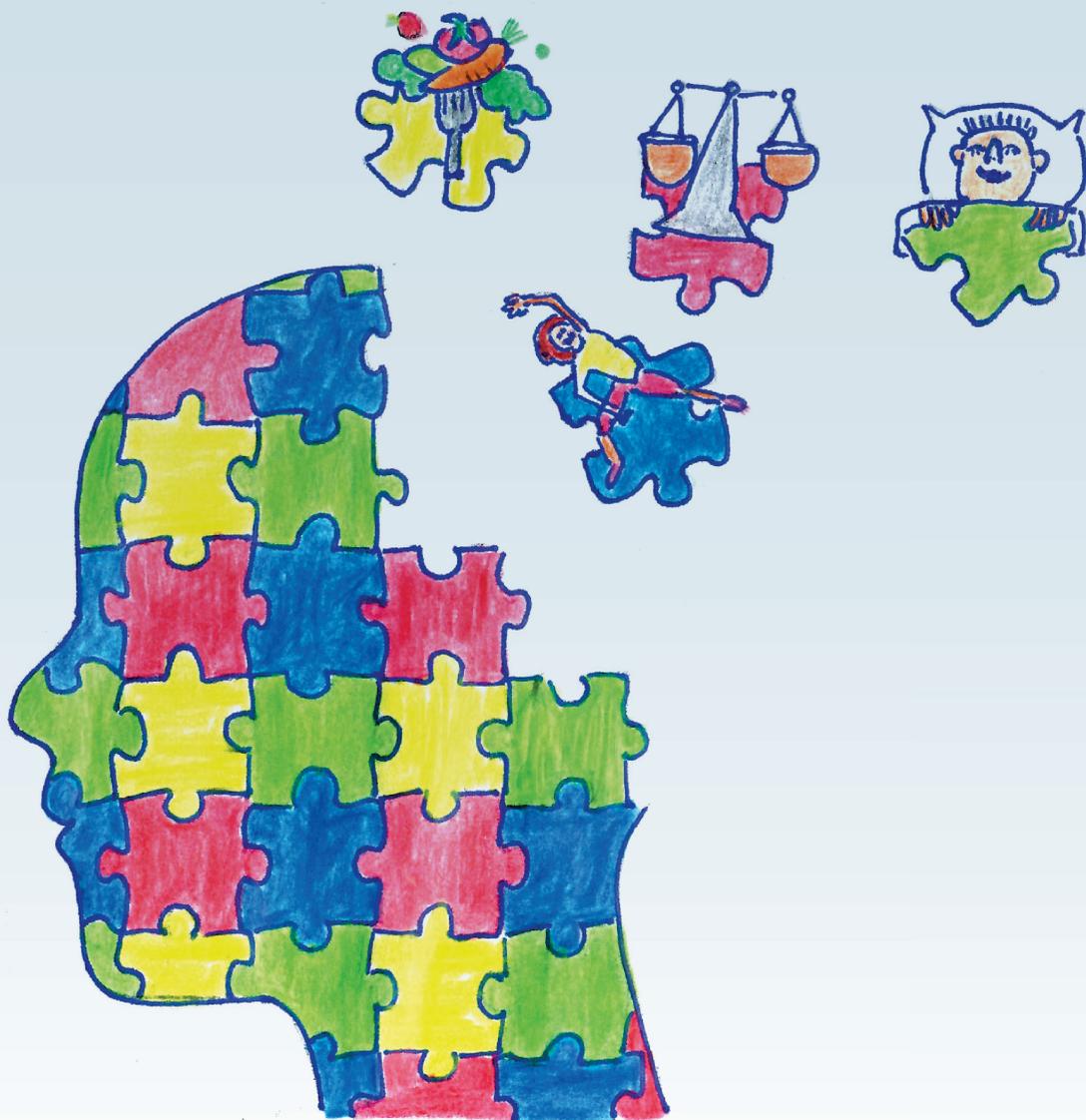


# Integrating health promotion into the everyday life of people with intellectual disabilities

*Noortje Kuijken*



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## **Colofon**

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Kaft: Jacqueline Kuijken-Hoven  
Design & lay-out: ProefschriftMaken || [Proefschriftmaken.nl](http://Proefschriftmaken.nl)  
Print: ProefschriftMaken || [Proefschriftmaken.nl](http://Proefschriftmaken.nl)  
ISBN: 978-94-6380-451-6

The work presented in this thesis was carried out within the Radboud Institute for Health Sciences.

# Integrating health promotion into the everyday life of people with intellectual disabilities

## **Proefschrift**

ter verkrijging van de graad van doctor  
aan de Radboud Universiteit Nijmegen  
op gezag van de rector magnificus prof. dr. J.H.J.M van Krieken,  
volgens besluit van het college van decanen  
in het openbaar te verdedigen op

dinsdag 3 september 2019

om 10.30 uur precies

door

**Noortje Maria Janine Kuijken**

geboren op 7 december 1987

te Eindhoven

**Promotoren**

Prof. dr. H.M.J. van Schrojenstein Lantman – de Valk

Prof. dr. M.W.G. Nijhuis – van der Sanden

**Copromotoren**

Dr. ir. J. Naaldenberg

Prof. dr. G.L. Leusink

**Manuscriptcommissie**

Prof. dr. C. Noordam

Prof. dr. D.H.J. Thijssen

Prof. dr. A.A.J. van der Putten (Rijksuniversiteit Groningen)

*Voor Bas en Suus*

*Het gaat niet om wat je doet, maar om wie je bent.*

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## CHAPTER 1

# General introduction



A healthy lifestyle is important for one's health and wellbeing. To promote good health, governments recommend people to stay physically active (American Heart Association, 2014; Commissie Beweegrichtlijnen, 2017; Harris, Melville, Murray, & Hankey, 2018), limit sedentary behaviour (Commissie Beweegrichtlijnen, 2017), and have a diet low in saturated fat, salt, and refined sugar (World Health Organization, 2015). For people with intellectual disabilities (ID) however, engaging in these health behaviours is not self-evident and health promotion activities are often not easily accessible to them (Krahn, Hammond, & Turner, 2006). This thesis aims to analyse stakeholders' perspectives on, and the context of, current health promotion for people with ID in order to help better tailor health promotion initiatives to the needs, interests, and capabilities of people with ID.

This general introduction starts with the story of an expert by experience, highlighting several aspects that are important to take into account when supporting people with ID to live healthily. This is followed by background information on intellectual disabilities, the health disparities that people with ID encounter, and the contribution of health promotion to reduce these disparities. Next, the overall aim and research questions of this thesis are described. This chapter ends with methodological considerations and the outline of the thesis.

## 1.1 Story of an expert by experience

At the start of my research into health promotion for people with ID, I met Frank. Frank is a 43-year-old man with mild ID, who lives independently with ambulatory support. He joined the participatory planning group of my research, and we worked together for five years. Frank has two lung conditions (chronic asthma and COPD) for which he regularly visits the lung specialist at the hospital. One day, his doctor told him: "Living more healthily would be of great benefit for your lung conditions and you would feel much better." In response, Frank tried to change his lifestyle and indeed felt a lot better. After a while, he realized that he wanted to help others to change their lifestyles as well. By sharing his story, he wants to inspire other people.

Every Thursday, Frank has dinner with his friend Anton; one week at Frank's place, the other at Anton's. He visits Anton by bike, one with an electric motor, which he uses only when he feels the need to do so. Anton lives on the third floor of an apartment block with stairs and a lift. Frank aims to take both flights of stairs, as "If my lungs don't let me take both flights, I can always take the lift from the second floor to the third." Frank enjoys the dinners with his friend: "We cook and eat together, I very much enjoy spending time together. And if you cook yourself a dinner, you eat more healthily."

Frank's everyday-life story shows that living healthily does not have to be a big issue; it is in the little things: travelling by bike, taking the stairs, cooking yourself a dinner. Everyone can start to make a change today, and you can do it on your own level, taking into account what you *can* do, just like Frank. The social environment is also very important in this, especially for people with ID who are often in a (semi-)dependent relationship with others. You need someone to encourage you to start, or to support you in the changes you make. And most of all, as Frank states, living healthily is more fun when you do it together!

## 1.2 Intellectual disabilities and health disparities

An intellectual disability is characterized by significant limitations in both intellectual functioning and adaptive behaviour, originating before the age of 18 (Schalock et al., 2010). Adaptive behaviour comprises conceptual, social, and practical skills, which people learn and perform in their everyday life. Examples are language and literacy, self-esteem, and the ability to avail of healthcare, respectively. However, human functioning is influenced not only by intellectual abilities and adaptive behaviour, but also by one's health, participation, context, and support received (Schalock et al., 2010). The present research was conducted in the Netherlands, where approximately 142,000 people with ID live (0.8% of the Dutch population) (De Koning & Kroon, 2015). They are supported by service providers who provide residential and community living arrangements as well as day-activity care. Service provision may vary from ambulatory support for several hours a day or week to people living alone (such as Frank) or with a roommate/family, to 24-hour staffed residential care, where people with ID live together in small group homes in the community or on a campus. Because of government regulations, increasingly more people with ID will live (semi-)independently in the community. People with mild to profound ID are supported mainly by daily care professionals who are trained in social work and/or assistant nursing. Tasks include assisting people with ID in personal, daily, social, and health care (Heutmekers et al., 2016). Other professionals who are often (but not always) employed by service providers for people with ID include, e.g., allied health professionals, ID physicians (medical specialists who have completed a 3-year postgraduate training course), and general practitioners (GPs).

Although ID in itself is not a disease, health problems can be related to co-morbidities, and people with ID face significant disparities, including inequitable attention to care needs, prevention, and health promotion, that influence their health (Krahn et al., 2006; Ouellette-Kuntz et al., 2005; van Schrojenstein Lantman-de Valk & Walsh, 2008). As a result, people with ID experience significantly more health problems than the general population (Carey et al., 2016; Straetmans, van Schrojenstein Lantman-de Valk, Schellevis, & Dinant, 2007) and are more likely to suffer from multi-morbidity (Hermans & Evenhuis, 2014), which is a strong predictor of mortality (Schoufour et al., 2018). They have a shorter lifespan and increased risk of early death when compared with people without ID (Heslop & Glover, 2015). Personal health risks and health behaviours are defined as key determinants of inequity in the health status of people with ID (Emerson & Baines, 2010). Several of the health problems that they encounter, such as obesity (National Institute for Health and Care Excellence, 2014) and diabetes (Balogh, Lake, Lin, Wilton, & Lunsy, 2015), are at least partly related to an unhealthy lifestyle and a lack of access to health promotion practices. People with ID engage in extremely low levels of physical activity (Dairo, Collett, Dawes, & Oskrochi, 2016; Hsieh, Heller, Bershadsky, & Taub, 2015; Stancliffe & Anderson, 2017) and high levels of sedentary behaviour (Melville et al., 2018; Melville et al., 2017), and they tend to consume an unhealthy diet (Gephart & Loman, 2013; Phillips & Holland, 2011).

### 1.3 Health promotion and the socio-ecological model

Effective and accessible health promotion could contribute to a healthier lifestyle for people with ID, thereby reducing the above-described lifestyle-related health problems (Taggart & Cousins, 2014; van Schrojenstein Lantman-de Valk & Walsh, 2008). However, researchers and governments worldwide have pointed out that the international focus on health promotion for people with ID is inadequate and requires more attention (Taggart & Cousins, 2014); (Pomona project, 2008; U.S. Government, 2010). Health promotion is defined as “the process of enabling people to increase control over, and to improve, their health” (World Health Organization, 1986). Although it is often used interchangeably with the terms ‘disease prevention’ and ‘health education’, some distinctions can be made. Disease prevention is directed towards preventing the initial occurrence of disease by means of risk factor reduction (primary prevention); seeks to arrest or retard existing disease and its consequences through early detection and appropriate treatment (secondary prevention); or aims to reduce the occurrence of relapses and the establishment of chronic conditions by means of, for example, effective rehabilitation (tertiary prevention) (Nutbeam, 1998). Health education is comprised of communication of information as well as fostering the skills, motivation, and confidence (self-efficacy) necessary for people to take action to improve their health (Nutbeam, 1998). Health promotion, however, is a comprehensive social and political process, which consists not only of strengthening the skills and capabilities of individuals, but also of changing social, environmental, and economic conditions in such a way that they have a positive impact on public and individual health (Nutbeam, 1998).

The Ottawa Charter for Health Promotion emphasizes the importance of involving the social and the physical environment (World Health Organization, 1986); this is especially important for people with ID as they often depend heavily on their social and environmental context to support them to make healthy choices and access facilities (Caton et al., 2012; Temple, 2009). Yet, current health promotion models for people with ID focus mostly on individual behaviour change (Taggart & Cousins, 2014), and many interventions use behaviour change techniques focused on the individual with ID (Castro, Ng, Novoradovskaya, Bosselut, & Hassandra, 2018; Steenbergen, Van der Schans, Van Wijck, De Jong, & Waning, 2017). To emphasize the interaction between, and the interdependence of, factors influencing health across multiple levels, theoretical models that incorporate several environmental levels, such as the socio-ecological model (SEM) (McLeroy, Bibeau, Steckler, & Glanz, 1988), can be useful in research on health promotion for people with ID. In this thesis, the SEM is used to emphasize the central role of the person with ID and to oversee the opportunities and pitfalls in their empowerment to live healthily. The SEM distinguishes five levels in which resources and hindering factors for (promoting) a healthy lifestyle can be categorized:

1. The individual level, in which, e.g., motivation, cognitive function, and physical abilities play a role (Bergstrom, Elinder, & Wihlman, 2014; Caton et al., 2012);
2. The interpersonal level, where emotional, instrumental, informational, or appraisal support from people in the social environment are found to be facilitators (Bergstrom et al., 2014; Frey, Buchanan, & Rosser Sandt, 2005; Temple, 2009);

3. The organizational level, in which, e.g., time and money provided for health promotion by service providers are recognized as important (Bodde & Seo, 2009; Sundblom, Bergstrom, & Ellinder, 2015);
4. The physical environment and the community level, with factors such as stress and safety, available facilities, and transport options (Brooker et al., 2015; Caton et al., 2012); and
5. The public policy level, where governmental factors such as health policies and insurance systems play an important role (Sundblom et al., 2015; Wahlström, Bergström, & Marttila, 2014).

Service providers are increasingly paying more attention to health promotion for people with ID, and many small-scale and ad hoc initiatives are organized in care settings. These care settings are complex systems in which many different stakeholders and contextual factors from all socio-ecological levels influence the success of these initiatives (Naaldenberg et al., 2009). A lack of attention to these contextual factors and to the needs, interests, and capabilities of the different stakeholders in the development and implementation of these initiatives may be the reason why many initiatives are not reaching their full potential and are used only for a short period of time (Checkland, 2000).

Perceptions of both people with ID and other relevant stakeholders on healthy living may differ from those used in research and policymaking (Naaldenberg et al., 2009; van Raak & Paulus, 2001). By studying both the context and the knowledge and experiences of diverse stakeholders, a broader evidence base will be reached while taking into account the complex context of initiatives (de Savigny & Adam, 2009). Insight into the complex interaction between individual needs and contextual resources and barriers can facilitate the co-creation of health promoting initiatives that fit the reality of practice and that are experienced as meaningful by all stakeholders involved (Checkland, 2000).

## **1.4 Overall aim and research questions**

This thesis aims to better tailor health promotion initiatives to the needs, interests, and capabilities of people with ID. To guide the analysis of stakeholders' perspectives on, and the context of, current health promotion for people with ID, the following research questions were formulated:

What can be learned from

1. the context of existing health promotion initiatives for people with ID?
2. the views and perspectives of different stakeholders, including people with ID?
3. co-creating a health promotion approach in everyday-life practice and testing its feasibility?

## 1.5 Methodological considerations and outline of this thesis

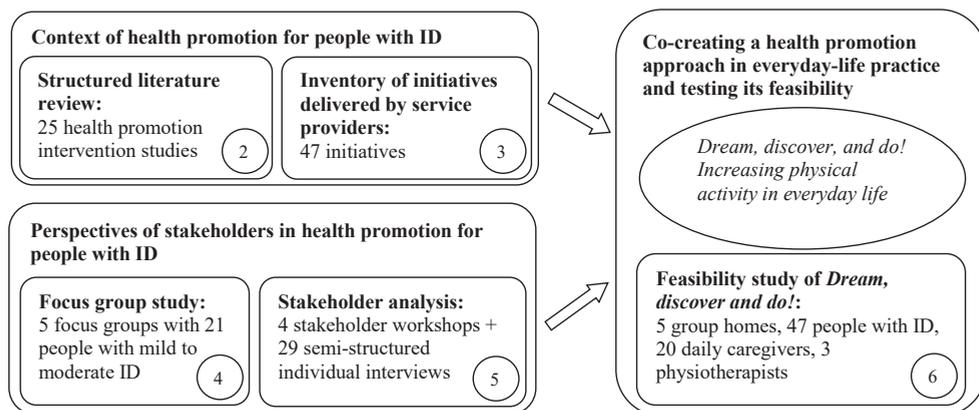
This research was conducted within the setting of an Academic Collaborative, Stronger on Your Own Feet (*Sterker op eigen benen*), a collaboration between the Radboud University medical center and nine regional service providers for people with ID. The Academic Collaborative aims to improve the health of, and healthcare for, people with ID by integrating research, education, and patient care, in which people with ID and their supporters – rather than disease or disability – take a central role. The chapters in this thesis present the studies that address the research questions above, followed by a general discussion. Each chapter elaborates on methodologies used in that chapter. Some methodological considerations have shaped the research approach throughout this thesis; these are addressed below.

