben wij een training voor begeleiders geïmplementeerd en geëvalueerd waarin zij werden geschoold in het bevorderen van zelfmanagement. In deze training werd begeleiders geleerd een positieve houding aan te nemen ten aanzien van hun cliënten en cliënten dingen zelf te laten uitvoeren in plaats van deze van hen over te nemen. Hoewel de effecten van de training beperkt waren, gaf deze studie richting aan de verdere ontwikkeling, implementatie en evaluatie van vergelijkbare trainingen voor begeleiders. Naast het evalueren van deze training voor begeleiders, hebben wij ook een zelfrapportagevragenlijst voor begeleiders ontwikkeld welke meet in welke mate begeleiders de zelfstandigheid bevorderen van hun cliënten met VB. Uit deze studie bleek dat bij begeleiders een aantal gedragingen van belang is bij het bevorderen van de zelfstandigheid van mensen met VB. Dit betreft een goede communicatie en afstemming tussen alle betrokkenen, een geïndividualiseerde aanpak, het positief aanmoedigen van mensen met VB tijdens het leerproces en het zoveel mogelijk laten uitvoeren door mensen met VB zelf. De lessen die wij hebben geleerd van de bovengenoemde studies hebben wij verwerkt in onze laatste studie, waarbij wij een zelfmanagementtraining hebben geïmplementeerd en geëvalueerd voor mensen met VB. In deze training hebben zij gewerkt aan een breed scala aan zelfgekozen zelfmanagementdoelen. In deze op maat gemaakte training werd ook aandacht besteed aan de *transfer* naar het dagelijks leven en het betrekken van het steunnetwerk. Deze training bleek positief bij te dragen aan het behalen van zelfmanagementdoelen en aan het verminderen van de ondersteuningsbehoeften, hoewel de algehele mate van zelfstandigheid, het voorkomen van problemen in emotie en gedrag, en de kwaliteit van leven onveranderd bleven. Verder onderzoek kan op de bevindingen beschreven in dit proefschrift voortborduren om zo het begrip verder te vergroten over hoe zelfmanagement nog effectiever bevorderd kan worden bij mensen met VB.

References

1. Bond, R.J., & Hurst, J. (2010). How adults with learning disabilities view living independently. *British Journal of Learning Disabilities, 38*(4), 286-292.
2. Haigh, A., Lee, D., Shaw, C., Hawthorne, M., Chamberlain, S., Newman, D.W., Clarke, Z., & Beail, N. (2013). What things make people with a learning disability happy and satisfied with their lives: An inclusive research project. *Journal of Applied Research in Intellectual Disabilities, 26*(1), 26-33.
3. Kuijken, N.M.J., Naaldenberg, J., Nijhuis-van der Sanden, M.W., & Van Schrojenstein-Lantman de Valk, H.M.J. (2016). Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives. *Journal of Intellectual Disability Research, 60*(3), 228-241.
4. Dollar, C.A., Fredrick, L.D., Alberto, P.A., & Luke, J.K. (2012). Using simultaneous prompting to teach independent living and leisure skills to adults with severe intellectual disabilities. *Research in Developmental Disabilities, 33*(1), 189-195.
5. Sigafoos, J., O'Reilly, M., Cannella, H., Upadhyaya, M., Edrisinha, C., Lancioni, G.E., Hundley, A., Andrews, A., Garver, C., & Young, D. (2005). Computer-presented video prompting for teaching microwave oven use to three adults with developmental disabilities. *Journal of Behavioral Education, 14*(3), 189-201.
6. Hale, L.A., Trip, H.T., Whitehead, L., & Conder, J. (2011). Self-management abilities of diabetes in people with an intellectual disability living in New Zealand. *Journal of Policy and Practice in Intellectual Disabilities, 8*(4), 223-230.
7. Vilaseca, R., Gràcia, M., Beltran, F.S., Dalmau, M., Alomar, E., Adam-Alcocer, A.L., & Simó-Pinatella, D. (2017). Needs and supports of people with intellectual disability and their families in Catalonia. *Journal of Applied Research in Intellectual Disabilities, 30*(1), 33-46.
8. Young, A.F., Naji, S., & Kroll, T. (2012). Support for self-management of cardiovascular disease by people with learning disabilities. *Family Practice, 29*(4), 467-475.
9. American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Association.
10. Schalock, R.L., Borthwick-Duffy, S.A., Bradley, V.J., Buntinx, W.H.E., Coulter, D.L., Craig, E.M., Gomez, S.C., Lachapelle, Y., Luckasson, R., Reeve, A., Shogren, K.A., Snell, M.E., Spreat, S., Tasse, M.J., Thompson, J.R., Verdugo-Alonso, M.A., Wehmeyer, M.L., & Yeager, M.H. (2010). *Intellectual Disability: Definition, Classification, and Systems of Supports* (11th ed.). Washington, D.C.: American Association on Intellectual and Developmental Disabilities.
11. Netherlands Institute for Social Research. (2014). *Zorg Beter Begrepen. Verklaringen voor de groeiende vraag naar zorg voor mensen met een verstandelijke beperking.* Den Haag: Sociaal en Cultureel Planbureau.
12. Dannenberg, M., Mengoni, S.E., Gates, B., & Durand, M. (2016). Self-management interventions for epilepsy in people with intellectual disabilities: A scoping review. *Seizure, 41*, 16-25.
13. Taggart, L., Coates, V., Clarke, M., Bunting, B., Davies, M., Carey, M., Northway, R., Brown, M., Truesdale-Kennedy, M., Martin-Stacey, L., Scott, G., & Karatzias, T. (2015). A study protocol for a pilot randomised trial of a structured education programme for the self-management of Type 2 diabetes for adults with intellectual disabilities. *Trials, 16*, 8.
14. Whitehead, L.C., Trip, H.T., Hale, L.A., & Conder, J. (2016). Negotiated autonomy in diabetes self-management: the experiences of adults with intellectual disability and their support workers. *Journal of Intellectual Disability Research, 60*(4), 389-397.