At the start of this research project, a participatory planning group was established (Bartholomew, Parcel, Kok, Gottlieb, & Fernández, 2011) to provide ideas for, and give feedback on, the various studies in this research. This group included 17 people: four self-advocates, an ID physician, two parents, a legal representative, a movement teacher, a physiotherapist, a dietician, a project manager for healthy living, a unit chief, a manager, a senior researcher, and two daily caregivers in day-activity care. In various compositions, this group gathered cyclically throughout the research and provided ideas and feedback on, for example, semi-structured interview guides for qualitative research, stakeholder analysis, and the development, implementation, and feasibility testing of a health promotion approach.

People with ID form a very heterogeneous group with regard to limitations in intellectual functioning and adaptive behaviour as well as in the support needed in everyday life. This research focused on health promotion for people with mild to moderate ID and their context. In this way, the intended users were able to participate in the participatory planning group, as well as in qualitative interviews.

A broad spectrum of qualitative methods was used in this thesis, interviewing people with ID in focus groups and various other stakeholders in individual interviews. In addition to semi-structured (group) interviews, a qualitative literature review, an inventory of initiatives, and a mixed-methods feasibility study were used in this research. The combination of different methods and information from different perspectives and sources increases validity by providing triangulation of methods and data sources (Koelen, Vaandrager, & Colomer, 2001).

This research consisted of five studies (Chapters 2–6), which are briefly described below. These chapters are followed by a general discussion of the results in Chapter 7. The outline of this thesis, including methods used and participants per chapter (Chapters 2–6; chapter number is indicated within a circle in each case), is depicted in Figure 1.1, with a subdivision based on the research questions.



**Figure 1.1** Thesis outline and chapters

To answer the first research question: *What can be learned from the context of existing health promotion initiatives for people with ID?*, Chapter 2 provides a structured review of literature on the main characteristics of published health promotion intervention studies for people with ID. It identifies challenges, best practices, research priorities, and knowledge gaps in the context of existing health promotion initiatives. This chapter focuses on the health promotion activity implemented; research design employed, including the recruitment strategy used; and outcome measures used in the reviewed studies. The 25 included papers were assessed using qualitative data analysis software.

Chapter 3 answers the first research question by compiling an inventory, aiming to gain insight into available health promoting physical activity and nutrition initiatives in the everyday life of people with ID. Telephone surveys among 44 employees of service providers were used to gain insight into the characteristics of the initiatives and into the attention given by initiatives to resources and hindering factors for healthy living for people with ID. The data were analysed descriptively using SPSS Statistics 20.

Chapter 4 focuses on research question 2: *What can be learned from the views and perspectives of different stakeholders, including people with ID?* and presents a focus group study exploring the views and perspectives of people with mild to moderate ID on healthy living, as well as the personal and environmental factors that they perceive as relevant for realizing a healthy lifestyle. Discussions focused on three main themes: (1) perceptions of their own health, (2) what participants consider as healthy living, and (3) factors experienced as related to the ability to live healthily. Twenty-one people with mild to moderate ID participated in five focus groups. Data were analysed using a combination of domain analysis and thematic analysis.

Chapter 5 answers research question 2 from the perspective of other stakeholders and describes a two-phase stakeholder analysis aiming to gain insight into (1) the health promotion stakeholders within the network of people with ID and (2) their expectations

of, perceived roles and responsibilities in, and perceived facilitating and hindering factors for health promotion for people with ID. In phase 1, four workshops were conducted to provide insight into involved stakeholders. In phase 2, 29 semi-structured interviews were conducted with various stakeholders regarding their views on health promotion. Data were analysed using stakeholder matrices and a combination of domain and thematic analysis.

The results in Chapters 2–5 informed the co-creation of *Dream, discover and do! Increasing physical activity in everyday life*. This approach aims to help people with ID and their daily caregivers to become more aware of possible scenarios to increase physical activity in everyday life and to think about how to incorporate these activities into everyday routines, eventually leading to a more active and less sedentary lifestyle. Chapter 6 reports on a feasibility study that answers research question 3: What can be learned from co-creating a health promotion approach in everyday life practice and testing its feasibility? by assessing whether *Dream, discover and do! Increasing physical activity in everyday life* can work and is feasible to implement and evaluate. Five group homes including 47 people with ID, 20 daily caregivers, and three physiotherapists participated in this feasibility study. The study had a mixed-methods pre-post-test design with baseline measurement and post-test after 2.5–4 weeks. Accelerometers and questionnaires were used to collect data that were analysed both qualitatively and quantitatively.

Finally, the main findings of the studies in Chapters 2–6 are discussed in Chapter 7, including a reflection on the most important findings, strengths and limitations, and recommendations for health promotion practice. Chapter 7 also provides suggestions for future research.

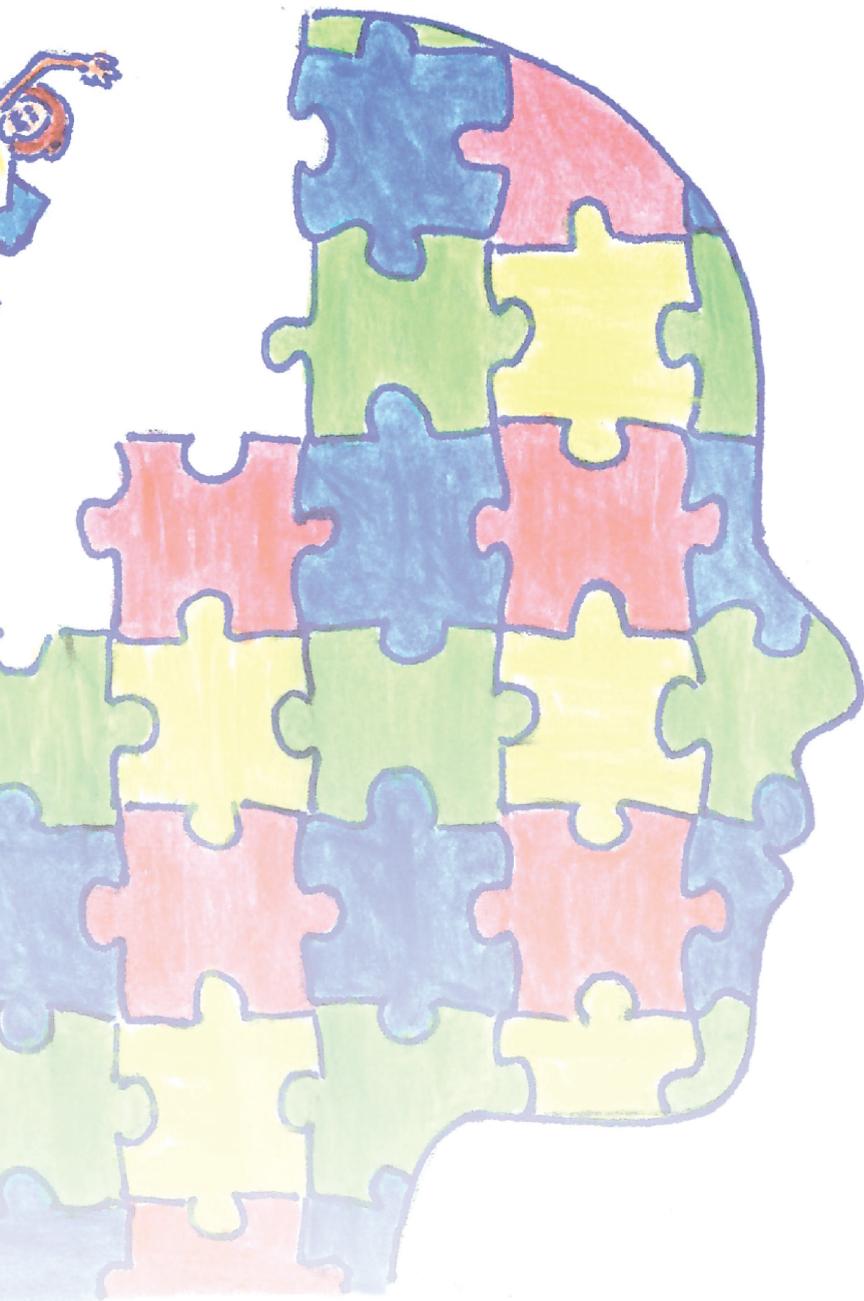
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## CHAPTER 2

# Topics, methods and challenges in health promotion for people with intellectual disabilities: a structured review of literature

### **Published as:**

Naaldenberg J., Kuijken N., van Dooren K. & van Schroyen Lantman de Valk H. (2013). Topics, methods and challenges in health promotion for people with intellectual disabilities: a structured review of literature.

People with intellectual disabilities (ID) experience substantial health inequities compared with the general population. Many secondary conditions and lifestyle related health problems could be prevented with adequate health promotion. The aim of this structured review is to provide insight into the main characteristics of published health promotion intervention studies for people with ID and, in doing so, to identify best practice and knowledge gaps. Relevant studies were identified through a structured literature search of multiple electronic databases (PubMed, CINHAS, Scopus, PsychINFO); the search strategy covered health promotion and intellectual disabilities for available papers published between February 2002 and 2012. In total, 25 studies were included and analyzed. Overall, studies were diverse and explored a variety of health issues. Papers included a variety of participants (in relation to level of disability) and intervention approaches. With regard to quality, many studies failed to report how they recruited their participants, and there were substantial challenges identified by authors in relation to recruitment, implementation of interventions, and the selection of outcome measures used as well as the usability of measures themselves. Our findings suggest that this field experiences methodological weaknesses and inconsistencies that make it difficult to compare and contrast results. Theoretically driven studies that take into account the views and expectations of participants themselves are needed, as is research that investigates the reliability and validity of outcome measures for the ID population. Collaboration with mainstream health promotion research is critical.

## 2.1 Introduction

People with intellectual disabilities (ID) experience poorer health and higher risk of health problems compared with the general population. Although ID in itself is not a disease, health problems can originate from disabilities and the health of people with ID is adversely influenced by a cascade of disparities including inequitable access to health services (Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz, et al., 2005; Van Schrojenstein Lantman-de Valk & Walsh, 2008). Many secondary conditions, co morbid conditions and lifestyle-related health problems experienced by people with ID can be prevented (Van Schrojenstein Lantman-de Valk & Walsh, 2008). Effective and accessible health promotion could contribute significantly to improve quality of life of people with ID and reduce costs related to preventable health problems (Van Schrojenstein Lantman-de Valk & Walsh, 2008). However, currently international focus on health promotion for people with ID is inadequate and needs more attention from researchers and decision makers (Krahn, et al., 2006), as is reflected in several policy documents from the United States and Europe that make improving the health of people with ID a specific aim (Pomona project, 2008; US government, 2010).

The World Health Organization defines health promotion as: *the process of enabling people to increase control over and improve their health* (WHO, 1986). The term health promotion is often used interchangeably with other terms such as 'health education' and 'disease prevention'. Although all of these strategies aim to improve health, some distinctions can be made. Disease prevention aims to prevent the occurrence of disease by reducing risk factors for and the consequences of disease through early detection and treatment (WHO, 1998). Health education is concerned with the communication of information about health and fostering skills, motivation and confidence necessary for people to take action to improve their health (WHO, 1998). Finally, health promotion not only embraces actions directed at strengthening the skills and capabilities of individuals, but those directed at changing social, environmental and economic conditions to alleviate their impact on public and individual health as well (WHO, 1998). Since people with ID often depend heavily on their social and environmental context to support them to make choices and access facilities (Messent, Cooke, & Long, 2000; Segal, 1993) health promotion strategies offer important advances over prevention or health education.

People with ID experience important health determinants and disease-related risk factors differently from the general population due to physical, cognitive and behavioral impairments; and inequalities across mobility, income, living conditions, housing schemes and social networks. Thus, they have different health promotion needs, particularly in relation to the accessibility of health promoting activities (Robertson, et al., 2000). The perceptions and knowledge of supporters with regard to healthy lifestyles, possibilities and needs of people with ID for health promotion are also important (Temple & Walkley, 2007; Young, Chesson, & Wilson, 2007). Available health promotion activities for the general population often assume a certain level of independence, can be difficult to understand, expensive, inaccessible or invisible to people with ID or their supporters — all barriers to participation (Messent, Cooke, & Long, 1999; Messent, et al., 2000). Further, public health research that aims to evaluate health promotion activities may passively or

actively exclude people with ID due to the challenges of recruiting and working with this group (Lennox, et al., 2005). In the context of health disparities encountered by people with ID and their special needs for health promotion as outlined above, insight in existing health promotion projects for people with ID would be helpful in identifying research priorities, best practice and knowledge gaps.

The aim of this structured review is to identify papers that present an evaluation of a health promotion activity targeting people with ID and to describe the (1) health promotion activity implemented; (2) research design employed, including the recruitment strategy used; and (3) outcome measures used. A secondary objective is to describe the challenges associated with implementing and evaluating the interventions.

## 2.2 Methods

### 2.2.1 Search strategy

The Cochrane Database of Systematic Reviews was searched confirming that a systematic review of health promotion intervention studies for people with ID did not already exist. A structured literature search was conducted in the bibliographic databases PubMed, CINHAS, Scopus and PsychINFO. The search strategy was built with the assistance of an information specialist and covered two key topics: 1) health promotion; and 2) intellectual disabilities. Table 2.1 provides an overview of search terms used. Searches were limited to publications written in English, published between 2002 and 2012.

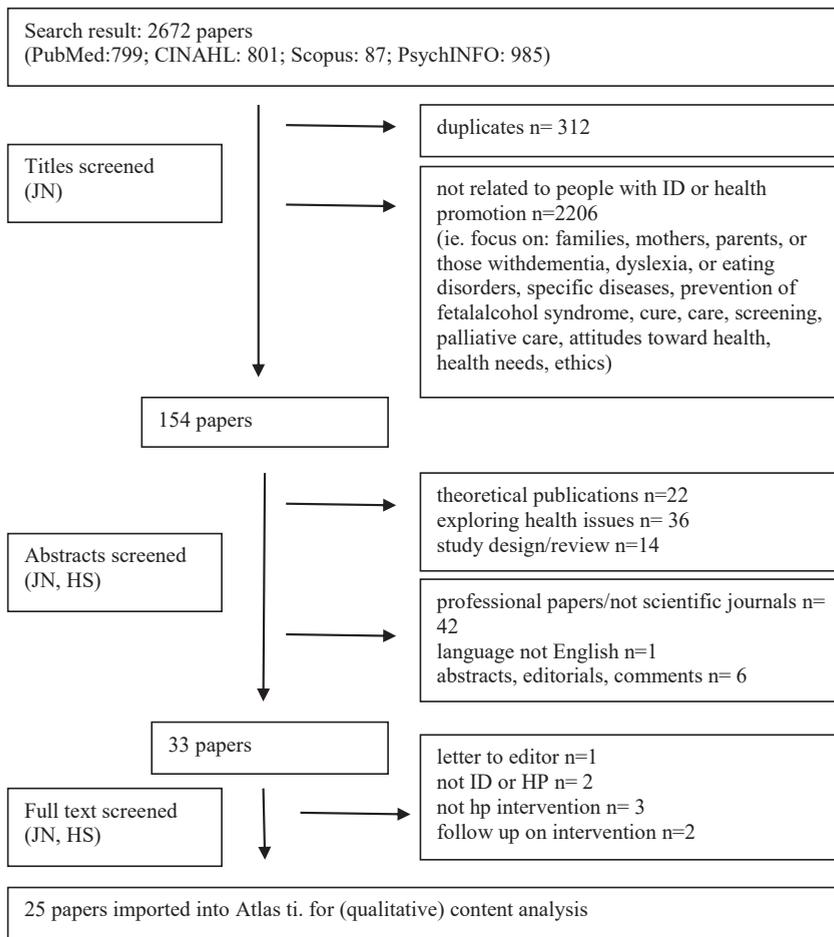
The search yielded 2,672 results. Criteria for inclusion in this study were: empirical studies of interventions, identified as health promotion/education, and targeted to people with ID. Duplicates were removed and titles, abstracts and full texts were screened following the procedures outlined in Figure 2.1. This process resulted in 25 included papers.