15. Silverstein, R. (2003). Statutory changes in disability policy: Types of legislation, policies, and goals. In S.S. Herr, L.O. Gostin, & H.H. Koh (Eds.), *The human rights of persons with intellectual disabilities* (pp.263-284). Oxford: Oxford University Press.
16. Thompson, J.R., Wehmeyer, M.L., Shogren, K.A., & Seo, H. (2017). The supports paradigm and intellectual and developmental disabilities. In K.A. Shogren, M.L. Wehmeyer, & N.N. Singh (Eds.), *Handbook of positive psychology in intellectual and developmental disabilities* (pp. 22-36). Cham: Springer.
17. Wehmeyer, M.L., Shogren, K.A., Singh, N.N., & Uyanik, H. (2017). Strengths-based approaches to intellectual and developmental disabilities. In K.A. Shogren, M.L. Wehmeyer, & N.N. Singh (Eds.), *Handbook of positive psychology in intellectual and developmental disabilities* (pp. 13-21). Cham: Springer.
18. United Nations (2006). *Convention on the rights of persons with disabilities*. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.
19. Hermsen, M.A., Embregts, P., Hendriks, A.H.C., & Frielink, N. (2014). The human degree of care. Professional loving care for people with a mild intellectual disability: an explorative study. *Journal of Intellectual Disability Research, 58*(3), 221-232.
20. Van der Kwartel, A. (2013). *Brancherapport Gehandicaptenzorg 2012*. Utrecht: Kiwa Prismant.
21. Malli, M., Sams, L., Forrester-Jones, R., Murphy, G., & Henwoord, M. (2018). *Austerity and the lives of people with intellectual and developmental disabilities (IDD): A thematic synthesis of the current literature*. Paper presented at the 5th IASSID Europe Congress, Athens, Greece.
22. Dusseljee, J.C.E., Rijken, P.M., Cardol, M., Curfs, L.M.G., & Groenewegen, P.P. (2011). Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research, 55*, 4-18.
23. Ramdoss, S., Lang, R., Fragale, C., Britt, C., O'Reilly, M., Sigafoos, J., Didden, R., Palmen, A., & Lancioni, G.E. (2012). Use of computer-based interventions to promote daily living skills in individuals with intellectual disabilities: A systematic review. *Journal of Developmental and Physical Disabilities, 24*(2), 197-215.
24. Smith, K.A., Shepley, S.B., Alexander, J.L., & Ayres, K.M. (2015). The independent use of self-instructions for the acquisition of untrained multi-step tasks for individuals with an intellectual disability: A review of the literature. *Research in Developmental Disabilities, 40*, 19-30.
25. Browder, D.M., & Shapiro, E.S. (1985). Applications of self-management to individuals with severe handicaps: A review. *Journal of the Association for Persons with Severe Handicaps, 10*(4), 200-208.
26. Sexton, E., O'Donovan, M.A., Mulryan, N., McCallion, P., & McCarron, M. (2016). Whose quality of life? A comparison of measures of self-determination and emotional wellbeing in research with older adults with and without intellectual disability. *Journal of Intellectual & Developmental Disability, 41*(4), 324-337.
27. Shogren, K.A., Wehmeyer, M.L., Palmer, S.B., Forber-Pratt, A.J., Little, T.J., & Lopez, S. (2015). Causal Agency Theory: Reconceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities, 50*(3), 251-263.
28. Wehmeyer, M.L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self determined behavior of individuals with mental retardation. *American Journal on Mental Retardation, 100*(6), 632-642.

29. Michie, S., Richardson, M., Johnston, M., Abraham, C., Francis, J., Hardeman, W., Eccles, M.P., Cane, J., & Wood, C.E. (2013). The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: Building an international consensus for the reporting of behavior change interventions. *Annals of Behavioral Medicine, 46*(1), 81-95.
30. Bouck, E.C., Satsangi, R., & Bartlett, W. (2017). Supporting grocery shopping for students with intellectual disability: a preliminary study. *Disability and Rehabilitation-Assistive Technology, 12*(6), 605-613.
31. Wu, P.F., Wheaton, J.E., & Cannella-Malone, H.I. (2016). Effects of video prompting and activity schedules on the acquisition of independent living skills of students who are deaf and have developmental disabilities. *Education and Training in Autism and Developmental Disabilities, 51*(4), 366-378.
32. Lancioni, G.E., & O'Reilly, M.F. (2001). Self-management of instruction cues for occupation: Review of studies with people with severe and profound developmental disabilities. *Research in Developmental Disabilities, 22*(1), 41-65.
33. Wilson, P.M., & Goodman, C. (2011). Evaluation of a modified chronic disease self-management programme for people with intellectual disabilities. *Journal of Nursing and Healthcare of Chronic Illness, 3*, 310-318.
34. Gilson, C.B., Carter, E.W., & Biggs, E.E. (2017). Systematic review of instructional methods to teach employment skills to secondary students with intellectual and developmental disabilities. *Research and Practice for Persons with Severe Disabilities, 42*(2), 89-107.
35. Gomes-Machado, M.L., Santos, F.H., Schoen, T., & Chiari, B. (2016). Effects of vocational training on a group of people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 13*(1), 33-40.
36. Davies, D.K., Stock, S.E., Holloway, S., & Wehmeyer, M.L. (2010). Evaluating a GPS-based transportation device to support independent bus travel by people with intellectual disability. *Intellectual and Developmental Disabilties, 48*(6), 454-463.
37. Bartholomew, L.K., Parcel, G.S., Kok, G., Gottlieb, N.H., & Fernández, M.E. (2011). *Planning health promotion programs: An intervention mapping approach* (3 ed.). San Francisco: Jossey-Bass.
38. Totsika, V., Toogood, S., Hastings, R.P., & Nash, S. (2008). Interactive training for active support: Perspectives from staff. *Journal of Intellectual and Developmental Disability, 33*(3), 225-238.
39. Douglas, K.H., Ayres, K.M., & Langone, J. (2015). Comparing self-management strategies delivered via an iPhone to promote grocery shopping and literacy. *Education and Training in Autism and Developmental Disabilities, 50*(4), 446-465.
40. Goldschmidt, J., & Song, H.J. (2017). Development of cooking skills as nutrition intervention for adults with autism and other developmental disabilities. *Journal of the Academy of Nutrition and Dietetics, 117*(5), 671-679.
41. Van Asselt-Goverts, A.E., Embregts, P., & Hendriks, A.H.C. (2013). Structural and functional characteristics of the social networks of people with mild intellectual disabilities. *Research in Developmental Disabilities, 34*(4), 1280-1288.
42. Petner-Arrey, J., & Copeland, S.R. (2015). 'You have to care.' perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities, 43*(1), 38-48.
43. Power, A. (2008). Caring for independent lives: Geographies of caring for young adults with intellectual disabilities. *Social Science & Medicine, 67*(5), 834-843.

44. Strnadová, I., & Evans, D. (2015). Older women with intellectual disabilities: Overcoming barriers to autonomy. *Journal of Policy and Practice in Intellectual Disabilities, 12*(1), 12-19.
45. Caton, S., Chadwick, D., Chapman, M., Turnbull, S., Mitchell, D., & Stansfield, J. (2012). Healthy lifestyles for adults with intellectual disability: Knowledge, barriers, and facilitators. *Journal of Intellectual and Developmental Disability, 37*(3), 248-259.
46. Aldridge, J. (2010). Promoting the independence of people with intellectual disabilities. *Learning Disability Practice, 13*(9), 31-36.
47. Rose, N., Rose, J., & Kent, S. (2012). Staff training in intellectual disability services: A review of the literature and implications for mental health services provided to individuals with intellectual disability. *International Journal of Developmental Disabilities, 58*(1), 24-39.
48. Cavkaytar, A., Acungil, A.T., & Tomris, G. (2017). Effectiveness of teaching cafe waitering to adults with intellectual disability through audio-visual technologies. *Education and Training in Autism and Developmental Disabilities, 52*(1), 77-90.
49. Deci, E.L., & Ryan, R.M. (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry, 11*(4), 227-268.
50. Dawson, F., Shanahan, S., Fitzsimons, E., O'Malley, G., Mac Giollabhui, N., & Bramham, J. (2016). The impact of caring for an adult with intellectual disability and psychiatric comorbidity on carer stress and psychological distress. *Journal of Intellectual Disability Research, 60*(6), 553-563.
51. Sandjojo, J., Gebhardt, W.A., Zedlitz, A.M.E.E., Hoekman, J., den Haan, J.A., & Evers, A.W.M. (2018). Promoting independence of people with intellectual disabilities: A focus group study. Perspectives from people with intellectual disabilities, legal representatives, and support staff. *Journal of Policy and Practice in Intellectual Disability.*
52. Van Laarhoven, T., & Van Laarhoven-Myers, T. (2006). Comparison of three video-based instructional procedures for teaching daily living skills to persons with developmental disabilities. *Education and Training in Developmental Disabilities, 41*(4), 365-381.
53. García-Villamisar, D., Dattilo, J., & Matson, J.L. (2013). Quality of life as a mediator between behavioral challenges and autistic traits for adults with intellectual disabilities. *Research in Autism Spectrum Disorders, 7*(5), 624-629.
54. Sandjojo, J., Zedlitz, A.M.E.E., Gebhardt, W.A., Hoekman, J., Dusseldorp, E., den Haan, J.A., & Evers, A.W.M. (2018). Training staff to promote self-management in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*, 840-850.
55. Wehmeyer, M.L., & Abery, B.H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities, 51*(5), 399-411.
56. Rusch, F.R., & Dattilo, J. (2012). Employment and self-management: A meta-evaluation of seven literature reviews. *Intellectual and Developmental Disabilities, 50*(1), 69-75.
57. Storey, K. (2007). Review of research on self-management interventions in supported employment settings for employees with disabilities. *Career Development for Exceptional Individuals, 30*(1), 27-34.
58. Graham, L., Wright, J., Walwyn, R., Russell, A.M., Bryant, L., Farrin, A., & House, A. (2016). Measurement of adherence in a randomised controlled trial of a complex intervention: supported self-management for adults with learning disability and type 2 diabetes. *BMC Medical Research Methodology, 16*(1), 132.
59. Koyama, T., & Wang, H.T. (2011). Use of activity schedule to promote independent performance of individuals with autism and other intellectual disabilities: A review. *Research in Developmental Disabilities, 32*(6), 2235-2242.

60. Michie, S., Ashford, S., Sniehotta, F.F., Dombrowski, S.U., Bishop, A., & French, D.P. (2011). A refined taxonomy of behaviour change techniques to help people change their physical activity and healthy eating behaviours: The CALO-RE taxonomy. *Psychology & Health, 26*(11), 1479-1498.
61. Willems, M., Hilgenkamp, T.I.M., Havik, E., Waninge, A., & Melville, C.A. (2017). Use of behaviour change techniques in lifestyle change interventions for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities, 60*, 256-268.
62. Willems, M., Waninge, A., Hilgenkamp, T.I.M., van Empelen, P., Krijnen, W.P., van der Schans, C.P., & Melville, C.A. (2018). Effects of lifestyle change interventions for people with intellectual disabilities: Systematic review and meta-analysis of randomized controlled trials. *Journal of Applied Research in Intellectual Disabilities, 31*(6), 949-961.
63. Crnic, K.A., & Pym, H.A. (1979). Training mentally retarded adults in independent living skills. *Mental Retardation, 17*(1), 13-16.
64. Davies, D.K., Stock, S.E., & Wehmeyer, M.L. (2003). Application of computer simulation to teach ATM access to individuals with intellectual disabilities. *Education and Training in Developmental Disabilities, 38*(4), 451-456.
65. Dukes, E., & McGuire, B.E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research, 53*(8), 727-734.
66. Faloon, B.J., & Rehfeldt, R.A. (2008). The role of overt and covert self-rules in establishing a daily living skill in adults with mild developmental disabilities. *Journal of Applied Behavior Analysis, 41*(3), 393-404.
67. Faw, G.D., Davis, P.K., & Peck, C. (1996). Increasing self-determination: Teaching people with mental retardation to evaluate residential options. *Journal of Applied Behavior Analysis, 29*(2), 173-188.
68. Feldman, M.A., Ducharme, J.M., & Case, L. (1999). Using self-instructional pictorial manuals to teach child-care skills to mothers with intellectual disabilities. *Behavior Modification, 23*(3), 480-497.
69. Feldman, M.A., Owen, F., Andrews, A., Hamelin, J., Barber, R., & Griffiths, D. (2012). Health self-advocacy training for persons with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(11), 1110-1121.
70. Gilson, C.B., & Carter, E.W. (2016). Promoting social interactions and job independence for college students with autism or intellectual disability: A pilot study. *Journal of Autism and Developmental Disorders, 46*(11), 3583-3596.
71. Goodson, J., Sigafoos, J., O'Reilly, M., Cannella, H., & Lancioni, G.E. (2007). Evaluation of a video-based error correction procedure for teaching a domestic skill to individuals with developmental disabilities. *Research in Developmental Disabilities, 28*(5), 458-467.
72. Hällgren, M., & Kottorp, A. (2005). Effects of occupational therapy intervention on activities of daily living and awareness of disability in persons with intellectual disabilities. *Australian Occupational Therapy Journal, 52*(4), 350-359.
73. Johnson, B.F., & Cuvo, A.J. (1981). Teaching mentally retarded adults to cook. *Behavior Modification, 5*(2), 187-202.
74. Katz, R.C., & Singh, N.N. (1986). Comprehensive fire-safety training for adult mentally retarded persons. *Journal of Mental Deficiency Research, 30*(1), 59-69.
75. Kottorp, A., Hallgren, M., Bernspang, B., & Fisher, A.G. (2003). Client-centred occupational therapy for persons with mental retardation: Implementation of an intervention programme in activities of daily living tasks. *Scandinavian journal of occupational therapy, 10*(2), 51-60.
76. LaCampagne, J., & Cipani, E. (1987). Training adults with mental retardation to pay bills. *Mental Retardation, 25*(5), 293-303.