**Table 2.1** Search strategy

Database	Block I Intellectual Disabilities	Block II Health promotion
PubMed	Search ("Developmental Disabilities"[Mesh] OR "Intellectual Disability"[Mesh] OR "Learning Disorders"[Mesh] OR ((intellectual*[tiab] OR development*[tiab]) AND (disable*[tiab] OR disabilit*[tiab])) OR (learning[tiab] AND (disable*[tiab] OR disabilit*[tiab] OR disorder*[tiab])) OR mental retardation[tiab])	Search ("Health Promotion"[Mesh] OR "Preventive Health Services"[Mesh:noexp] OR "Health Education"[Mesh] OR disease prevention[tiab] OR health education[tiab] OR (Health[tiab] AND (Promoting[tiab] OR promotion[tiab])))
CINAHL	(MH "Mental Retardation+") (MH "Developmental Disabilities") (MH "Learning Disorders+") TI ( ((intellectual* OR development*) AND (disable* OR disabilit*)) OR (learning AND (disable* OR disabilit* OR disorder*)) OR mental retardation ) OR AB ( ((intellectual* OR development*) AND (disable* OR disabilit*)) OR (learning AND (disable* OR disabilit* OR disorder*)) OR mental retardation )	(MH "Health Promotion+") (MH "Health Education+") TI (Health Promotion OR Preventive Health Services OR Health Education OR disease prevention OR health education OR (Health AND (Promoting OR promotion)))

SCOPUS	((("Developmental Disabilities" OR "Intellectual Disability" OR "Learning Disorders" OR (intellectual* AND (disable* OR disabilit*)) OR mental retardation OR (learning AND (disable* OR disabilit* OR disorder*)) OR (development* AND (disable* OR disabilit*)))	("Health Promotion" OR "Preventive Health Services" OR "Health Education" OR disease prevention OR health education OR (health AND (promoting OR promotion))
PsychINFO	(intellectual disabilit* OR developmental disabilit* OR mental retardation).ti,ab (intellectual disorder* OR developmental disorder*).ti,ab	((Health Promotion or Preventive Health Services or Health Education or disease prevention or health education or health) and promoting) or promotion).ti,ab

Final search performed on 29 February 2012; Plurals were allowed by including wildcards (\*)  
Block I and II were combined by the use of operator AND



**Figure 2.1** Flowchart of the structured literature search

### 2.2.2 Analysis

Full text copies were imported in ATLAS.ti software for qualitative data analysis (Scientific Software Development). A first qualitative content analysis (Silverman, 2006) of papers (JN) was used to develop a coding scheme (Table 2.2). Next, the documents were coded by all authors applying the coding scheme. Discrepancies in assigned codes were discussed between researchers at several times during the analytical process until consensus was reached.

A qualitative analysis was performed to identify and categorize challenges authors encountered with their project as described in the papers. First, text fragments reporting on challenges were coded by (JN, NK and KD), and then all coded segments were grouped into similar themes and discussed between all researchers until a set of categories was reached.

**Table 2.2** Coding scheme used by all authors

General	Approach	Recruitment	Outcomes
Sample size: <i>reported n</i>	- Health education: <i>focus on skills and information</i>	Included groups: <i>as described in paper</i>	Check if used: <i>-physical measures</i>
Informed consent: <i>provided y/n</i>	- Health promotion: <i>additional focus on supportive environments, empowerment</i>	Place of recruitment: <i>as described in paper</i>	<i>-skills</i>
Study topic: <i>as described in paper</i>	- Other approach: <i>as specified in paper</i>	Way participants were contacted: <i>as described in paper</i>	<i>-quality of life</i>
General aim: <i>-physical exercise</i>	- Research design: <i>as described in paper</i>		<i>-nutrition</i>
<i>-healthy lifestyles: combining exercise and nutrition</i>			<i>-physical activity</i>
<i>-other</i>	- intervention origin <i>Developed for ID population</i>		<i>-behavior</i>
	<i>Adaptation of general population</i>		<i>-social outcomes</i>
	<i>General population</i>		<i>-system outcomes</i>
			<i>-process measures (specify)</i>
			-Outcome origin: <i>A General population</i>
			<i>B Adaptation of general pop.</i>
			<i>C Developed for ID population</i>
			<i>(if more outcomes were used, check option of highest relation to ID)</i>

### 2.2.3 Quality assessment

Since different types of studies were included, the quality of the papers was assessed (JN, NK) based on the following criteria: 1) clear description of aim(s) and research question(s); 2) description and discussion of rationale for sample size chosen; 3) description and discussion of research population; 4) attrition rate provided and discussed; 5) description and discussion of measurements used; 6) discussion of study limitations; 7) description of intervention development; and 8) description of intervention content. In total, 16 points could be assigned to each paper, two points per criteria if information was provided and elaborated, one point if marginal information was provided and discussion or elaboration was lacking and zero points no information was provided. All papers were assessed by two raters after which discrepancies were discussed using ATLAS.ti coded pieces of text from

the papers. Remaining discrepancies were discussed with all authors until agreement was reached.

## **2.3 Results**

The following sections report findings originating from the analysis of included papers. These findings will be discussed in the discussion/conclusion paragraph.

### **2.3.1 Main study characteristics**

Table 2.3 describes the main characteristics of the included papers. Most studies originated from the USA (n=14). For one paper the origin could not be identified from the text or authors' affiliations. The quality ratings for the papers ranged between 3 (lowest quality) and 16 (highest quality). Four papers could not be scored on all quality indicators because of specific design characteristics. Excluding these papers without full scores, the mean quality score was 10.7. Of the 21 full score papers, 10 scored below the mean and 11 above the mean.

### **2.3.2 Approach and topics**

Of the included papers, nine followed a health education approach and nine a health promotion approach. For three papers both approaches were applied and four papers could not be classified as following either a health promotion or health education approach. These papers were considered to have met the inclusion criteria because of their empirical nature and relevance of their topics. Of the included papers, 11 had a primary focus on physical activity and eight on healthy lifestyles combining physical activity and nutrition. The specific study topics for all papers are listed in Table 2.3. Furthermore, 17 of the included papers used interventions that were specifically developed for the ID population, three papers adapted their intervention from general population interventions and five papers did not provide sufficient information to be able to determine the origin of the intervention.

### **2.3.3 Design**

Nine papers reported using a pre test/post test single group design, making this the most prevalent research design. Seven used a pre/post control group design and three a pre/post comparative group design. Other designs used were single group descriptive designs, process evaluations and one n=1 case study (Table 2.3).

**Table 2.3** General characteristics of included papers

<b>Author, year origin</b>	<b>Main topic study design</b>	<b>Sample</b>	<b>Approach</b>	<b>Outcome measures</b>	<b>Quality score</b>
Altabet et al., 2003. USA	Oral hygiene, Pre-post control group design	39 intervention/40 control	health promotion	-Physical	9 / 16
Aman et al., 2007. USA	Safe medication Single group descriptive	361	health education	-Skills -Process: Readability of the text, areas of information covered, respondents' impressions of how much they learned	10 / 16
Aronow et al., 2005. USA	Preventive healthcare Pre-post comparative	201 participants randomly assigned into 2 groups. 162 completed at least 2 interviews	health education	-Physical -QOL -Activity -Behavior	12 / 16
Bazzano et al., 2009. USA	Community based lifestyle Pre-post single group	85 signed up, 68 attended 44 complete data	health education / health promotion	-Physical -Skills -QOL -Nutrition -Activity -Social -Behavior -Process: Participant experiences with the program	13 / 16
Bizarra et al., 2009. Portugal	Oral hygiene Pre-post single group	135 initial, 107 completed	health education	-Physical -Skills	8 / 16
Bodde et al., 2012. USA	Physical activity Reflexive	42	health education	-Skills -Process: Pilot test experiences with the program; assess implementation fidelity; assess achievement of learning objectives with process measures	8 / 16

Table 2.3 continued

Author, year origin	Main topic study design	Sample	Approach	Outcome measures	Quality score
Carter et al., 2004 USA	Physical exercise Pre-post single group	25 potential participants, 20 signed waiver, 15 pretest, 11 posttest, 6 complete data	health education / health promotion	-Physical -System -Process: evaluation of staff experiences with used measures (draw blood)	11 / 16
Chapman et al., 2005 USA	Lifestyles, obesity Pre-post control group	38 intervention, 50 control	health promotion	-Physical	7 / 16
Davis et al., 2011. USA	Exercise program Pre-post single group	38 initial, 25 completed	health education	-Physical	16 / 16
Elinder et al., 2010. Sweden	Supportive environments Cluster randomized trial	description of study design	health promotion	-Physical -QOL -Nutrition -Activity -Social -Systems -Process: Fidelity, experiences with the program, evaluation of barriers and facilitators of implementation.	12 / 12
Ewing et al., 2004. USA	Cardiovascular risk reduction Pre-post comparative	154 id population initial, 92 completed 207 general population initial, 97 completed	health education	-Physical -Skills -nutrition -Activity -Process: adherence to the curriculum	13 / 16
Hayashi et al., 2011 Japan	Sexual education Pre-post control group	17 intervention, 10 completed 17 control group	health education	-Social -Process: Experiences with the program (enjoyment, difficulty and usefulness)	12 / 16

Table 2.3 continued

Author, year origin	Main topic study design	Sample	Approach	Outcome measures	Quality score
Heller et al., 2004. USA	Physical exercise, education Pre-post control group	initial 89, 53 completed: 32 intervention, 21 control	health education / health promotion	-Activity -Social -skills -QOL -behavior	15 / 16
Humphries et al., 2008. USA	Nutrition, supportive environments Pre-post comparative case study	4 group homes	health promotion	-Nutrition -Systems -Process: implementation fidelity, degree of implementation by staff	15 / 16
Lante et al., 2011. Australia	Community based physical activity Pre-post single group	2 + support staff	health promotion	-Activity -Social -Process: program attendance and participant experiences with the program	12 / 14
Lotan et al., 2010. Israel	Exercise virtual reality Pre-post control group	20 intervention, 24 control	other	-Physical -Process: Experiences with the program: choice of games, satisfaction and attitudes of the caregivers participating in the program	11 / 16
Lynnes et al., 2009. Canada	Exercise skills Process evaluation	4	health education	-Skills -Behavior -Process: Program attendance adherence and experiences with the program.	12 / 14
Mann et al., 2006. USA	Nutrition, exercise, stress reduction Pre-post single group	324 initial, 192 completed	health promotion	-Physical -Skills -Nutrition -Activity	13 / 16

Table 2.3 continued

Author, year origin	Main topic study design	Sample	Approach	Outcome measures	Quality score
Marks et al., 2010. USA	Community based health promotion Pre-post single group	56	health promotion	-Physical -Nutrition -Social -Behavior -Process: Satisfaction with program	10 / 16
Marshall et al., 2003. UK	Weight reduction Pre-post single group	25, 1 person dropped out	health education	-Physical	7 / 16
Rimmer et al., 2004. USA	Physical fitness Pre-post control group	52	health promotion	-Physical	10 / 16
Singh et al., 2008. Not provided	Mindfulness, eating behavior ABCD experimental design	1	other	-Physical	8 / 14
Thomas et al., 2011. UK	Exercise program Single group descriptive	215 initial, 125 follow-up	health promotion	-Physical -Process: Barriers and accessibility (participation and continuation)	14 / 16
Tsimaras et al., 2003 Greece	Exercise program Pre-post control group	15 intervention, 10 control	other	-Physical	8 / 16
Wu et al., 2010. Taiwan	Exercise program Pre-post single group	146	other	-Physical	3 / 16

### 2.3.4 Outcome measures

Table 2.4 provides the frequencies for used outcome measures. Physical measures such as BMI, blood pressure, blood sugar levels, stamina and muscle strength were most often used. System-related outcomes such as changes in environments, policies or organizational changes were used least frequently.

**Table 2.4** Frequencies of outcome measure used

	Physical outcomes	Quality of life	Skills	Nutrition and diet	Physical activity	Social outcomes	Systems outcomes	Behaviour	Process measures
Times used in total (25)	18	4	8	6	7	7	3	6	13
HP approach (9)	7	1	1	4	3	3	2	1	5
HE approach (9)	5	1	5	1	2	2	0	3	5
HP and HE approach (3)	2	2	2	1	2	2	1	2	2
'Other' approach (4)	4	0	0	0	0	0	0	0	1

Total outcome measures used per study ranged from one to eight (mean = 3). Twenty-one papers used five or less outcome measures and four papers used six or more measures. The papers that used a single outcome measure all used a physical outcome (Table 2.3). Ten papers used outcome measures that were developed for the general population that were predominantly physical measures. Six papers adapted general population outcome measures to the ID population, and eight papers used outcome measures that were developed for the ID population. One paper did not provide enough information to determine the origin of the outcome measures.

Thirteen papers reported the use of process evaluations and measures, often assessed qualitatively (Table 2.3). These process evaluations included an evaluation of the usability of materials, experiences with the program according to participants, implementation fidelity, experiences with the program according to staff, attitude of staff towards the program and encountered barriers. In four papers process measures were used to gain additional information concerning the programs' main outcome measures.

### 2.3.5 Inclusion, recruitment, and informed consent

The number of participants in the included studies ranged from 1 to 361 at the start of the projects. Of the 19 projects applying a pre-post test design, seven did not provide information on attrition rates. Two additional papers did not report attrition, but because of their design (very small samples) attrition was not an issue. Of the ten papers reporting attrition, the percentages for attrition ranged between 4% and 76% with a mean attrition percentage of 36.5%.

The majority of the papers (n=11) included people with a mild to moderate intellectual disability, five papers included participants with mild to profound disabilities and one paper focused on profound disabilities alone. Eight papers did not provide information on level of disability of participants. To describe participants of the study, the term 'intellectual disabilities' was used by 14 authors. Other terms included mental retardation, developmental disabilities, learning disabilities, mental disabilities and syndrome specific terms such as Down syndrome, and Prader-Willi syndrome.

Most papers recruited participants at supported living facilities of local service providers or from attendees of social services such as physiotherapy practices (n=15). Other places to recruit participants were day programs such as schools or day resource centers (n=3), leisure activities (n=3), and other places (n=3) such as family practices or through pharmacy distributed booklets. One paper did not describe where participants were recruited. Personal contact between potential participants and health professionals, managers or coaches was the most frequent way used to invite potential participants (n=7). Direct referrals to the program by physicians or health professionals (n=4) and invitation through written information were also used (n=4). Two projects used multiple approaches to invite participants and eight papers did not provide information on how participants were invited. For most studies, obtaining informed consent was part of the information process. Five papers did not provide information about informed consent procedures or whether informed consent was obtained and from whom.

### **2.3.6 Challenges and best practices**

For this review, the described challenges were grouped into four main categories and a category of best practice. These will be described below.

#### *2.3.6.1 Study design and representativeness*

With regard to study design, several difficulties with using control groups and randomized designs were discussed in the analyzed papers. Papers that did not use such a design discuss the fact that this is a weakness in the evaluation of their intervention. The context sensitivity (cultural context, restrictive settings) of the intervention and non-randomized inclusion of participants (which was often not an option) were discussed to influence the representativeness. Studies often reported having limited power due to small sample sizes. Reasons for not using a control group design were: ethical issues (everybody should receive intervention), time issues (only time for a pilot study, need for a quick evaluation) and financial constraints. Time issues were also mentioned with regard to the time it takes for an intervention to be effective which might exceed the time projects were run (often between 8 and 10 weeks) and the adherence to healthy behaviors after projects were ended. Additionally, some interventions consisted of several components. In this regard, papers' authors discuss difficulties in telling from their evaluation which feature led to positive effects.

#### *2.3.6.2 Intervention content, setting and materials*

With regard to the content of interventions, issues concerning ethics, inclusion, and autonomy were discussed. People with ID strongly depend on staff or family to enable them to participate in projects, and do not always have volitional control over their actions. At the

same time they have a basic right to autonomy and self-determination. Authors discuss that these issues are difficult to take into consideration when developing a health promotion program.

The uncertainty with regard to whether the actual content of the intervention (i.e. diet, physical activity) would be associated with desired effects among this population in contrast to the general population is a challenge. Also, the difference between the program setting and the real world setting was highlighted by several authors: complex projects were not likely to be used in actual practice and financial constraints and time investments of staff could influence the future implementation of projects in “true field settings”.

Used materials such as information leaflets were often developed for the general population and needed adaptation before they could be used for people with ID. Examples of encountered difficulties were: need for simplifications because of difficulties in understanding concepts such as portion size, need for more concise and modified language in information materials, problems with using devices such as DVD players, and problems with the use of treadmills in fitness settings.

#### *2.3.6.3 Implementation and participation*

Challenges to implementation included: financial constraints, the lack of local partnerships with mainstream sport and care providers, transportation issues, negative perceptions of the program with staff, availability of staff to accompany participants, lack of control participants have over choices such as food choices, lack of internet access for participants, managers and staff being too busy to follow the program, and lack of support for the program among relevant stakeholders.

The participation of people with ID in the programs was not always successful. Programs often encountered a high attrition rate and non-attendance for appointments and meetings. Recruitment of participants was hindered when the content of the intervention and consequences of participation were not well understood or an existing relationship with participants was necessary to convince participants to join in. Time conflicts with participants’ work schedules or day service program, lack of motivation to participate, and the use of invasive techniques such as drawing blood to evaluate blood sugar levels, were reasons for low participation or high attrition rates.

#### *2.3.6.4 Measures and outcomes*

Three main themes related to the quality of data collection in the evaluation of projects. The first theme related to the lack of suitable and standardized scales for people with ID. Validated general population scales needed to be adapted first. Time and resources to adequately validate these adapted scales and assess their psychometric properties often was not available. Furthermore, the use of BMI for people with ID was debated and limitations to its use were mentioned. However, BMI was also used as an outcome without further discussion of its limitations and suitability.

Second, it was suggested that the way data were collected challenged the data-quality: data was collected through proxy reports and not from participants themselves, data could

be incomplete or difficult to verify whether data was complete (food intake journals, self reports) and intervening factors could not always be controlled (i.e., time of the day, mood of participant, influence of accompanying staff, family visits). Data collection with people with ID by means of face-to face interviews or surveys may have involved the risk of participants providing social desirable answers to questions. Participating in physical tests or invasive assessment measures were also mentioned to be difficult in the ID population compared to data collection in the general population.

Finally, the selection of relevant outcome measures also proved challenging. Intermediate outcomes were often used because of the limited time-span of the study. Long-term outcomes (such as weight loss, increased strength or better fitness) were discussed in terms of not being sensitive enough to make effects visible. One of the authors indicated that regardless of actual weight reduction, a positive change in activity, stress reduction and nutrition could be beneficial to participants.

#### 2.3.6.5 *Best practice*

Based on their experiences, authors also discussed best practice for future research, including methods that:

- seek direct input of participants towards finding solutions as well as to identifying problems;
- integrate health promotion in a person's natural settings such as where they live, work or engage in recreation activities as opposed to clinic or lab based settings;
- incorporate a broad base of outcome measures, including qualitative methods;
- develop links and partnerships with mainstream providers of health promotion and sports activities;
- use multiple strategies to recruit participants and include personal contact.

## 2.4 Discussion and conclusion

### 2.4.1 Discussion

The aim of this study was to gain insight into published health promotion interventions for people with ID. In total 25 papers were analyzed. Overall, studies were diverse and explored a variety of health issues. Papers included a variety of recruitment strategies, participants (in relation to level of disability) and intervention approaches. With regard to quality, many studies failed to report how they recruited their participants, and there were substantial challenges identified by authors in relation to recruitment, implementation of interventions, and the selection and application of outcome measures. We believe this study represents an important step forward for health promotion research for people with ID – our description of this body of work allows for critical reflection about research approaches and identification of research gaps, therefore helping to establish the agenda for future research efforts.

Our findings suggest that there is heterogeneity in terms used by authors in this area. Authors sometimes explicitly described following a health promotion approach even

when it was clear that they were using a health education approach. Since the overall aim of these interventions was to promote the health of participants, this is perhaps unsurprising. However, when searching for publications on health promotion or health education, the inconsistent use of terminology might influence results. Similarly, differences in terminology used to describe the research population (intellectual disability, mental retardation, learning disabilities) may serve to complicate and confuse search results. To improve the visibility of papers in this field, standard terminology would be beneficial. The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) has moved to make 'intellectual disabilities' standard. This term could therefore serve as main keyword when publishing studies.

The majority of the included papers focused on exercise or healthy nutrition. To improve the health of people with ID these topics are pertinent; however, there are several other key issues that must be addressed through health promotion including: healthy aging; osteoporosis, fractures and the prevention of falling incidents; constipation; mental health and wellbeing, stress reduction and social wellbeing (Van Schrojenstein Lantman-De Valk, 2005). Our findings suggest that the field of health promotion research is underdeveloped for this group. This is consistent with commentary that people with ID represent a marginalized and too often overlooked population group in public health (Krahn, et al., 2006; Ouellette-Kuntz, et al., 2005).

Given the health inequities they experience, it is critically important that public health and health promotion researchers ensure their study designs are inclusive of people with ID. The fact that most of the included papers strongly depended on the collaboration of service providers to recruit participants, is illustrative of the need for attention to recruitment and participation. People with ID living in independent housing schemes or community settings should also be able to benefit from health promotion interventions (Lennox, et al., 2005). Best practices derived from the papers showed that inviting participants through personal contact is a good place to start.

Collaboration between ID health researchers and 'mainstream' researchers can encourage methodology to be more inclusive towards this group. In health promotion research, reducing health inequities is a major objective (Dahlgren & Whitehead, 2006) and building on existing health promotion research could lessen the 'cascade of disparities' faced by people with ID. Only 25 studies were included in this review, of which only three used interventions adapted from general population interventions, demonstrating the urgent need for collaboration between mainstream and ID related health promotion research.

A main challenge identified in this study is also dominant in mainstream health promotion research (Hawe & Potvin, 2009; Rootman, et al., 2001) and relates to the use of evaluation designs. Typically, (randomized) controlled designs are seen as the 'gold standard' in evaluating health promotion (Tones, 2000). A form of control group design was used in only seven of the 25 papers. Analysis of the challenges showed that using control groups was difficult because of ethical issues and time and financial constraints. The use of designs without a control group was discussed as diminishing the quality of the studies. However, the complexity of the interventions made randomization difficult;

ethical issues arise with control groups, it is difficult to organize a control group that is kept apart from the intervention group, and for health promotion projects it is unsound to treat people as passive recipients of interventions since they require active participation. Additionally, RCTs provide information on whether an intervention was successful but do not necessarily illuminate the reasons for success (or otherwise) (Tones, 2000). Thus, it is important to recognize the value of other study designs that are less expensive, more easily implemented and can be more readily adapted to ethically and meaningfully include people with ID. Theories and experiences originating from mainstream research can be used to inform the design of projects for people with ID.

Outcome measures used in included studies largely concentrated around physical outcomes. Quality of life was used in only four cases. Ideally, health promotion research will take steps to recognize that improvements to one aspect of health behavior (e.g., physical health) do not necessarily lead to better overall experiences of quality of life or overall health for participants. Research is needed that investigates overlapping health needs and that takes a holistic approach to health that is consistent with the WHO definition that health is more than the absence of disease (World Health Organisation, 1986). This is also reflected in the core principles for (mainstream) health promotion research being: empowerment, participation, holistic view of health, intersectoral collaboration, equity in health, sustainability and the use of multi-strategies (Rootman, et al., 2001); and the recent calls for a positive (Huber, et al., 2011; Naaldenberg, et al., 2013) and assets based approaches towards health (Morgan & Ziglio, 2007). For future research, outcome measures could include self-reported health status, measures such as BMI or weight, or tools such as the SF-36 (or the short form SF-12). It may also be useful to measure mental health and wellbeing. However, it is important to consider whether such tools have undergone psychometric testing among adults with intellectual disability. A separate research agenda testing the usefulness of such measures among this population group is critically important.

#### **2.4.2 Strengths and limitations**

Although our search strategy identified a variety of papers and topics, specific keywords relating to common health promotion topics (such as physical activities, obesity prevention, healthy nutrition, stress reduction, sexual education, prevention of smoking and alcohol abuse) were not included in the search strategy. The number of results would exceed the scope of this paper and an unworkable amount of (often irrelevant) data. However, by not including specific topics we may have missed some papers reporting on health promotion interventions for people with ID. This further demonstrates the need for authors to identify their studies as being health promotion interventions through the use of relevant keywords, wording in abstracts, and MeSH terms.

The coding process used in this review had a large qualitative component in which researchers had to judge which code to assign. The research team took several steps to increase methodological rigor. First, multiple researchers with different backgrounds were involved in the selection of papers. Second, multiple researchers with different backgrounds independently analyzed the papers and sought consensus on assigned codes to ensure more accurate coding. Consequently, we are confident in the resultant

coding and believe that this paper accurately captures the themes of the included papers and provides descriptions that are valid and reliable.

### **2.4.3 Future research**

Despite the limitations discussed above, we believe that we have highlighted important insights into research relating to health promotion for people with ID. In doing so, we can clearly describe research gaps. First, researchers should be as transparent as possible when describing their sampling strategies, in terms of recruitment of participants. It is important that researchers begin to more comprehensively and consistently identify the level of disability or disability-type for their participants. Intellectual disability is a heterogeneous and wide-reaching category that covers numerous syndromes and levels of impairment. As a field, we need to begin to acknowledge this heterogeneity in our study design.

Second, before 'leaping' into RCTs, we respectfully recommend the need for research that: (1) actively bridges the gap between mainstream and ID health promotion research by building on existing mainstream knowledge and theories, tailoring mainstream projects towards the needs of people with ID, and making their methods more inclusive; (2) qualitatively explores facilitators and barriers to positive health behaviors among people with ID and key decision makers in their lives including family members and carers, as well as barriers and facilitators to the implementation of interventions; (3) qualitatively explores expectations of involved stakeholders with regard to urgent health needs, intervention outcomes and measures for success; (4) tests the validity and reliability of tools and outcome measures (e.g., pedometers, food diaries, BMI, scale constructs i.e. to measure attitude or wellbeing etc.) for people with ID and examines the acceptability and appropriateness of these tools and measures for a range of disabilities; and (5) quantitatively examines the effects of health promotion activities that occur in the natural environment of participants to ensure sustainability of programs and long-term health impacts.

### **2.4.4 Conclusion**

We identified 25 papers that met our inclusion criteria for health promotion interventions for people with ID. Our findings suggest a great diversity of interventions exist; however, the field experiences methodological weaknesses and inconsistencies that make it difficult to compare and contrast results. Theoretically driven studies that take into account the views and expectations of participants themselves is needed, as is research that investigates the reliability and validity of outcome measures for the ID population. Collaboration with mainstream health promotion research could be a way to move forward in reaching this.

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# Integrating health promotion in everyday life of people with ID - extent to which current initiatives take context into account

## **Accepted for publication as:**

Kuijken, N.M.J., Naaldenberg, J., Vlot-van Anrooij, K., Nijhuis-van der Sanden, M.W.G., van Schrojenstein Lantman-de Valk, H.M.J., & Leusink, G.L. (Accepted for publication). Integrating health promotion in everyday life of people with ID - extent to which current initiatives take context into account

Taking the dynamics of everyday life into account is important for health behaviour change. Surveys were conducted to gain insight into available health promoting physical activity and nutrition initiatives in everyday life of people with intellectual disabilities (ID), their characteristics and the attention they give to resources and hindering factors of healthy living for people with ID. The 47 initiatives mostly focused on physical activity and consisted of regularly organized stand-alone activities. Care professionals rather than health professionals were involved. Organizational resources and hindering factors received relatively little attention. Health promotion for people with ID could benefit from incorporating health behaviour into routines of daily living, more attention for organizational resources and collaboration between health and care professionals.

### 3.1 Introduction

To support healthy lifestyles, it is important to take the dynamics of everyday life into account (Van Woerkum & Bouwman, 2014). For people with intellectual disabilities (ID), everyday life is largely influenced by service providers (Ras, Verbeek-Oudijk, & Eggink, 2013). However, studies on health promotion for this group, mostly focus on interventions in program settings, i.e. interventions that are provided as a separate program that participants can attend sometimes organized as (temporary) projects (Naaldenberg, Kuijken, van Dooren, & van Schrojenstein Lantman de Valk, 2013), and provide little insight into lifestyle support in everyday life (Steenbergen, van der Schans, van Wijck, de Jong, & Waninge, 2017). Knowledge on factors that facilitate or hinder everyday life health promotion for people with ID helps to prevent lifestyle related health problems and to improve quality of life (de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012; Straetmans, van Schrojenstein Lantman-de Valk, Schellevis, & Dinant, 2007), and needs to be taken into account when developing programs to facilitate healthy living (Heller, McCubbin, Drum, & Peterson, 2011).

The socio-ecological model (Rimer & Glanz, 2005) can be useful as theory based framework to understand the multi-faceted and interrelated factors influencing health behaviour for people with ID. Five levels are distinguished: 1) the individual level, including resources and hindering factors such as motivation, cognitive functioning and physical abilities (Bergstrom, Elinder, & Wihlman, 2014; Caton, Chadwick, Chapman, Turnbull, Mitchell, & Stansfield, 2012); 2) the interpersonal level, addressing support from the social environment (Bergstrom et al., 2014); 3) the organizational level, including time, money and prerequisites (Sundblom, Bergström, & Elinder, 2015); 4) the physical environment and community level, with available facilities and transport options, stress and safety (Brooker, Mutch, McPherson, Ware, Lennox, & van Dooren, 2015; Caton et al., 2012; Kuijken, Naaldenberg, Nijhuis-van der Sanden, & van Schrojenstein-Lantman de Valk, 2016); and 5) the public policy level, including health policies and insurance systems (Sundblom et al., 2015).

Health promotion is becoming increasingly important to service providers for people with ID and the topic gains interest among policy makers. As a result, many small scale and ad hoc initiatives are organized in care settings. Although these small scale initiatives are an important part of the everyday life of people with ID and a significant source of practical knowledge, these initiatives are often not part of health promoting interventions and evaluations and not visible in scientific or white paper publications. To gain more insight into ways people with ID are supported to live healthily in their everyday life settings and how this can be improved, this study aimed to explore the myriad of health promoting initiatives delivered by service providers. The following research questions needed to be answered:

- Which everyday life health promoting initiatives, focusing on physical activity and nutrition, are available to people with ID receiving support from Dutch service providers?

- What are the characteristics of these initiatives, as well as the extent to which these initiatives take into account the context with known resources and hindering factors of healthy living?

## 3.2 Method

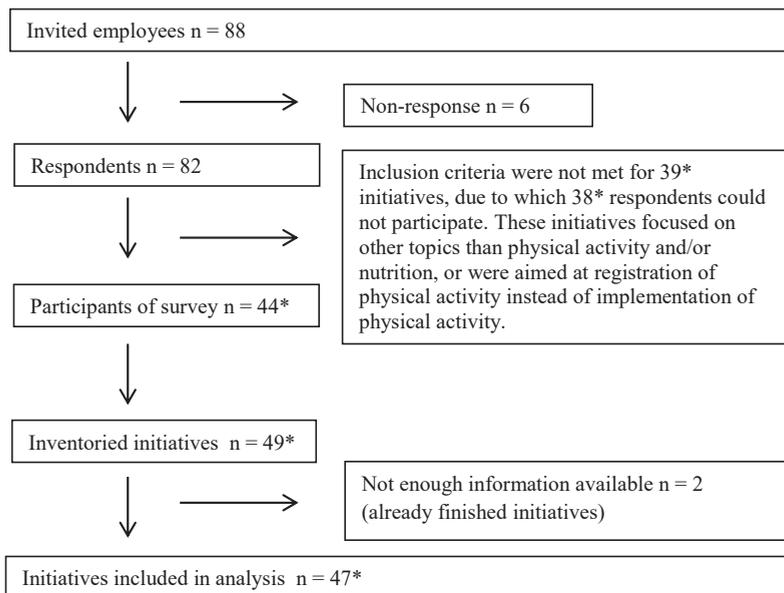
### 3.2.1 Respondents

#### 3.2.1.1 Setting

This study was performed within the setting of service providers providing ambulatory support (intermittent support based on a needs assessment given to people who live (semi-)independently), day support (weekly support provided during scheduled daytime hours, including recreational or (un)paid labour activities) and 24-hour support in small-scale accommodations to people with ID in the Netherlands. Recent national government regulations lead to increasingly more people with ID living (semi-)independently in the community. In the Netherlands, people with ID – varying from mild to profound – are mainly supported by daily care professionals who are trained in social work and/or assistant nursing. Tasks include assisting people with ID in personal, daily, social and health care (Heutmekers et al., 2016).