77. Lovett, D.L., & Haring, K.A. (1989). The effects of self-management training on the daily living of adults with mental retardation. *Education and Training in Mental Retardation, 24*(4), 306-323.
78. Marchetti, A.G., McCartney, J.R., Drain, S., Hooper, M., & Dix, J. (1983). Pedestrian skills training for mentally retarded adults: Comparison of training in two settings. *Mental Retardation, 21*(3), 107-110.
79. Martin, J.E., & Rusch, F.R. (1987). Use of the partial-sequential withdrawal design to assess maintenance of mentally retarded adults' acquired meal preparation skills. *Research in Developmental Disabilities, 8*(3), 389-399.
80. Matson, J.L. (1981). Use of independence training to teach shopping skills to mildly mentally retarded adults. *American Journal of Mental Deficiency, 86*(2), 178-183.
81. Matson, J.L. (1982). Independence training vs modeling procedures for teaching phone conversation skills to the mentally retarded. *Behaviour Research and Therapy, 20*(5), 505-511.
82. Matson, J.L., & Long, S. (1986). Teaching computation/shopping skills to mentally retarded adults. *American Journal of Mental Deficiency, 91*(1), 98-101.
83. McInerney, C.A., & McInerney, M. (1992). A mobility skills training program for adults with developmental disabilities. *American Journal of Occupational Therapy, 46*(3), 233-239.
84. Michie, A.M., Lindsay, W.R., Smith, A.H., & Todman, J. (1998). Changes following community living skills training: A controlled study. *British Journal of Clinical Psychology, 37*, 109-111.
85. Neef, N.A., Lensbower, J., Hockersmith, I., DePalma, V., & Gray, K. (1990). In vivo versus simulation training: an interactional analysis of range and type of training exemplars. *Journal of Applied Behavior Analysis, 23*(4), 447-458.
86. Ores, L., & Parent, L.H. (1984). Telephone Call Aid for problems of visual sequencing. *American Journal of Occupational Therapy, 38*(1), 40-43.
87. Rehfeldt, R.A., Dahman, D., Young, A., Cherry, H., & Davis, P. (2003). Teaching a simple meal preparation skill to adults with moderate and severe mental retardation using video modeling. *Behavioral Interventions, 18*(3), 209-218.
88. Richman, G.S., Reiss, M.L., Bauman, K.E., & Bailey, J.S. (1984). Teaching menstrual care to mentally retarded women: Acquisition, generalization, and maintenance. *Journal of Applied Behavior Analysis, 17*(4), 441-451.
89. Risley, R., & Cuvo, A.J. (1980). Training mentally retarded adults to make emergency telephone calls. *Behavior Modification, 4*(4), 513-525.
90. Sarber, R.E., Halasz, M.M., Messmer, M.C., Bickett, A.D., & Lutzker, J.R. (1983). Teaching menu planning and grocery shopping skills to a mentally retarded mother. *Mental Retardation, 21*(3), 101-106.
91. Taber-Doughty, T., Shurr, J., Brewer, J., & Kubik, S. (2010). Standard care and telecare services: comparing the effectiveness of two service systems with consumers with intellectual disabilities. *Journal of Intellectual Disability Research, 54*(9), 843-859.
92. Tam, S.F., Man, D.W.-K., Chan, Y.P., Sze, P.C., & Wong, C.M. (2005). Evaluation of a computer-assisted, 2-D virtual reality system for training people with intellectual disabilities on how to shop. *Rehabilitation Psychology, 50*(3), 285-291.
93. Taylor, I., & O'Reilly, M.F. (1997). Toward a functional analysis of private verbal self-regulation. *Journal of Applied Behavior Analysis, 30*(1), 43-58.
94. Taylor, I., & O'Reilly, M.F. (2000). Generalization of supermarket shopping skills for individuals with mild intellectual disabilities using stimulus equivalence training. *The Psychological Record, 50*(1), 49-62.
95. Wacker, D.P., Berg, W.K., Visser, M.B., & Egan, J.E. (1986). A preliminary evaluation of independence in a competitive employment setting. *Journal of the Association for Persons with Severe Handicaps, 11*(4), 246-254.

96. Didden, R., Duker, P., & Seys, D. (2003). *Gedragsanalyse en -therapie bij mensen met een verstandelijke beperking* (2nd ed.). Maarssen: Elsevier gezondheidszorg.
97. Webb, T.L., Joseph, J., Yardley, L., & Michie, S. (2010). Using the internet to promote health behavior change: A systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. *Journal of Medical Internet Research, 12*(1), 1-18.
98. Dwan, K., Altman, D., Arnaiz, J., Bloom, J., Chan, A., Cronin, E., Decullier, E., Easterbrook, P., Von Elm, E., Gamble, C., Ghersi, D., Ioannidis, J., Simes, J., & Williamson, P. (2008). Systematic review of the empirical evidence of study publication bias and outcome reporting bias. *PloS one, 3*(8), e3081.
99. Smith, K.A., Ayres, K.A., Alexander, J., Ledford, J.R., Shepley, C., & Shepley, S.B. (2016). Initiation and generalization of self-instructional skills in adolescents with autism and intellectual disability. *Journal of Autism and Developmental Disorders, 46*(4), 1196-1209.
100. Harchik, A.E., Sherman, J.A., & Sheldon, J.B. (1992). The use of self-management procedures by people with developmental disabilities: A brief review. *Research in Developmental Disabilities, 13*(3), 211-227.
101. Mastropieri, M.A., Scruggs, T.E., & Shiah, R.L. (1997). Can computers teach problem-solving strategies to students with mild mental retardation? A case study. *Remedial and Special Education, 18*(3), 157-165.
102. Schalock, R.L. (2004). The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research, 48*(3), 203-216.
103. Cannella-Malone, H., Sigafoos, J., O'Reilly, M., de la Cruz, B., Edrisinha, C., & Lancioni, G.E. (2006). Comparing video prompting to video modeling for teaching daily living skills to six adults with developmental disabilities. *Education and Training in Developmental Disabilities, 41*(4), 344-356.
104. Mechling, L.C., Gast, D.L., & Gustafson, M.R. (2009). Use of video modeling to teach extinguishing of cooking related fires to individuals with moderate intellectual disabilities. *Education and Training in Developmental Disabilities, 44*(1), 67-79.
105. American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association.
106. Frankena, T.K., Naaldenberg, J., Cardol, M., Linehan, C., & Lantman-de Valk, H.V. (2015). Active involvement of people with intellectual disabilities in health research - A structured literature review. *Research in Developmental Disabilities, 45-46*, 271-283.
107. Krueger, R.A., & Casey, M.A. (2015). *Focus groups: A practical guide for applied research*, (5th ed.). Thousand Oaks: SAGE Publications, Inc.
108. Thomas, D.R. (2006). A general inductive approach for analysing qualitative evaluation data. *American Journal of Evaluation, 27*(2), 237-246.
109. Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2016). Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities, 29*(5), 409-421.
110. Van Oorsouw, W.M.W.J., Embregts, P.J.C.M., Bosman, A.M.T., & Jahoda, A. (2009). Training staff serving clients with intellectual disabilities: A meta-analysis of aspects determining effectiveness. *Research in Developmental Disabilities, 30*(3), 503-511.

111. Fisher, M.H., Baird, J.V., Currey, A.D., & Hodapp, R.M. (2016). Victimisation and social vulnerability of adults with intellectual disability: A review of research extending beyond Wilson and Brewer. *Australian Psychologist, 51*(2), 114-127.
112. Wilson, C. (2016). Victimisation and social vulnerability of adults with intellectual disability: Revisiting Wilson and Brewer (1992) and responding to updated research. *Australian Psychologist, 51*(1), 73-75.
113. Prime Minister's Strategy Unit (2005). *Improving the life chances of disabled people*. Retrieved from http://webarchive.nationalarchives.gov.uk/+/http:/www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf.
114. Ferretti, R.P., Cavalier, A.R., Murphy, M.J., & Murphy, R. (1993). The self-management of skills by persons with mental-retardation. *Research in Developmental Disabilities, 14*(3), 189-205.
115. Tonkens, E., & Weijers, I. (1999). Autonomy, solidarity, and self-realization: Policy views of Dutch service providers. *Mental Retardation, 37*(6), 468-476.
116. Embregts, P.J.C.M. (2003). Using self-management, video feedback, and graphic feedback to improve social behavior of youth with mild mental retardation. *Education and Training in Developmental Disabilities, 38*(3), 283-295.
117. Adkins, A.D., Singh, A.N., Winton, A.S.W., McKeegan, G.F., & Singh, J. (2010). Using a mindfulness-based procedure in the community: Translating research to practice. *Journal of Child and Family Studies, 19*(2), 175-183.
118. Rossiter, R., Hunnisett, E., & Pulsford, M. (1998). Anger management training and people with moderate to severe learning disabilities. *British Journal of Learning Disabilities, 26*(2), 67-74.
119. Benson, B.A. (1994). Anger management training: A self-control programme for persons with mild mental retardation. In N. Bouras & N. Bouras (Eds.), *Mental health in mental retardation: Recent advances and practices* (pp. 224-232). New York, NY, US: Cambridge University Press.
120. Dixon, D.R., Bergstrom, R., Smith, M.N., & Tarbox, J. (2010). A review of research on procedures for teaching safety skills to persons with developmental disabilities. *Research in Developmental Disabilities, 31*(5), 985-994.
121. Wright, T., & Wolery, M. (2011). The effects of instructional interventions related to street crossing and individuals with disabilities. *Research in Developmental Disabilities, 32*(5), 1455-1463.
122. Graves, T.B., Collins, B.C., & Schuster, J.W. (2005). Using video prompting to teach cooking skills to secondary students with moderate disabilities. *Education and Training in Developmental Disabilities, 40*(1), 34-46.
123. Lancioni, G.E., & O'Reilly, M.F. (2002). Teaching food preparation skills to people with intellectual disabilities: a literature overview. *Journal of Applied Research in Intellectual Disabilities, 15*(3), 236-253.
124. Kottorp, A., Hällgren, M., Bernspång, B., & Fisher, A.G. (2003). Client-centred occupational therapy for persons with mental retardation: Implementation of an intervention programme in activities of daily living tasks. *Scandinavian Journal of Occupational Therapy, 10*(2), 51-60.
125. Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-centred active support - Increasing choice, promoting independence and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disabilities, 25*(4), 291-307.
126. Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B., & Macdonald, S. (2002). Engagement in meaningful activity and "active support" of people with intellectual disabilities in residential care. *Research in Developmental Disabilities, 23*(5), 342-352.