#### 3.2.1.2 Respondents

The first selection focused on a convenient representative sample of service providers who provide support to approximately 2000 people with ID in three different regions of the Netherlands, while in the next step a representative sample was taken of professionals working in these settings and with the initiatives under research. Given the different organizational structures of the included service providers, snowball sampling was chosen as appropriate method to select all potentially relevant respondents in this second step. Managers of the service providers referred employees who could provide information on specific initiatives that 1) were run within the past three years, and 2) focused on nutrition, physical activity or both. The initiatives were the unit of analysis in this study (Figure 3.1). Respondents acted as informants and were asked to focus on one or more initiatives that was/were provided to people with ID who received support from the service provider the respondents were employed by.



\* Number of participants is different from number of initiatives as some participants could provide information on more than one initiative.

**Figure 3.1** Flowchart of response and in- and exclusion of initiatives

### 3.2.2 Measures

A structured questionnaire with pre-defined answers was used to gain information on the initiatives. The questionnaire consisted of two parts (Table 3.1). Part I was based on general health promotion literature, including criteria for well substantiated and effective interventions (Centrum Gezond Leven, 2013), and steps in adoption, implementation, sustainability and evaluation of a program (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). Example questions of part I are “What is the focus of the initiative?” (answer options: physical activity/nutrition/both) and “Who executes the activities that are part of the initiative?” (answer options: family/friend/care professionals providing support in residential settings / care professionals providing support in day activity settings / personal care professional / dietician / physiotherapist / remedial therapist / sports instructor / volunteer / other / I don’t know).

Part II was based on literature describing the resources and hindering factors of healthy living for people with ID (Bergstrom et al., 2014; Brooker et al., 2015; Caton et al., 2012; Kuijken et al., 2016; Sundblom et al., 2015) and the socio-ecological model (Rimer & Glanz, 2005). The public policy level of the socio-ecological model was not included in this study, since the focus of this study was if and how service providers for people with ID provide health promoting initiatives. This could have been by working together with public initiatives. Public policy is a more overarching level, in which the facilitating

or hindering factors influence the instigation of initiatives rather than the execution of provided initiatives within service providers.

The questions of part II were measured on a 6-point summated rating scale, 0 being strongly disagree and 5 strongly agree (Jamieson 2004). An even scale was chosen to avoid neutral responses and an 'I don't know' option was included to avoid guessing. Example questions of part II are "To what extent does the initiative take into account physical disabilities of participants of the initiative?" and "Do the executers of the initiative have enough knowledge and skills to execute the initiative?". A pilot survey was conducted among three employees of the service providers to check for possible misinterpretation of the questions. As this resulted in only small amendments, it was decided to include the rich information of this pilot in the analyses.

**Table 3.1** Overview of themes, question topics and answer options of the questionnaire

Theme	Questions on (answer options)
<b>Part I Characteristics of the initiative</b>	
<b>General</b>	<ul style="list-style-type: none"> <li>• Focus (physical activity/nutrition/both)</li> <li>• Name of the initiative (open-ended)</li> <li>• Aim (open-ended)</li> <li>• Location (open-ended)</li> <li>• Activities (open-ended)</li> </ul>
Organizational	<ul style="list-style-type: none"> <li>• Type of initiative (regular/project)</li> <li>• Costs for people with ID to participate (yes/no)</li> <li>• People with ID are invited to participate by (care professionals providing support in residential settings / care professionals providing support in day activity settings / personal care professional / dietician / physiotherapist / movement teacher / legal representative / across the organization / without involvement of the organization/other)</li> <li>• Initiative is executed by (family/friend/care professionals providing support in residential settings / care professionals providing support in day activity settings / personal care professional / dietician / physiotherapist / remedial therapist / sports instructor / volunteer / other / I don't know)</li> <li>• Involvement of participants in development of the initiative (yes/no/I don't know)</li> <li>• Promotion of the initiative (open-ended)</li> <li>• Type of involvement of participants in development of the initiative (open-ended)</li> </ul>
Targeted audience	<ul style="list-style-type: none"> <li>• Type of targeted audience (individual/group/social environment of people with ID)</li> <li>• Level of ID (mild/moderate/severe/profound)</li> <li>• Sensory impairments (yes/no/partly/I don't know)</li> <li>• Physical impairments (yes/no/partly/I don't know)</li> <li>• Age (0–12 / 13–18 / 18–40 / 40–60 / 60+ / I don't know)</li> <li>• Residential status (independent / independent with ambulatory support / with family /</li> <li>• 24-hours care (with or without treatment))</li> <li>• Level of support needed to participate (no/some/tailored support)</li> </ul>

<b>Theme</b>	<b>Questions on (answer options)</b>
Participation in the initiative	<ul style="list-style-type: none"> <li>• How often people participate (daily / 1–3 times a week / weekly / 2 times a month / monthly / 1–4 times a year / yearly / once)</li> <li>• How long people participate per time (0–15 / 15–30 / 30–45 / 45–60 / 60–90 / &gt;90 minutes)</li> <li>• Average number of participants per time (open-ended)</li> <li>• Total number of participants (open-ended)</li> </ul>
<b><i>Part II Extent to which initiatives give attention to factors related to healthy living</i></b>	
<b>Individual level</b>	<ul style="list-style-type: none"> <li>• Motivation (0/1/2/3/4/5/I don't know, accounts for all factors below)</li> <li>• Preference</li> <li>• Knowledge</li> <li>• Level of ID</li> <li>• Physical disabilities</li> <li>• Support needed to participate</li> <li>• Financial situation</li> </ul>
Interpersonal level	<ul style="list-style-type: none"> <li>• Emotional support</li> <li>• Instrumental support</li> <li>• Informational support</li> <li>• Appraisal support</li> </ul>
Organizational level	<ul style="list-style-type: none"> <li>• Time and money provided by organization</li> <li>• Communication between employees</li> <li>• Knowledge and skills of employees</li> <li>• Information for employees</li> </ul>
Physical environment and community level	<ul style="list-style-type: none"> <li>• Transport options</li> <li>• Level of stress and safety in environment</li> <li>• Norms and values</li> <li>• Facilities</li> </ul>

### **3.2.3 Procedure**

Telephone surveys among employees were used to collect data between March and June 2015. During each telephone conversation the researcher (KV) entered the answers to the survey questions into an online survey application (Lime-Survey). In the main time the conversation was audio recorded for future reference and validation of the survey answers, after which the audiotapes were destroyed. To increase validity, clarification was allowed and available documentation of initiatives was cross-checked with survey answers.

Prior to participation in the telephone survey, respondents were informed about the aim of the study, voluntary participation, estimation of the length of the telephone conversation and anonymity of respondents. Informed consent was obtained verbally (recorded) from all respondents. Only the answers to the structured questions were recorded; personal identifying information of the respondent was not recorded. This study gathered information and opinions of professionals on health promoting initiatives and did not include sensitive, personal data regarding people. Nor did this study influence respondents. This study has been conducted conform the Declaration of Helsinki and did

not need ethical approval in The Netherlands as confirmed by the accredited Medical Research Ethics Committee (MREC) (registration number 2018-4977).

Descriptive statistics (SPSS version 20.0) were used to quantitatively describe the answers to the questions of the survey. Answers of the open-ended questions (part I) were quantified based on communalities in the answers. To provide insight into the extent to which initiatives take into account known resources and hindering factors of healthy living for people with ID, median and mode were calculated for the answers to the questions of part II.

### 3.3 Results

#### 3.3.1 Respondents

In total, 82 employees responded of which 44 (twelve managers/policy makers, fourteen health professionals and eighteen care professionals) were able to provide information on one or more initiatives that met the inclusion criteria. Health professionals who responded were movement teachers (+ two interns), physiotherapists, dieticians, an occupational therapist and a behavioural scientist). These health professionals were active in the initiatives beside their usual professional activities. Figure 3.1 provides an outline of the response and in- and exclusion of initiatives. Non-response was very low and data collection was extended until all potential respondents were contacted and no new initiatives were mentioned.

#### 3.3.2 Characteristics of the Initiatives

Initiatives predominantly focused on physical activity ( $n = 33$ ); only a few focused on nutrition ( $n = 5$ ) or both ( $n = 9$ ). Aims of the initiatives and means to accomplish these aims were often discussed interchangeably by respondents. Initiatives could have multiple aims, of which stimulating physical activity was mentioned most often, followed by social contact.

The top five most mentioned activities were all sports-related: sport and game *activities*, *group sports* and individual sports like *swimming*, *work out in the gym* and *horse-riding*. Most initiatives consisted of stand-alone activities and were organized on a regular basis ( $n = 39$ ), such as a weekly walking group.

The majority of the initiatives ( $n = 37$ ) was offered by the ID service providers themselves, while six were organized by other organizations, such as the municipality. Four initiatives mentioned collaboration between an ID service provider and another organization in the development and/or implementation of the initiative.

Daily care professionals and trainees/volunteers were most often mentioned as executors of the initiatives (in 37 and 18 initiatives respectively), while health professionals (e.g., physiotherapists, sport instructors, movement teachers, dieticians) were mentioned 22 times. Invitations to participate came from daily care professionals ( $n = 33$ ) through personal contact. Newsletters or emails were also used. For 15 initiatives, mainly physical

activities at external venues such as the gym, swimming pool or sports club, the participants needed to pay in order to participate.

Active participation of people with ID in the development of the initiatives was described 22 times. The level of participation varied between considering wishes and needs at the start of the developmental phase, to giving feedback and/or deciding on the proposition of activities. Sometimes people with ID assisted in further development of the initiative.

The initiatives mainly aimed to include individuals (n = 30). Eight initiatives aimed at existing groups of people with ID (e.g., residential group homes), four aimed at both individuals and groups and five at the social environment of people with ID (e.g., family, peers, volunteers and care professionals). Mostly tailored support (n = 29) or some support (n = 28) was needed to be able to participate; 14 initiatives could be used without support. Next to initiatives developed for people receiving 24-hour care (n = 43), initiatives could be used by people who lived independently with ambulatory support (n = 14), lived with family (n = 10) or lived independently without support (n = 6).

On average 49 people participated in an initiative (range 2–250). A session mostly lasted 60 to 90 minutes (n = 23), but varied from 15 minutes to more than 90 minutes. In most initiatives, people participated once a week (n = 25).

### 3.3.3 Attention to Resources and Hindering Factors

Table 3.2 shows the extent to which the initiatives gave attention to resources and hindering factors of healthy living. The N in Table 3.2 varies due to respondents choosing the 'I don't know' option. For two factors, *financial situation* on the individual level and *transport options* on the physical environment and community level, more than 70% of the respondents chose the 'I don't know' option. These factors were not included in the analysis.

Overall, respondents reported that initiatives gave attention to most factors as they scored a 4 or 5 for the majority of them. Looking at each level separately, most attention is given to individual and interpersonal factors. The organizational and environmental level scored somewhat lower. The individual factors *level of ID*, *physical disabilities*, *support needed to participate* and *preference* all scored a 5. As for type of support given by caregivers, friends and family (interpersonal level) *emotional* and *instrumental support* stood out positively. Least attention was given to the participant's *knowledge of healthy living* (individual level), *time and money provided by the organization* and *information for employees on healthy living and health promoting initiatives* (both organizational level). *Existing norms and values in the living environment* (physical environment and community level) also scored relatively low. When differentiating for level of ID of the targeted audience, the more severe the level of ID, the less attention was given to *knowledge* and *preference* of the participant.

**Table 3.2** The extent to which initiatives give attention to factors related to healthy living, categorized into four levels of the socio-ecological model (n = 47)

Level of socio-ecological model	Resource or hindering factor of healthy living	N	Median	Mode
Individual	Level of ID	43	5.0	5
	Physical disabilities	39	5.0	5
	Support needed to participate	44	5.0	5
	Preference	41	5.0	5
	Motivation	41	4.0	4
	Knowledge	35	3.0	3
Interpersonal	Emotional support	39	5.0	5
	Instrumental support	37	5.0	5
	Appraisal support	33	4.0	5
	Informational support	36	4.0	5
Organizational	Knowledge and skills of employees	42	4.0	5
	Communication between employees	43	4.0	4
	Information for employees	44	3.0	3
	Time and money provided by organization	40	3.0	3
Physical environment and community	Level of stress and safety in environment	39	4.0	5
	Facilities	42	4.0	5
	Norms and values	34	3.5	4

### 3.4 Discussion

Most of the 47 identified initiatives were individually oriented and consisted of stand-alone activities organized on a regular basis. This shows a lack of attention for healthy behaviour in the everyday life of people with ID, which is in line with Steenbergen et al. (2017). Taking an everyday life perspective in health promotion and incorporating health behaviour into routines of daily living, while including the social environment of people with ID, may be much more effective (Van Woerkum & Bouwman, 2014).

The focus of the majority of the initiatives in this study was on increasing physical activity. Previous research on health promotion for people with ID found a large focus on physical activity as well (Naaldenberg et al., 2013; Steenbergen et al., 2017; Willems, Hilgenkamp, Havik, Waninge, & Melville, 2017). These studies however also found many initiatives focused on combining physical activity and healthy nutrition. An explanation for the large focus on physical activity in the initiatives in our study could be that many initiatives in our study were organized bottom-up as stand-alone activities, while initiatives focused at nutrition need a change in financial and organizational routines, requiring a more top-down approach.

Individual factors, such as disabilities and support needs, received much attention in the organization of the initiatives which helps to increase the accessibility (Kuijken et al., 2016). The knowledge on healthy living of people with ID themselves, however, received

little attention. People with mild to moderate ID do have knowledge on healthy living, but have trouble translating this knowledge into behaviour and therefore need others to support them (Kuijken et al., 2016). Attention for their knowledge can help to tailor the initiative to their level of knowledge and to support participants adequately to apply this knowledge in everyday life.

Organizational resources and hindering factors such as provided time and money received little attention, which impedes profound embedment within organizational structures and routines. The frequent use of trainees and volunteers as executors of initiatives might impede sustainability of the initiatives as well, as they often work temporarily in an organization. Next to that, daily care professionals were often involved, while support from health professionals in the implementation of initiatives was lacking. Though daily care professionals are in a good position to support people with ID in everyday life, their knowledge and skills regarding promotion of healthy behaviour are limited (Cardol, Rijken, & van Schroyen Lantman-de Valk, 2012; Leser, Pirie, Ferketich, Haverkamp, & Wewers, 2018; Sundblom et al., 2015). Health professionals do have the necessary knowledge and skills to activate people and support good dietary habits (Hilgenkamp, 2012; Van Riper & Wallace, 2010). This implies that health professionals should be more involved in health promotion efforts for people with ID (Van Schijndel-Speet, Evenhuis, Van Wijck, Empelen, & Echteld, 2014), however, our study indicates that health professionals are only marginally involved in prevention of health problems by means of health promotion.

For people with ID, everyday life in residential and day activity settings often takes place in groups (Ras et al., 2013). More attention to existing norms and values among peers and professionals is therefore important (Van Woerkum & Bouwman 2014). Additional to individually oriented activities, lifestyle interventions at the group level could be more effective, as they benefit from modelling and social support (Heller, Fisher, Marks, & Hsieh, 2014; Van Schijndel-Speet, Evenhuis, van Wijck, & Echteld, 2014).

Our study is one of the first studies providing insight into the characteristics of current everyday life health promotion for people with ID. Since the included service providers provide different types of support to people with ID in three different regions of the Netherlands, we think this study included a representative sample of employees in support for people with ID and of health promoting initiatives that are offered to people with ID in the Netherlands. It is, however, important to recognize that our findings are based on the organization and use of health promotion initiatives within Dutch service providers. The enthusiasm of the respondents about the initiatives might have led to a positive bias. However, their close involvement in the initiatives ensured rich information. Validity was enhanced by: using telephone surveys to minimise interviewer effects (Phellas, Bloch, & Seale, 2011); allowing clarification (Jones, Baxter, & Khanduja, 2013), and data triangulation by cross checking with available documentation.

### **3.4.1 Conclusion**

Health promotion for people with ID could benefit from an integrated focus on both physical activity and nutrition, with an everyday life perspective taken by all stakeholders involved. At organizational level, service providers could benefit from a mission-statement on creating a supportive environment for healthy behavior, which includes incorporating healthy behavior into routines of daily living and having more attention to existing norms and values of people with ID and their social environment. To ensure sustainable health promotion in everyday life, i.e. supporting people with ID to become more active and to improve their diet and to maintain these changes in the long term, resources on the organizational level could be better utilized in initiatives and greater involvement of health professionals for collaboration with care professionals is needed.

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## CHAPTER 4

# Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives

### **Published as:**

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.

**Background:** A healthy lifestyle can prevent several health problems experienced by adults with intellectual disabilities (ID). For the development of effective and usable health promoting interventions for people with ID, the perspective of the intended audience should be taken into account. The aim of this qualitative study was to gain insight into the perspectives of people with mild to moderate ID on healthy living.