127. Riches, V.C., Harman, A.D., Keen, D., Pennell, D., Harley, J.H., & Walker, M. (2011). Transforming staff practice through active support. *Journal of Intellectual and Developmental Disability, 36*(3), 156-166.
128. Beadle-Brown, J., Bigby, C., & Bould, E. (2015). Observing practice leadership in intellectual and developmental disability services. *Journal of Intellectual Disability Research, 59*(12), 1081-1093.
129. Parsons, M.B., Rollyson, J.H., & Reid, D.H. (2012). Evidence-based staff training: A guide for practitioners. *Behavior Analysis in Practice, 5*(2), 2-11.
130. Scholten, G., & Schuurman, M. (2008). *Eigenwaarde. Leermethodiek Op Eigen Benen achtergrond en toepassing*. Wezep: INVRA.
131. Feuerstein, R., Rand, Y., & Rynders, J.E. (1993). *Don't accept me as I am: Helping "retarded" people to excel*. New York: Plenum Press.
132. Timmer, J.T., & De Vries, A. (2014). Begeleid Ontdekkend Leren volgens het Eigen Initiatief Model. In B. Twint & J. De Bruijn (Eds.), *Handboek verstandelijke beperking, 24 succesvolle methoden* (pp. 98-115). Amsterdam: Uitgeverij Boom.
133. Seligman, M.E.P. (2002). *Authentic happiness. Using the new positive psychology to realize your potential for lasting fulfillment*. New York: Free Press.
134. Vygotski, L.S. (1964). *Denken und Sprechen*. Berlin: Akademie Verlag.
135. Kraijer, D.W., Kema, G.N., & De Bildt, A.A. (2004). *SRZ/SRZ-I Sociale Redzaamheidsschaal voor verstandelijk gehandicapten*. Amsterdam: Pearson.
136. Egberink, I.J.L., Janssen, N.A.M., & Vermeulen, C.S.M. (2004). COTAN beoordeling 2004, Sociale-redzaamheidsschalen [COTAN review 2004, Social functioning scale for the mentally retarded]. Retrieved 5 January 2016 from www.cotandocumentatie.nl.
137. Thompson, J.R., Bryant, B.R., Campbell, E.M., Craig, E.M., Hughes, C.M., Rotholz, D.A., Schalock, R.L., Silverman, W.P., Tassé, M.J., & Wehmeyer, M.L. (2010). *Supports Intensity Scale. Schaal Intensiteit van Ondersteuningsbehoeften. Handleiding SIS NL 1.2* (W.H.E. Buntinx, Trans.). Houten: BSL.
138. Claes, C., Van Hove, G., Van Loon, J., Vandevelde, S., & Schalock, R.L. (2009). Evaluating the inter-respondent (consumer vs. staff) reliability and construct validity (SIS vs. Vineland) of the Supports Intensity Scale on a Dutch sample. *Journal of Intellectual Disability Research, 53*, 329-338.
139. Koot, H.M., & Dekker, M.C. (2001). *Handleiding voor de VOG. Ouder- en leerkrachtversie*. Rotterdam: Erasmus Universiteit.
140. Van Wouwe, H., & Simons, L. (2013). Implementatie van Triple-C: Veranderingen in vaardigheden en probleemgedrag; een longitudinale studie bij cliënten met ernstig probleemgedrag. In R. Didden & X. Moonen (Eds.), *Met het oog op behandeling 3: diagnostiek en behandeling van gedragsproblematiek bij mensen met een licht verstandelijke beperking* (pp. 33-39). Utrecht: LKC LVB.
141. Dekker, M.C., Nunn, R.J., Einfeld, S.E., Tonge, B.J., & Koot, H.M. (2002). Assessing emotional and behavioral problems in children with intellectual disability: Revisiting the factor structure of the Developmental Behavior Checklist. *Journal of Autism and Developmental Disorders, 32*(6), 601-610.
142. Dekker, M.C., Nunn, R., & Koot, H.M. (2002). Psychometric properties of the revised Developmental Behaviour Checklist scales in Dutch children with intellectual disability. *Journal of Intellectual Disability Research, 46*, 285-285.
143. Egberink, I.J.L., Janssen, N.A.M., & Vermeulen, C.S.M. (2007). COTAN beoordeling 2007, Vragenlijst over Ontwikkeling en Gedrag [COTAN review 2007, Developmental Behaviour Checklist]. Retrieved 10 May 2016 from www.cotandocumentatie.nl

144. Kitzinger, J. (1995). Qualitative research - Introducing focus groups. *British Medical Journal, 311*(7000), 299-302.
145. Kraijer, D.W., & Kema, G.N. (2004). *Sociale Redzaamheidsschaal voor verstandelijk gehandicapten van hoger niveau*. Amsterdam: Pearson.
146. Achenbach, T.M., & Rescorla, L.A. (2003). *Manual for the ASEBA Adult Forms & Profiles* (F.C. Verhulst & J. van den Ende, Trans.). Burlington, VT: University of Vermont, Research Center for Children, Youth & Families.
147. Spriggs, A.D., Mims, P.J., van Dijk, W., & Knight, V.F. (2017). Examination of the evidence base for using visual activity schedules with students with intellectual disability. *Journal of Special Education, 51*(1), 14-26.
148. Felce, D., Bowley, C., Baxter, H., Jones, E., Lowe, K., & Emerson, E. (2000). The effectiveness of staff support: evaluating Active Support training using a conditional probability approach. *Research in Developmental Disabilities, 21*, 243-255.
149. Hastings, R.P. (2010). Support staff working in intellectual disability services: The importance of relationships and positive experiences. *Journal of Intellectual and Developmental Disability, 35*(3), 207-210.
150. Wong, P.K.S., & Wong, D.F.K. (2008). Enhancing staff attitudes, knowledge and skills in supporting the self-determination of adults with intellectual disability in residential settings in Hong Kong: a pretest-posttest comparison group design. *Journal of Intellectual Disability Research, 52*, 230-243.
151. Sandjojo, J., Eltringham, E.G., Gebhardt, W.A., Zedlitz, A.M.E.E., Hoekman, J., den Haan, J.A., Embregts, P.J.C.M., & Evers, A.W.M. (2018). *Self-management interventions for people with intellectual disabilities: A systematic review.* Manuscript submitted for publication.
152. French, D.P., Cooke, R., Mclean, N., Williams, M., & Sutton, S. (2007). What do people think about when they answer theory of planned behaviour questionnaires? A 'Think Aloud' study. *Journal of Health Psychology, 12*(4), 672-687.
153. Field, A. (2009). *Discovering statistics using SPSS* (3rd ed.). SAGE Publications: London.
154. Evers, A.W.M., Gieler, U., Hasenbring, M.I., & van Middendorp, H. (2014). Incorporating biopsychosocial characteristics into personalized healthcare: A clinical approach. *Psychotherapy and Psychosomatics, 83*(3), 148-157.
155. Van de Mortel, T.F. (2008). Faking it: social desirability response bias in self-report research. *Australian Journal of Advanced Nursing, 25*(4), 40-48.
156. Revilla, M.A., Saris, W.E., & Krosnick, J.A. (2014). Choosing the number of categories in agree-disagree scales. *Sociological Methods & Research, 43*(1), 73-97.
157. Holtgraves, T. (2004). Social desirability and self-reports: Testing models of socially desirable responding. *Personality and Social Psychology Bulletin, 30*(2), 161-172.
158. Cullen, J.M., Alber-Morgan, S.R., Simmons-Reed, E.A., & Izzo, M.V. (2017). Effects of self-directed video prompting using iPads on the vocational task completion of young adults with intellectual and developmental disabilities. *Journal of Vocational Rehabilitation, 46*(3), 361-375.
159. Ryan, R.M., & Deci, E.L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68-78.
160. Academie voor Zelfstandigheid (2015). Academie voor Zelfstandigheid Kenniscentrum (voor trainers en begeleiders). Retrieved 29 March 2017 from http://zelfstandigzijn.nl/index.php/trainingen-voor-thuis-en-werk