**Method:** Qualitative study. Five semi-structured focus groups were conducted with a total of 21 adults with mild to moderate ID in the Netherlands. Discussions focused on three main themes: 1) perceptions of own health, 2) what participants consider as healthy living and 3) factors experienced to be related to the ability to live healthily. Interviews were analysed thematically resulting in two main domains: 1) perceptions of what is healthy and unhealthy and 2) factors that participants experience to be related to their ability to live healthily.

**Results:** For participants, healthy living entails more than healthy food and exercising: feeling healthy, happiness and level of independence are perceived as important as well. Factors experienced to relate to their ability to live healthily were (a lack of) motivation, support from others, and environmental factors such as available health education, (a lack of) facilities and a(n) (dis)advantageous location of work or residence.

**Conclusions:** This qualitative study shows that adults with mild to moderate ID have a good understanding of what being healthy and living healthily constitutes. As they face several difficulties in their attempts to live healthily, existing health promotion programmes for people with ID must be tailored to individual preferences and motivations and adapted for individual physical disabilities. Moreover, due to their dependency on others, tailoring should also be focused on the resources and hindering factors in their physical and social environment.

## 4.1 Introduction

People with intellectual disabilities (ID) experience significantly more health problems than the population without ID. Some of these health problems, such as being overweight, obesity (de Winter et al. 2012b; Henderson et al. 2008; Hsieh et al. 2013), diabetes (de Winter et al. 2012a) and cardiovascular disease (Draheim 2006) are at least partly related to unhealthy lifestyles. Sedentary lifestyles and poor dietary habits particularly have been found to be highly prevalent among people with ID (Draheim et al. 2002; Emerson 2005; Haveman et al. 2011; Hsieh et al. 2013; Robertson et al. 2000). Generally, health promotion is seen as a cost-effective way of tackling these lifestyle-related health problems. In the development of health promotion programmes, taking the views of the intended audience into account is very important, as this ensures attention is given to individual, interpersonal and environmental factors in planning, implementation and evaluation of health promotion initiatives (Bartholomew et al. 2011; Green & Kreuter 2005).

The need to improve the health of people with ID is reflected in several policy documents from the United States (US) and Europe (Department of Health 2001; Emerson & Baines 2010; Pomona project 2008; U.S. Government 2010). Although accessible and evidence-based health promotion initiatives could significantly contribute to a healthier lifestyle and lead to an increase in quality of life (Haveman et al. 2011; Taggart & Cousins 2014; van Schroyen et al. 2008), such programmes specifically tailored to people with ID are not common (Krahn et al. 2006). Programme development for this group could benefit from research on bridging the gap between mainstream and ID health promotion (Naaldenberg et al. 2013). Existing mainstream projects can be adapted towards the needs of people with ID by using research methods that include the direct input of participants with ID to identify problems and find solutions. As a first step towards this more inclusive involvement, *exploration of what people with ID understand about being healthy and keeping themselves healthy* has been identified as an important research topic by people with ID themselves, their caregivers and care-workers (Young & Chesson 2008).

To get insight into the needs, interests and capabilities of people with ID related to healthy living, this qualitative study aims to answer the following research questions:

- What are the views and perspectives of people with mild to moderate ID on healthy living?
- Which personal and environmental factors are perceived as relevant by people with mild to moderate ID to realising a healthy lifestyle?

## 4.2 Method

### 4.2.1 Procedures

Participants were recruited from three regional expertise centres providing support to people with ID. Both purposive sampling and snowball sampling were used. Participants could be included if they were adults aged 18 years and older with mild to moderate ID, who were able to communicate verbally. After receiving easy-to-read information on the content and procedure of the focus group and stating their interest to an independent contact person, potential participants were contacted by the researcher (NK). Focus groups were scheduled with the help of the participants' personal caregivers.

Prior to each focus group, written informed consent was obtained from all participants. The participants did not receive any incentive for participation. The study has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki. The accredited Medical Research Ethics Committee (MREC) of the Arnhem-Nijmegen region approved the study (registration number 2013/300).

### 4.2.2 Participants

Twenty-one persons with mild to moderate ID participated in this study. Most participants lived semi-independently with ambulatory support (Table 4.1).

### 4.2.3 Data collection

Five focus groups, each consisting of four or five participants, took place in November and December 2013. All meetings were held in accordance with guidelines for conducting focus groups with people with ID (Fraser & Fraser 2001; Kaehne & O'Connell 2010).

A semi-structured discussion guide (Table 4.2) was constructed around the following topics: 1) *the participants' perception of their own health*; 2) *what participants consider to be healthy living in general*; and 3) *which factors participants experience to be related to their ability to live healthily*. The questions started broadly, allowing the participants to raise issues they considered to be relevant. Prompts were used to enable participants to elaborate on their views and experiences, as well as to talk about areas of interest on the topic of healthy living which had not been covered. The focus groups were moderated by a trained researcher (NK) and two assistants. All focus groups were recorded digitally and transcribed verbatim.

**Table 4.1** Background information of the participants

Focus group	Participant	Sex	Age*	Residential status and form of support**
I	A	Male	22	Group home on campus, full-time access to support
	B	Male	48	Community group home, full-time access to support
	C	Male	38	Semi-independent (alone), part-time access to support
	D	Female	31	Semi-independent (alone), part-time access to support
	E	Female	65	Semi-independent (alone), part-time access to support
II	F	Male	60	Community group home, full-time access to support
	G	Female	64	Community group home, full-time access to support
	H	Female	60	Community group home, full-time access to support
	I	Female	58	Community group home, full-time access to support
III	J	Male	34	Semi-independent (alone), full-time access to support
	K	Male	29	Semi-independent (with roommate), full-time access to support
	L	Female	31	Semi-independent (alone), full-time access to support
	M	Female	40	Semi-independent (with partner), full-time access to support
IV	N	Male	27	Group home on campus, full-time access to support
	O	Male	19	Group home on campus, full-time access to support
	P	Male	47	Group home on campus, full-time access to support
	Q	Male	61	Group home on campus, full-time access to support
V	R	Male	57	Semi-independent (alone), part-time access to support
	S	Male	56	Semi-independent (with brother), part-time access to support
	T	Female	47	Semi-independent (alone), part-time access to support
	U	Female	53	Semi-independent (alone), part-time access to support

\* In years,  $M$  age = 45.1 years,  $SD$  = 14.40

\*\*Details on residential status and form of support have been provided by caregivers of the participants

Several materials were used to support participants and to structure the focus groups:

- All participants introduced themselves by rolling a big dice with themes on the faces rather than dots (*hobbies, food and drinks, family and friends, music, sports or leisure*) and saying something about the theme they had rolled.
- Self-perceived health was visualised by a vertical 'ladder' ranging from *very healthy* (green) to *very unhealthy* (red). Participants were asked to rank themselves by placing a figurine on the ladder and to elaborate on their decision.
- Pictures relating to four major health determinants derived from the Dutch Public Health Status and Forecasts model (De Hollander et al. 2007), were used to visualise health behaviours. The determinants were 1) personal characteristics, 2) lifestyle, 3) the physical and social environment, and 4) healthcare, including prevention.

Participants were asked to choose two healthy and two unhealthy pictures, to place these pictures on either a green (healthy) sheet or a red (unhealthy) sheet and to elaborate on this.

A pilot focus group, conducted at the university medical centre, resulted in an extension of meeting time from 60 to 90 minutes and some amendments to supporting materials. The decision was made to include the rich information from this pilot in the analyses. The other four focus groups all took place at a location that was convenient for the participants.

**Table 4.2** Key questions and examples of prompting questions from the focus group interviews

Topic	Key question / supporting questions
The participants' perception of their own health	Please show us how healthy you consider yourself! (by putting your figurine on the magnetic ladder)  <i>Why do you think you are this (un)healthy?</i> <i>What tips on how to live healthy can you give to other participants who find themselves less healthy?</i>
What participants consider to be healthy living in general	What is healthy according to you? (choose two pictures that represent something healthy and two pictures that represent something unhealthy)  <i>Why do you find this (un)healthy?</i> <i>Which of these (un)healthy things do you do yourself?</i>
Which factors participants experience to be related to their ability to live healthily	<i>Which of these (un)healthy things do you like to do, or would you like to do?</i> <i>Which of these (un)healthy things do you dislike?</i> <i>Why can some people do this, but others cannot?</i>

#### 4.2.4 Data analysis

Data analysis was performed using ATLAS.ti software 7.1.4 (scientific software development) (Friese 2012). As this study aimed to explore lay perspectives regarding healthy living, a combination of domain analysis (Atkinson & Abu el Haj, 1996) and thematic analysis (Braun & Clarke, 2006) was used. Table 4.3 provides an overview of the aims and data actions for the consecutive steps of the coding process. The actions and results of each step were cyclically discussed among all authors.

**Table 4.3** Consecutive steps of the coding process

Step	Action	Aim
1	Repeated reading of the first three transcripts and coding of the topics of discussion line by line (NK)	First identification of relevant topics and fragments
2	Clustering of these codes into more broad domains (NK, JN)	Achievement of coded and reduced data
3	Independent coding of the fourth and fifth transcript by two researchers using these broad domains as codes (NK, JN) and subsequent seeking of consensus on assigned codes	Achievement of coded and reduced data and more accurate coding

Step	Action	Aim
4	Arranging the actual text fragments into the primary domains	Construction of a taxonomy of primary domains and subcategories
5	Identifying relations between subcategories and primary domains	Achievement of primary domains and their subcategories as presented in the results section

#### 4.2.5 Validity

To support participants, caregivers were present during some of the focus groups. They were briefed and asked not to provide opinion to minimise their influence on the group process. To facilitate the participant check, a short summary was given by the moderator at the end of each focus group. During the fourth and fifth focus groups, the content of the group discussion started to show a lot of overlap with the previous three discussions, indicating data saturation. Therefore, the optional sixth focus group was not conducted.

### 4.3 Results

#### 4.3.1 General results

The group process was dynamic within the groups and differences between groups existed with regard to the level of communication and interaction. In one group (III, Table 4.1), participants had a relatively high level of thinking and communication skills compared to the other groups. In two groups (I and V, Table 4.1), participants had to be asked to respond to each other, while in the other groups (II, III and IV, Table 4.1), interaction occurred more naturally. Group V (Table 4.1) faced more persistent physical disabilities which dominated the topics discussed and influenced the group process.

Two primary domains were chosen related to the research questions: 1) *perceptions of what is healthy and unhealthy*, and 2) *factors experienced to relate to the ability to live healthily*. Analyses of the data resulted in several subcategories of these domains. The first domain gathers all aspects of the participants' views and perspectives on what is part of a healthy or unhealthy lifestyle. The second domain encapsulates the various resources and hindering factors which the participants experience in realising a healthy lifestyle. These domains and their subcategories will be elaborated on below. Quotes have been translated from Dutch to English by a professional interpreter.

#### 4.3.2 Perceptions of what is healthy and unhealthy

In their discussions on (un)healthy products and behaviours, the participants emphasised that, firstly, is it important to find out *what is healthy for you individually*. In doing so, they also talked about their *knowledge on what is (un)healthy*. Another subcategory that could be identified was *feeling healthy*, which is related to the participants' perception of their own health, happiness, whether or not participants feel the need to do something (un) healthy, and the participants' level of independence.

### 4.3.3 What is healthy for you individually

According to the participants, knowing what is healthy for you individually is the most important first step in living healthily: they emphasised that what is considered healthy in general, is not necessarily healthy for them. The participants stated that it is also important to take your personal situation into account when thinking about healthy behaviours. The following interaction illustrates both points:

Participant C: *Take the definition of 'healthy', right? You could call fruit healthy, and generally speaking, it is. But if you're allergic to kiwi, then it's not healthy for you. It could actually land you in the hospital. (Male, 38 years, FG<sup>1</sup> I)*

Participant B: *Yes, but when you say fruit, you're using a general term. If someone's allergic to ... uh ... kiwis, then they already know to avoid them. But they could grab an orange, a tangerine, an apple or grapes. (Male, 48 years, FG I)*

Moderator: *Yes.*

Participant C: *But I was talking about a definition. It's not that ... um ... Yes, people should know what isn't healthy for them and need to find that out for themselves. (Male, 38 years, FG I)*

The importance of taking your personal situation into account is underpinned by the response of a female participant (L, 31 years, FG III), as she disagreed with another participant (K, male, 29 years, FG III) who stated that *'sugary drinks are just bad'*. She argued that due to her metabolic disorder, sugary drinks are healthy for her. Other examples of this were being aware of being overweight, of being at risk of developing diabetes, and of being hard to influence when it comes to healthy living.

### 4.3.4 Knowledge on what is (un)healthy

When talking about what is healthy, participants know what is healthy in general. Participants discussed a large list of healthy and unhealthy products and behaviours: they discussed fruits and vegetables, exercising, buying and cooking healthy foods, eating regularly, taking enough rest, sleeping well at night and having good social contact as being healthy; fast-food, chips, sweets, smoking and a lack of exercise were offered as being unhealthy. However, merely knowing what is (un)healthy did not always seem to result in a healthy lifestyle, and reasoning about this topic was often influenced by a straightforward way of thinking and misinterpretation of knowledge sources. For example, one participant said:

Participant B: *But the point is you must either get an appetizer or a dessert, so you get sufficient nutrients. (Male, 48 years, FG I)*

Moreover, according to the participants, knowing what is healthy is quite difficult since many things have to be taken into account, and guidelines these days say that almost everything is unhealthy:

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1 FG = focus group

Participant A: *It all depends. The thing is, everything seems to be harmful, or unhealthy. These days, we see so many shady things going on in the Dutch food industry. ... Take pudding, for example. It contains artificial colourings that are supposed to be really bad for you. So, there are so many things you have to watch out for.* (Male, 22 years, FG I)

This quote also illustrates how the concept of moderation of unhealthy behaviour can be confusing for the participants. On the one hand, they are aware that a product (e.g. pudding) or certain behaviour is unhealthy, but on the other hand, they are not able to differentiate between living unhealthily or the occasional indulgence, because knowing something is unhealthy without knowing why and when seems to be confusing for them.

#### 4.3.5 Feeling healthy

According to the participants, feeling healthy can support a healthy lifestyle and lead to better health, as well as be the result of these two factors. Whether or not you feel healthy was perceived to be related to four aspects. Table 4.4 provides an overview of these aspects of feeling healthy with supporting quotes. Firstly, *the perception of your own health* is related to how healthy you feel. When using the ladder to elaborate on their self-perceived health, participants discussed that their position on the ladder fluctuates over time and that, ultimately, their goal is to climb the ladder. In this, participants stated that both being physically healthy or unhealthy and mentally healthy or unhealthy are related to how healthy you feel yourself (quote 1, Table 4.4). According to the participants, you are physically healthy when you do not have a negative health condition and when you are fit and full of energy. Frequently going to hospital and having major disabilities, physical injuries or a medical condition such as osteoporosis or obesity were examples given by participants of being physically unhealthy. Being mentally unhealthy is related to stress and feeling insecure, and according to the participants, having common sense, feeling good on the inside which shows on the outside and the absence of mental conditions such as delusions indicate that you are mentally healthy. Participants of group V (Table 4.2) predominantly related their health to their physical disabilities, while other groups also related their health to their lifestyle, such as getting enough exercise and eating healthily.

Secondly, participants discussed *happiness* as being interrelated with feeling healthy and living healthily (quotes 2 and 3, Table 4.4). According to the participants, being and feeling happy is important in a healthy lifestyle and can help you to live healthily.

Thirdly, whether or not you *feel the need to do something (un)healthy* also determines the choices you make. Not feeling the need to do something unhealthy, such as smoking or drinking alcohol, contributes to a healthy lifestyle and feeling healthy. Having a desire to live more healthily in the future, e.g. feeling the need to walk better or to exercise more, also contributes to this (quote 4, Table 4.4).

Fourthly, the participants pointed out that your *level of independence* is also important (quotes 5 and 6, Table 4.4). Next to that, not being able to independently do daily living activities due to your disabilities can be hard to accept, and affects how healthy you feel (quote 6, Table 4.4).

### 4.3.6 Factors experienced to relate to the ability to live healthily

The participants were able to describe resources for and factors that stimulate a healthy lifestyle very well, which could be divided into three subcategories: *motivation*, *resources in the social environment* and *resources in the physical environment*. Participants also pointed out that, in their ability to make use of these resources, physical disabilities can play a hindering role:

Participant H: *Yeah, I can't cycle because of my balance impairment.* (Female, 60 years, FG II)

This hindering role of physical disabilities was most prominent in the discussions of one focus group (V, Table 4.1). Below, the three types of resources are elaborated on.

**Table 4.4** Aspects of feeling healthy and supporting quotes

Aspect of feeling healthy	Quote number	Quote
The perception of your own health	1	Moderator: <i>Yes, and how does participant P feel about this? Since you placed your figurine on the healthy side of the ladder, could you tell us a little about that?</i>
		Participant P: <i>Yes, um, I went to my doctor a few times. I had a blood test done, which was normal. They didn't find anything unusual. Of course, my doctor did prescribe pills to help me handle things better emotionally. So, now I feel like I'll get healthy again.</i> (Male, 47 years, FG IV)
		Moderator: <i>Yes.</i>
		Participant P: <i>That is, if they help, the pills from my doctor. Other than that, um, they said I don't have anything to worry about. That means I'm healthy. It means I don't have epilepsy and delusions and that I'm eating healthily, food-wise.</i>
Happiness	2	Moderator: <i>Does anyone else here want to comment on why you might feel healthy or unhealthy?</i>
		Participant D: <i>Um, I think the way people feel in their own skin is really what's most important.</i> (Female, 31 years, FG I)
	3	Participant L: <i>I also think, um, that it might be related to a healthy lifestyle or overall happiness. That could also be part of it. ... Sometimes, even if someone's diet is healthy, if they're not really happy, yeah.</i> (Female, 31 years, FG III)
Feeling the need to do something (un)healthy	4	Participant I: <i>I wish I could walk better. I'm still not able to walk the way I'd like. I'm working on it. It's because my legs hurt so badly. Sometimes, it's almost as though they don't want to move anymore.</i> (Female, 58 years, FG II)

Aspect of feeling healthy	Quote number	Quote
Level of independence	5	<p>Participant H: <i>I can do a lot of things myself.</i> (Female, 60 years, FG II)</p> <p>Moderator: <i>Really, can you name some examples?</i></p> <p>Participant H: <i>Yesterday, I helped cook and, um, I do my own laundry. I always do laundry on Fridays. I do it by myself, the washing machine and taking everything out. In the beginning, it was supervised. They'd stand there to make sure the sorting was done properly. But, um, it's all going very well.</i></p> <p>Moderator: <i>And do you all feel these things go together with being healthy or unhealthy?</i></p> <p>Participant H: <i>Healthy.</i></p> <p>Moderator: <i>Yes, doing the laundry.</i></p> <p>Participant H: <i>Yes, the fact that it gets done independently.</i></p>
	6	<p>Participant U: <i>One thing I had a hard time accepting was wanting to work four days. But I can't anymore because of my disability.</i> (Female, 53 years, FG V)</p>

#### 4.3.7 Motivation

Participants mentioned several factors that stimulate a healthy lifestyle. According to them, you are more likely to live healthily when you:

- know that a product or behaviour is good for your health;
- can be proud of yourself by doing something;
- think exercising makes you feel good;
- can exercise together with someone, because this is more fun and increases your social contact;
- want to be like a famous role model who exercises a lot;
- can raise money for charity with an activity;
- experience healthy activities and food as enjoyable;
- dislike unhealthy activities and food:

Participant K: *When I'm around smoking, I think it's disgusting. I work at the Spar supermarket. And we get these smokers, who come in right after they finish off their cigarettes and throw them out. And then they stop you to ask something and you get blasted with their breath. It's so gross.* (Male, 29 years, FG III)

All of these factors can increase one's own *motivation* to live healthily, which can help to actively incorporate positive health behaviours into your daily routines:

Participant B: *In the morning, when I arrive at the department where I'm working that day, I deliberately put my bag in another department. That forces me to walk to my bag for my lunchbox. In the evenings when it's time to leave, I'm forced to return to that other department again to pick up my bag so I can go home.* (Male, 48 years, FG I)

A *lack of motivation*, however, which was mostly described as ‘not feeling like doing something healthy’ was frequently mentioned as a hindering factor of a healthy lifestyle. The following sources of a lack of motivation were mentioned:

- being lazy;
- not having fun exercising;
- not feeling the need to stop doing something unhealthy;
- disliking healthy activities or foods;
- experiencing unhealthy activities or foods as enjoyable.

Examples of how some of the above mentioned sources of a lack of motivation hinder a healthy lifestyle are given in the following quotes:

Participant K: *Then you get home, and that's when you usually go to the snack bar.* (Male, 29 years, FG III)

Participant J: *Yeah, it's 'cause I don't feel like cooking.* (Male, 34 years, FG III)

Participant L: *Yes, and most of the time, I'm just not in the mood for fruit. Ha ha ha ....* (Female, 31 years, FG III)

Participant F: *I inhale deep into my lungs when I smoke. ... I think deep inhalation tastes better. I just like it more.* (Male, 60 years, FG II)

To overcome a lack of motivation, participants also shared tips with each other:

- asking help from a dietician;
- making menu and grocery lists;
- doing grocery shopping together or exercising together;
- taking fruit or vegetables as a snack instead of crisps;
- avoiding the supermarket aisles with unhealthy snacks that you really like.

#### **4.3.8 Resources in the social environment**

According to the participants, there are many ways in which others can be resources for a healthy lifestyle. Table 4.5 provides an overview of these ways including supporting quotes or examples given by the participants.

**Table 4.5** Overview of ways in which others can be resources for a healthy lifestyle for people with ID

Role of others: others can	Examples / quotes
Motivate or stimulate people with ID to live healthily	Participant I: <i>Yeah, they can, um, encourage you to keep up things you're already doing to live healthily. For example, participant G sees things very differently than I do. But then you can learn a lot from each other. I can learn a lot from participant H and participant G.</i> (Female, 58 years, FG II)
Invite people with ID to live healthily	Participant O: <i>Yes, yes, that's really true. My friend cycles to the grocery store sometimes. And then he'll ask me to go with him and says he'll walk with me there if I come along.</i> (Male, 19 years, FG IV)
Support or help people with ID to live healthily	<p>Persons who can support people with ID to live healthily:</p> <ul style="list-style-type: none"> <li>• a dietician</li> <li>• a doctor</li> <li>• a general practitioner's assistant</li> <li>• family members</li> <li>• other people with ID (friends or people you live with)</li> <li>• professional caregivers</li> </ul> <p>Ways to support people with ID:</p> <ul style="list-style-type: none"> <li>• providing structure during the day</li> <li>• supporting personal hygiene</li> <li>• doing grocery shopping together</li> <li>• escorting to a sports facility</li> <li>• providing mental support</li> <li>• providing support in quitting smoking</li> <li>• cooking or cooking together:</li> </ul> <p>Participant H: <i>Those that can do it without help do it by themselves, like participant G.. but I, um, said that I don't mind cooking but then, um, I need some supervision.</i></p> <p>Moderator: <i>Because it's too difficult to do by yourself?</i>                      Participant H: <i>No, because of the stove, I wanted to make tea one time... so then I was checking if the stove was on and then I burnt myself, third-degree burn.</i> (Female, 60 years, FG II)</p>
Provide information to people with ID on healthy lifestyles	<p>This mainly concerns healthy food. Much of the knowledge that interviewees had originates from information that others gave them:</p> <p>Participant H: <i>Yes. You know we had a period, where we ate white bread as well. But then the caregivers also said that white bread wasn't nearly as healthy as brown bread. So it is better to eat brown bread. It's healthier than white bread.</i>(Female, 60 years, FG II)</p>
Monitor the lifestyle of people with ID	<p>Persons who and the ways in which they monitor the lifestyle of people with ID:</p> <ul style="list-style-type: none"> <li>• professional caregivers: support people with ID in their daily living</li> <li>• dietician: provides a person with ID with rules on how to live healthily, which are then monitored by the daily caregivers of this person:</li> </ul> <p>Participant I: <i>The caregivers do pay attention to what we eat. ... My dietician has instructed them to watch what I eat.</i> (Female, 58 years, FG II)</p>

The analysis emphasised a two-sided dependence of the participants on their social environment when it comes to healthy living: they need others to positively influence their lifestyle, but they are also easily influenced by others in a negative way. Others, such as professional caregivers and peers, may *set the wrong example* by using drugs, smoking or not being able to quit smoking. It was also stated that when *caregivers do not have time*

to help with grocery shopping, food that is more unhealthy than usual is purchased. In addition, when others *push a person with ID to live healthily*, this can be counterproductive. When living together with other people and *having to decide together on what to eat*, this can also negatively influence your lifestyle:

Participant J: *It was because of my housemates who didn't want anything healthy. All they wanted were fatty foods. Whatever.* (Male, 34 years, FG III)

Related to this, participants expressed that when food is freshly prepared by professional caregivers, *not being involved in the meal plan* can hinder them to live healthily:

Participant Q: *Yeah, like red cabbage, beets and cauliflower. Those are delicious. And kohlrabi. That's also good and we never get any.* (Male, 61 years)

Moderator: *Are you allowed to choose what you want to eat, or how does that work?*

Participant Q: *Well, we eat red cabbage and vegetable-mashed potatoes. I like all those things. And now I'm being really honest. She always does this ... [looks at caregiver] always gives us soup. Yeah. Every Saturday, you get soup.*

Moderator: *And do you like it, or don't like it?*

Participant Q: *I don't like it! That's when I go out to eat!*

Participants also expressed that *reactions of others* can make it difficult to stick to your healthy lifestyle and that it is sometimes hard to cope with these reactions, particularly when it comes to their diet or disability:

Participant I: *Whenever treats are served at birthdays, I can't join in. It's a really sad feeling, sitting there watching it all while you make do with a dry rusk biscuit. ... Yeah, it's hard, and it usually depresses me. It's just not easy for me to deal with.* (Female, 58 years, FG II)

Participant G: *Them eating, while you can't.* (Female, 64 years, FG II)

Participant I: *Yeah, and then there's B., who keeps repeating how delicious it is. And you just sit there like.* (Female, 58 years, FG II)

### 4.3.9 Resources in the physical environment

Table 4.6 provides an overview of all mentioned resources in the physical environment related to their ability to live healthily, including supporting quotes or examples given by the participants. These can be placed under the following categories:

- health education
- facilities
- location of residence or work.

Looking at *health education* as a possible resource, in one of the community group homes a health educator visits the group to talk about what is healthy and unhealthy and health education is also available in a book. However, the participants admitted that they only occasionally read it.

*Facilities* in the environment of the participants can also stimulate a healthy lifestyle: being able to, for example, cook for yourself or eat at home due to good at-home catering is appreciated by the participants and positively influences how healthy they feel. The *location of residence and work* was also discussed as contributing to a healthy lifestyle. Living close to your work or the swimming pool, so that you can walk or cycle, is highly appreciated by the participants.

In contrast, participants pointed out that factors related to *facilities* and *location of residence or work* can also hinder them in living healthily. A lack of facilities as presented in Table 4.6 in the work or living environment of the participants is experienced as hindering. Besides, not only a lack of facilities, but also the presence of certain facilities is seen as a negative thing, as is illustrated by the following two quotes:

Participant A: *Yeah, the food itself is pretty ... ugh. I think it's bad. We get this brand of catering ... these heat-and-eat meals. Um ... yeah, personally, I think freezer food isn't fresh and doesn't have good vitamins and things like that.* (Male, 22 years, focus group I)

Participant B: *Our catering gives you different choices, but the food isn't always healthy.* (Male, 48 years, focus group I)

Therefore, no direct access to a supermarket, work and recreational sites makes the participants dependent on others for their daily living activities.

**Table 4.6** Overview of resources for a healthy lifestyle in the physical environment of people with ID

Resource	Examples / quotes
Health education	<ul style="list-style-type: none"> <li>• A visit to the hospital</li> <li>• A book</li> <li>• A health educator visits the group home</li> <li>• Television:</li> </ul> <p>Participant R: <i>I hear about it on TV. It comes on regularly and they give good advice and explain how things happen in your body.</i> (Male, 57 years, FG V)</p>
Facilities	<p>Good catering service</p> <ul style="list-style-type: none"> <li>• A gym or swimming pool</li> <li>• A sports facility</li> <li>• A vegetable garden</li> <li>• For people with ID who have physical disabilities as well, special facilities in the form of adjustments at home and at work</li> <li>• A kitchen in your own room</li> <li>• A job in which a degree of physical exercise is necessary:</li> </ul> <p>Participant O: <i>I'm more active in my new job. Before that I worked at the 'Posthoorn' and had to enter things into a computer. It really wasn't as good for me because it kept me sitting on my lazy butt all day. Ha ha ha. So yeah, now I can really do more work. Today, I cleaned the entire gymnasium. I mopped everywhere and dusted everything, everything.</i> (Male, 19 years, FG IV)</p>
Location of residence or work	<p>Living close to, e.g.:</p> <ul style="list-style-type: none"> <li>• work</li> <li>• vegetable garden</li> <li>• swimming pool</li> <li>• so that you can walk or cycle there</li> <li>• Having to use stairs at home or at work because you live or work on the second or third floor:</li> </ul> <p>Participant T: <i>Um, where I lived before this, the stairs were outside, and now I live downstairs, so um ...</i> (Female, 47 years, FG V)</p> <p>Moderator: <i>So, now you don't climb stairs as often?</i></p> <p>Participant T: <i>No, just now and then. I do climb them at school, like for example, when I have to give guest lectures at the ROC (Regional Educational Centre) in Veghel.</i></p>

## 4.4 Discussion

The aim of this study was to gain insight into the perspectives of people with mild to moderate ID on healthy living. Consistent with the findings of a previous study on how people with ID perceive healthy lifestyles (Caton et al. 2012), our results indicated that the participants have a good understanding of what healthy living entails: they are able to identify healthy and unhealthy foods, they are aware of the potential harms of alcohol and smoking and they are aware of the benefits of exercising regularly, cooking healthily and taking enough rest. However, our study found that when they have to translate these concepts into behaviours, they face several difficulties. Knowledge sources can be difficult for participants to interpret and merely knowing what is (un)healthy is not sufficient to be able to live healthily. Moreover, participants often displayed a straightforward way of thinking: they think in terms of right or wrong, healthy or unhealthy, thereby failing to see

the importance of moderation in unhealthy behaviours. This contradicts the findings of Caton et al. (2012), whose participants were aware of the concept of moderation and were even able to put it into practice. As both study populations are alike, this difference might be due to the concrete questions used in our interviews and the assignment of pictures to a healthy and unhealthy category.

Another finding of our study is that participants emphasised the importance of being and feeling healthy, both mentally and physically. Health perception was closely linked to happiness, independence and social participation. Not feeling well and being preoccupied with a mental or physical disability prevented participants from thinking about and getting engaged in lifestyle change. This means that health promotion interventions will only be effective in motivating and enabling persons with ID to change their behaviour if they fit the personal and environmental preconditions, as experienced by the person. This is in line with established behaviour change theories (De Vries et al. 2005; De Vries & Mudde 1998).

In previous research on facilitators and barriers to a healthy lifestyle in people with ID, participants with ID identified *support from caregivers* and *physical illness* as facilitators of their ability to engage in a healthy lifestyle (Caton et al. 2012). An example of the latter is that for people with chronic conditions, a healthy diet can be important and may compel participants to look after their health. In our study, however, the influence of *physical illness or disabilities* was mostly considered to be a hindering factor. Next to *support from others*, which was also identified as a resource in our study, other newly identified resources for a healthy lifestyle were *motivation, location of work and residence, health education and facilities in the environment*.

In the study of Caton et al. (2012), several barriers to the participants' ability to engage in a healthy lifestyle were also stated: *motivation and preference, transport, inadequate support and opportunity, perception of risk, stress and stressful situations, mood, and aging*. Some of these factors were also stated in our study. However, our participants had more difficulties in identifying factors that hinder a healthy lifestyle. They were better able to discuss and relate to positive stories and resources with regard to living healthily. Since health promotion policy and research tends to focus on barriers and problems, this might be problematic (Bergstrom et al. 2014; Caton et al. 2012; Robinson et al. 2006). A more assets-based approach, for instance Appreciative Inquiry (Cooperrider 2005; Cooperrider et al. 2005), might be helpful in this.

#### **4.4.1 Strengths, limitations and future research**

Our study is one of the first studies investigating the views on healthy living directly with people with ID, thereby contributing to tailored health promotion initiatives for this group.

The supporting materials used during the focus groups proved to be very helpful in visualising subjective health in people with mild to moderate ID and in actively involving all participants in the discussions. The ladder, for example, was successfully used to stimulate discussions on self-perceived health. It gave participants insight into the fact that their position on the ladder could fluctuate over time and they realised that, ultimately, they

should aim to climb the ladder. This indicates that the ladder may also be useful in lifestyle coaching for people with ID to evaluate changes in self-perceived health over time.

When interpreting the results of our study, there are several factors that must be taken into account. The concrete questions used in the focus groups and the assignment of pictures to a healthy and unhealthy category may have triggered the participants to think in contrasts, thereby overlooking the concept of moderation. The pictures did, however, facilitate the eliciting of new topics for discussion. In future research, the presentation of an 'in between' category for food which is not particularly healthy or unhealthy, or the use of weekly food menus to look at the overall diet as being healthy or unhealthy rather than individual food, can be added to avoid thinking in contrasts and to find out if a balanced judgement about their diet is possible.