161. Miller, W.R. (1996). Motivational interviewing: Research, practice, and puzzles. *Addictive Behaviors, 21*(6), 835-842.
162. Bovend'Eerdt, T.J., Botell, R.E., & Wade, D.T. (2009). Writing SMART rehabilitation goals and achieving goal attainment scaling: a practical guide. *Clinical Rehabilitation, 23*(4), 352-361.
163. Kiresuk, T.J., & Sherman, R.E. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal, 4*(6), 443-453.
164. Turner-Stokes, L. (2010). Goal attainment scaling (GAS) in rehabilitation: a practical guide. *Clinical Rehabilitation, 23*(4), 362-370.
165. Mate-Kole, C.C., Danquah, S.A., Twum, M., & Danquah, A.O. (1999). Outcomes of a nonaversive behavior intervention in intellectually impaired individuals using goal attainment scaling. *Nursing Research, 48*(4), 220-225.
166. Evers, A., van Vliet-Mulder, J.C., & Groot, C.J. (2000). *Documentatie van tests en testresearch in Nederland. Deel I Testbeschrijvingen.* Assen: Van Gorcum.
167. Douma, J., Mulder, M., & Scholten, G. (2001). *INVRA-Wonen. INventarisatie Van RedzaamheidsAspecten op het gebied van wonen. Handleiding.* Ede: Stichting Woldyne.
168. Douma, J., Mulder, M., & Scholten, G. (2001). *INVRA-Arbeid. Handleiding en verantwoording.* Ede: Stichting Woldyne.
169. Buntinx, W.H.E., Maes, B., Claes, C., & Curfs, L.M.G. (2010). De Nederlandstalige versie van de Supports Intensity Scale. Psychometrische eigenschappen en toepassingen. *Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen, 36*(1), 4-22.
170. Tenneij, N.H., & Koot, H.M. (2007). A preliminary investigation into the utility of the Adult Behavior Checklist in the assessment of psychopathology in people with low IQ. *Journal of Applied Research in Intellectual Disabilities, 20*(5), 391-400.
171. WHOQOL group (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28*, 551-558.
172. WHOQOL group (1998). The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. *Social Science & Medicine, 46*, 1569-1585.
173. Geyh, S., Fellinghauer, B.A.G., Kirchberger, I., & Post, M.W.M. (2010). Cross-cultural validity of four quality of life scales in persons with spinal cord injury. *Health and Quality of Life Outcomes, 8*, 16.
174. Power, M.J., Green, A.M., & WHOQOL-DIS group (2010). Development of the WHOQOL disabilities module. *Quality of Life Research, 19*, 571-584.
175. Chadwick, D.D., Quinn, S., & Fullwood, C. (2017). Perceptions of the risks and benefits of Internet access and use by people with intellectual disabilities. *British Journal of Learning Disabilities, 45*(1), 21-31.
176. Schalock, R.L., Verdugo, M.A., Gomez, L.E., & Reinders, H.S. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities, 121*(1), 1-12.
177. Nationaal Ethiek Overleg Sociale en Gedragswetenschappen (2018). Ethical code. Retrieved from http://nethics.nl/Gedragscode-Ethical-Code/
178. Bandura, A. (1991). Social cognitive theory of self-regulation. *Organizational Behavior and Human Decision Processes, 50*(2), 248-287.
179. Deci, E.L., & Ryan, R.M. (2008). Self-determination theory: A macrotheory of human motivation, development, and health. *Canadian Psychology-Psychologie Canadienne, 49*(3), 182-185.

List of publications

Publications

Sandjojo, J., Zedlitz, A.M.E.E., Gebhardt, W.A., Hoekman, J., Den Haan, J.A., & Evers, A.W.M. (2019). Effects of a self-management training for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *32,* 390-400. doi: 10.1111/jar.12536

Sandjojo, J., Gebhardt, W.A., Zedlitz, A.M.E.E., Hoekman, J., Dusseldorp, E., Den Haan, J.A., & Evers, A.W.M. (2018). Development of the Leiden Independence Questionnaire for Support Staff: A measure of staff behaviour regarding promoting independence of people with intellectual disabilities. *Journal of Intellectual Disability Research*. doi: 10.1111/jir.12574

Sandjojo, J., Gebhardt, W.A., Zedlitz, A.M.E.E., Hoekman, J., Den Haan, J.A., & Evers, A.W.M. (2018). Promoting independence of people with intellectual disabilities: A focus group study. Perspectives from people with intellectual disabilities, legal representatives, and support staff. *Journal of Policy and Practice in Intellectual Disabilities*. doi: 10.1111/jppi.12265

Sandjojo, J., Zedlitz, A.M.E.E., Gebhardt, W.A., Hoekman, J., Dusseldorp, E., Den Haan, J.A., & Evers, A.W.M. (2018). Training staff to promote self-management in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *31*, 840-850. doi: 10.1111/jar.124

Kist, N., **Sandjojo, J.**, Kok, R.M., & Van den Berg, J.F. (2014). Cognitive functioning in older adults with early, late, and very late onset alcohol dependence. *International Psychogeriatrics*, *26*, 1863-1869.

Submitted

Sandjojo, J., Eltringham, E.G., Gebhardt, W.A., Zedlitz, A.M.E.E., Hoekman, J., Den Haan, J.A., Embregts, P.J.C.M., Evers, A.W.M. Self-management interventions for people with intellectual disabilities: A systematic review. *Manuscript submitted for publication*.

Curriculum vitae

Janice Sandjojo was born on 17 March 1986 in The Hague, the Netherlands, where she also completed her secondary education at Dalton Den Haag in 2004. She obtained her bachelor's degree in Psychology at Utrecht University in 2007 (cum laude) and her master's degree in Clinical Neuropsychology at Leiden University in 2010 (cum laude). She wrote her master thesis about preterm born children at the Erasmus MC-Sophia, which was nominated for the Thesis Award of the Institute of Psychology (Leiden University). She did her clinical internship with people with acquired brain injury and comorbid psychiatric problems at Bavo Europoort, where she continued to work as a neuropsychologist afterwards.

Since 2011 Janice works as a lecturer at the Health, Medical and Neuropsychology unit of Leiden University. She coordinates, develops, and teaches several work groups and lectures about (neuro)psychology for various courses. In addition, she has supervised numerous master students who were working on their thesis, internship or 'Basisaantekening Psychodiagnostiek'. In the meantime she worked as a (neuro) psychologist at the Leiden University Medical Center, Rijnlands Revalidatiecentrum, Haags Centrum voor Onderwijsadvies, and Sophia Revalidatie. She was involved in the care for various client populations, amongst which adults with neurological, auto-immune, oncological, and respiratory diseases and children with learning problems.

Apart from her work as a university lecturer and a psychologist in a clinical setting, Janice started to work part time on her PhD study at the Health, Medical and Neuropsychology unit of Leiden University by the end of 2014. This study was conducted in collaboration with Raamwerk, a care organisation for people with disabilities. She gave many presentations about this study at various international conferences and symposia. At the International Association for the Scientific Studies of Intellectual Disabilities World Congress in Melbourne in 2016 she received a University of Vienna Fellowship and the award for the best poster presentation. In 2017, she won the award for best oral presentation at the Association for Researchers in Psychology and Health conference. After working on her PhD study for 4 years, she finished her dissertation in 2018.

Janice currently still works as a lecturer at Leiden University and also as a psychologist within rehabilitation services at Basalt in The Hague.

Dankwoord

Zonder de bijdrage van vele anderen, was dit proefschrift er niet geweest. Graag bedank ik hier een aantal mensen in het bijzonder.

Allereerst gaat mijn dank uit naar alle deelnemers van het onderzoek. Zonder jullie inzet waren de studies beschreven in dit proefschrift niet mogelijk geweest. Het meest heb ik genoten van de ontmoetingen met de mensen met een verstandelijke beperking. Het was ontzettend mooi te zien hoe jullie je ontwikkelden! Van de focusgroepdeelnemers heb ik veel geleerd over hoe het is te leven met een verstandelijke beperking en hoe de zorg voor mensen met een verstandelijke beperking geregeld is, of geregeld zou moeten zijn. Heel veel dank voor deze waardevolle inzichten.

Zonder de wetenschappelijke bijdrage van mijn (co)promotores, was dit proefschrift niet tot stand gekomen. Jullie waren er voor me als ik het nodig had. Andrea, vol vertrouwen gaf je mij de kans dit promotieonderzoek met veel vrijheid uit te voeren. Daar ben ik heel dankbaar voor. Ik heb ontzettend veel geleerd van je veelzijdige expertise en je oneindige optimisme. Aglaia en Winnie, dank voor jullie snelle en kritische feedback en het mij wegwijs maken in de wereld van de wetenschap. Net zo belangrijk voor mij is jullie aanmoediging, persoonlijke steun en betrokkenheid geweest, zeker op de momenten dat het even tegenzat.

Graag bedank ik ook de leden van de promotie- en oppositiecommissie voor het lezen en beoordelen van dit proefschrift. Prof. dr. Petri Embregts wil ik in het bijzonder bedanken voor de persoonlijke betrokkenheid en bijdrage aan de literatuurreview.

Joop Hoekman, ik heb veel gehad aan jouw expertise over mensen met verstandelijke beperkingen en jouw hartelijke persoonlijkheid maakte het heel prettig samenwerken, veel dank daarvoor.

De betrokken medewerkers van Raamwerk, de academie voor Zelfstandigheid en 's Heeren Loo wil ik graag bedanken voor al hun inspanningen, met in het bijzonder Iris Biezenaar, Jeanet den Haan, Marco van der Plas, Marijke van der Meer en alle begeleiders die op welke manier dan ook hebben bijgedragen aan het onderzoek.

Elise Dusseldorp en Mathilde Verdam, dank voor jullie begeleiding bij het uitvoeren van de statistische analyses.

Arthur van Rhijn en Marlou Gosman, dank voor jullie ondersteuning bij de data-invoer en het analyseren van de focusgroepen. Emma Eltringham, dank voor het vele werk wat je hebt verricht voor de literatuurreview, je pakte alles snel op en zo kon ik met een gerust hart van alles aan je overlaten.

Alle fijne collega's van de Faculteit Sociale Wetenschappen wil ik bedanken voor de gezellige momenten, jullie interesse, steun en adviezen! In het bijzonder de (oud-) collega's van de sectie Gezondheids-, Medische en Neuropsychologie.

Bernadet en Cornelie, heel fijn dat jullie mij willen bijstaan als paranimf! Dank voor jullie vriendschap, het kunnen ventileren tijdens 'lotgenotencontact' en al jullie adviezen omtrent promoveren.

Lieve vrienden, te veel om bij naam te noemen, mijn leven naast werk is mij heel dierbaar en jullie zijn daar een belangrijk onderdeel van. Dank voor jullie vriendschap, gezelligheid en luisterend oor!

Ten slotte, wil ik al mijn familieleden bedanken en dan met name de 'Sandjojo's'. Papa en mama, jullie hebben altijd hard gewerkt om ons een goede toekomst te kunnen bezorgen. Nog steeds doen jullie er alles aan om ons te helpen waar nodig. Overigens ook waar niet nodig, jullie liefde en zorg kennen geen grenzen. Virginia en Bram, dank voor alle gezellige etentjes en uitstapjes waardoor ik even 'los' van werk kon komen. Quinten en Vayenne, mijn allerliefste schatties, met jullie spelen, knuffelen en lachen is een feest. Misja, samen thuis is het fijnst. Bedankt voor al je goede zorgen en geduld. Nu samen op naar het volgende hoofdstuk en een nieuw leven, ik kijk er al naar uit!