The current lifestyle of participants was a potential source of recruitment bias, as people with a healthier lifestyle could be more eager to participate, or caregivers could select people with an unhealthy lifestyle to participate. However, as we found a large variation in lifestyles and encountered data saturation, this does not seem to have been a problem in our study. Nevertheless, it is important to recognise that our findings cannot be generalised to the whole population of people with ID, especially not to people with more severe or profound disabilities. The views on healthy living and factors related to the ability of people with more severe disabilities to live healthily need further investigation.

Although focus groups have proven to be helpful in needs assessment (Krueger & Casey, 2009), we found that some participants had difficulty in interacting with other participants on the topic of healthy living. The use of face-to-face interviews may have been more appropriate for these participants. Assessing the ability of participants to take part in either focus groups or individual interviews could contribute to the quality of future studies.

Lastly, the research team took several steps to increase methodological rigor: provision of a summary at the end of each focus group to facilitate the participant check, indication of data saturation, independent coding of the data by two researchers, and discussion of all steps of the coding process among all authors. Consequently, the authors are confident that the resulting paper accurately represents the participants' views and provides descriptions that are both valid and reliable. As this is an exploratory study, further research is required to take the next step towards implementation of these findings in health promotion for people with ID.

#### **4.4.2 Conclusions**

This study explored the perspectives of people with ID on healthy living. While there was awareness of the importance of healthy living and a good understanding of what healthy living entails, participants faced several challenges translating this into behaviours; merely knowing what is (un)healthy is not sufficient to be able to live healthily. These challenges make health promoting activities less accessible to them and there is a need for individually focused adaptations. The development and adjustment of health promotion for this group could benefit from taking into account not only the current lifestyle and

health needs of the person with ID, but also his/her preferences, motivation for (un) healthy behaviour, physical disabilities, mental state, dependence on others, and factors in the physical environment. Our results also indicate that health promotion initiatives for this group could benefit from being positively framed.

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## CHAPTER 5

# Stakeholder expectations, roles and responsibilities in Dutch health promotion for people with intellectual disabilities

### **Published as:**

Kuijken, N.M.J., Vlot-van Anrooij, K., van Schrojenstein Lantman-de Valk, H.M.J., Leusink, G., Naaldenberg, J., & Nijhuis-van der Sanden, M.W. (2018). Stakeholder expectations, roles and responsibilities in Dutch health promotion for people with intellectual disabilities.

This two-phase, qualitative study aims to obtain an overview of stakeholders in the network of people with intellectual disabilities (ID) and their perceived facilitating and hindering factors, expectations, and perceived roles and responsibilities with regard to health promotion. In phase 1, four workshops were conducted to provide insight into involved stakeholders. In phase 2, 29 semi-structured interviews were conducted with stakeholders regarding their views on health promotion. Data were analysed using stakeholder matrices and a combination of domain and thematic analysis. Daily caregivers were identified as the most important and influential stakeholders. Interviewed stakeholders perceived barriers to a healthy lifestyle as relating mainly to the person with ID and, although they stated that people with ID need support to be able to live healthily, there was ambiguity about roles and responsibilities for providing this support. Daily caregivers are not properly facilitated to support a healthy lifestyle. Stakeholders expressed the need for a culture change towards a greater health promotion ethos in care for people with ID. A facilitating context is needed in which the social network supports autonomy and offers opportunities to adapt to physical, social, and emotional challenges. Stakeholders see the importance of, and are willing to support, healthy behaviour. They are hindered by a lack of a shared vision and united system in which all stakeholders know their roles and responsibilities. Promotion of a healthy lifestyle should be part of every service provider employee's job and propagated throughout the organisation as part of its mission and vision.

## 5.1 Introduction

People with intellectual disabilities (ID) experience significantly more health problems compared to the general population. Some of these problems are lifestyle-related and could be prevented or reduced by effective and accessible health promotion (Van Schroyen Lantman – de Valk & Walsh, 2008). Current health promotion models for people with ID focus mostly on individual behaviour change (Taggart and Cousins, 2014) and many interventions use behaviour change techniques focused on the individual with ID (Castro et al., 2017; Steenbergen et al., 2017). However, people with ID expressed the need for positively framed support from their social environment to be empowered in their health behaviour (Kuijken et al., 2016). They experience specific barriers to achieving better health, many of which result from their (semi-)dependent relationship with (in) formal caregivers and service providers. Examples of such facilitating and hindering factors for health behaviour are (a lack of) guidance by others, positive or negative influences from key support persons, and service providers' (lack of) clear policies on promotion of health behaviour (Kuijken et al., 2016; Messent et al., 1999). Stakeholders' views and behaviour can positively or negatively influence the promotion of health behaviour, depending on their role and influence. To promote Huber et al.'s (2011) concept of *positive health* among people with ID, their interconnectedness with their families and support persons and the organisational culture of service providers are important (Taggart and Cousins, 2014). This network of stakeholders in health promotion for people with ID has never been structurally mapped.

Stakeholder analysis can be used to obtain insight into the network of stakeholders, their importance and influence on health promotion, and the underlying interests, values, knowledge, and perceptions of facilitating and hindering factors as seen by stakeholders from different backgrounds (Hoeijmakers et al., 2007; Lachat et al., 2011; Lezwijn et al., 2014; Naaldenberg et al., 2013; Petruney et al., 2010). Such an analysis provides a good understanding of organisations' culture and climate, and insight into perceptions on support needs of people with ID and involved stakeholders' own roles and responsibilities. This information is essential for implementing routines aimed at promoting and facilitating health behaviour in service providers for people with ID (Glisson, 2007), and it can point towards the appropriate type of participation by different stakeholders at successive stages of an implementation project (ODA, 1995).

The aim of the current study is to obtain: 1) an overview of health promotion stakeholders within the network of people with ID and 2) insight into perceived facilitating and hindering factors and stakeholders' expectations, perceived roles, and responsibilities.

## 5.2 Methods

This qualitative study consisted of two phases: 1) stakeholder workshops to identify relevant stakeholders and 2) interviews to explore these stakeholders' views.

### 5.2.1 Context

The study took place in The Netherlands, where people with ID are supported by service providers who provide residential and community living arrangements as well as day-activity care. Due to government regulations, increasingly more people with ID will live (semi-) independently in the community. People with ID (mild to profound) are mainly supported by daily care professionals who are trained in behaviour aspects and/or assistant nursing. Tasks include assisting people with ID in personal, daily, social and health care (Heutmekers et al., 2016). Other involved professionals who are often (but not always) employed by service providers for people with ID include, e.g., allied health professionals, ID physicians (medical specialists, trained postgraduate to provide medical care for people with ID) and general practitioners (GPs).

### 5.2.2 Phase 1: stakeholder identification

#### 5.2.2.1 Participants

A participatory planning group (Bartholomew Eldridge et al., 2016) of 14 network members participated in four consecutive stakeholder workshops between August 2013 and September 2014. These network members were purposively selected from three regional service providers who provide care to people from all ages with mild to profound ID. Figure 5.1 shows the participants and content of the workshops.

#### 5.2.2.2 Procedures

A combination of two stakeholder analysis methods was used to guide the workshops. Matrixes were employed to bring clarity and transparency to the process and facilitate the assessment of stakeholders' relative importance and influence (Rietbergen-McCracken and Narayan, 1998; ICRA, 2009). Four workshops were organized in iterative cycles where each workshop focussed on different aspects of stakeholder identification (see Figure 5.1) and built on the results of previous workshops. Workshops were facilitated by the first author.

All participants received written information on the aim, content, and procedure prior to the workshops. Respondents were sent a summary and asked to prepare for the next workshops by returning their comments to the researcher.

#### 5.2.2.3 Data analysis

Every workshop was recorded digitally and transcribed. During and after the workshops, the answers to the questions were summarized into matrixes to identify stakeholders and their influence and importance (ICRA, 2009). These matrixes formed the basis for 1) an overview of relevant stakeholders, 2) sampling participants for phase 2, and 3) the interview guide for phase 2 (see Figure 5.1).

### 5.2.3 Phase 2: stakeholder interviews

#### 5.2.3.1 Participants

To obtain the best possible representation of the stakeholders identified in phase 1, we aimed to include two of each (Figure 5.1). Additional inclusion criteria were 1) involved with people with mild to moderate ID and 2) aged  $\geq 18$  years. Purposive sampling was used to recruit from: four service providers providing residential and community care to people from all ages with mild to profound ID; three education centres for daily caregivers; two companies offering catering to service providers; two GP practices collaborating with ID service providers; and an independent weight consultancy for people with ID.

During data collection, it became clear that daily caregivers' opinions and experiences varied widely. Because of this and the high importance of daily caregivers identified in phase 1, we included more daily caregivers (seven in total). Stakeholders with overlapping roles (brother/sister/friend and food preparation/daily caregiver) were not sampled separately. The stakeholder workshops in phase 1 focused on identifying stakeholders that can facilitate people with ID in health promotion. People with ID themselves were therefore not included in phase 2. However, the views of people with ID were extensively explored in a previous study (Kuijken et al., 2016) and results were used in the design of this study.

**Phase 1: Stakeholder identification in stakeholder workshops**

<u>Content of the workshops</u>	<u>Participants</u>
#1. - Who are potential stakeholders in the field of health promotion for people with ID, and why?	- four self-advocates
#2. - What is the influence and importance of the stakeholder in the field of health promotion for people with ID, and why?	- two parents (also members of a board of self-advocates)
#3. - Who are key stakeholders in the field of health promotion for people with ID, and why?	- a legal representative
- Who are potential beneficiaries?	- a movement teacher
- Who might be adversely impacted?	- a physiotherapist
- Have vulnerable groups been identified?	- a dietician
- Have supporters and opponents been identified?	- an ID physician
#4. - Are these stakeholders indeed the most important stakeholders in the field of health promotion for people with ID, and is the list of stakeholders complete?	- a project manager for healthy living
- Do you know stakeholders who could take part in the upcoming stakeholder interviews?	- a unit chief
- What is the best way to invite these stakeholders to take part in these interviews?	- a manager
- Do you have feedback on the interview guide for the stakeholder interviews?	

**Phase 2: Stakeholder interviews**

<p><u>List of stakeholders envisaged to include in interviews (number of included persons)</u></p> <ul style="list-style-type: none"> <li>- Parents, other family or legal representatives at home (n=3)</li> <li>- Daily caregivers in residential (n=4) and day-activity care (n=3)</li> <li>- Members of a board of self-advocates (n=1 =family member as well)</li> <li>- Allied health professionals such as                             <ul style="list-style-type: none"> <li>- nutritionists (n=2)</li> <li>- physiotherapists/movement specialists (n=2)</li> <li>- behavioural specialists (n=2)</li> </ul> </li> <li>- ID physicians (n=3 + 1 practice nurse)</li> <li>- General practitioners (GPs) (n=1)</li> <li>- Managers (n=4)</li> <li>- Teaching staff of daily caregivers in residential and day-activity care (n=2)</li> <li>- Friends or acquaintances without ID (n=0)</li> <li>- Counsellors (n=1)</li> <li>- Caterers (n=1)</li> <li>- Those who cook for people with ID in group settings (n=0)</li> </ul>	<p><u>Research question and sub questions</u></p> <p>What are the views of these stakeholders on health promotion for people with ID?</p> <ol style="list-style-type: none"> <li>a) What do they perceive to be facilitating and hindering factors in this?</li> <li>b) What do they expect of health promoting activities?</li> <li>c) What do they perceive to be their own role and responsibilities in this?</li> </ol> <p><u>Topics in the interview guide</u></p> <ol style="list-style-type: none"> <li>1. The participant's definition of healthy living and his/her views on the health and lifestyle of people with ID</li> <li>2. Resources perceived to contribute to the health of people with ID</li> <li>3. Intervention profiles (level of support needed) for tailoring health-promoting initiatives</li> <li>4. The participant's expectations of health promotion for people with ID</li> <li>5. The participant's own role in health-promoting initiatives for people with ID</li> </ol>
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↑
<ul style="list-style-type: none"> <li>- Previous research on tailored intervention profiles</li> <li>- Previously conducted focus groups with people with ID</li> </ul>

**Figure 5.1** Participants and content of phases 1 and 2

### 5.2.3.2 Procedures

After receiving information on the content and procedure of the interview and stating their interest to an independent contact person, potential participants were contacted by the first author. Written informed consent was obtained from each participant. Twenty-nine face-to-face interviews took place between October 2014 and September 2015 and were conducted by the first author.

A semi-structured interview protocol was constructed based on: input from phase 1, two stakeholder analysis methods (ICRA, 2009; Rietbergen-McCracken and Narayan, 1998); previous research on tailored intervention profiles (de Vries et al., 2016); and input from previously conducted focus groups with people with ID (Kuijken et al., 2016). The research questions, topics of the interview protocol, and their origin are outlined in Figure 5.1. The eliciting questions started broadly, allowing the participants to raise issues they considered relevant. Prompts were used to help the participants to elaborate on their views and experiences.

All interviews were recorded digitally and transcribed verbatim. Two pilot interviews were conducted, resulting in the addition of visual supporting materials. Because of the rich information provided by the pilot, these transcripts were also included in the analyses. To increase validity through a participant check, the interviewer gave a summary at the end of each interview, which the participant could confirm, correct, or add to. Data saturation was achieved after 29 interviews, as the answers in the last five interviews overlapped considerably with those in the previous 24, and almost no new information came up.

### 5.2.3.3 Data analysis

Data analysis of the transcripts was supported by ATLAS.ti software 7.1.4 (scientific software development). As this study aimed to explore both professional and lay perspectives regarding health promotion for people with ID, in which commonly used terms are of great importance, a combination of domain analysis (Atkinson and Abu el Haj, 1996) and thematic analysis (Braun and Clarke, 2006) was used. This combination resulted in four steps conducted by two researchers (NK and KV): step 1 consisted of grouping fragments of the transcripts using the five topics of the interview protocol; in step 2 we selected respondent perspective keywords from fragments within each of the five segments; step 3 consisted of arranging the actual text fragments into three primary domains, each related to one research question; and step 4 consisted of discussing relations between primary domains and subcategories. Table 5.1 provides an extensive overview of the aims, actions and results for the consecutive steps of the coding process. The actions and results of each step were cyclically discussed among all authors.

**Table 5.1** Consecutive steps, aims and results of the coding process

Step	Action	Aim	Result
1	Grouping fragments of the transcripts using the five topics of the interview protocol (NK)	First, top-down segmentation of data	Raw data divided into five segments: views, resources, profiles, expectations, and own role
2	Selecting respondent perspective keywords from fragments within each of the five segments (NK)	Bottom-up coding and focusing of data	Coded and focused text fragments
3	Arranging the actual text fragments into three primary domains, each related to one research question (NK, KV)	Identifying possible subcategories within each primary domain	A taxonomy of primary domains and possible subcategories
4	Discussing relations between primary domains and subcategories (all authors)	Identifying definite subcategories and their mutual relations within each primary domain	Three primary domains and their subcategories as presented in the results section and below*

\*Result of step 4: primary domains and their subcategories:  
Facilitating and hindering factors for a healthy lifestyle for people with ID

- The person with ID him/herself
  - Support from the social network
- Expectations of health promotion
- Autonomy of people with ID
  - Culture change in care for people with ID
  - Facilitation of (supporting) health behaviour
- Roles and responsibilities
- Planning health-promoting initiatives
  - Implementation of health-promoting initiatives
  - Sustained implementation of health-promoting initiatives
  - Need to fulfil roles
  - Hindering factors
    - Resistance from others
    - Other hindering factors

## 5.3 Results

### 5.3.1 Phase 1: stakeholder identification

The brainstorming session around the question: *“Who are potential stakeholders in the field of health promotion for people with ID, and why?”* during the first stakeholder workshop led to the list of stakeholders displayed in Table 5.2. Positive and negative reasons why these groups of people are stakeholders were discussed during three workshops. Having a signalling function was often mentioned, as well as the need for collaboration and support between informal and formal caregivers. It was emphasized that stakeholders should make use of one another’s knowledge, experience, and influence.

**Table 5.2** Identified stakeholders, their influence and importance, and reported reasons for being stakeholders

Stakeholders, influence and importance	Why are these persons seen as stakeholders?
Daily caregivers in residential care <i>very influential; critical player</i>	<ul style="list-style-type: none"> <li>• role modelling</li> <li>• provide information on healthy lifestyles</li> <li>• decide on menu, order menu at caterer</li> <li>• support a healthy lifestyle</li> <li>• provide (un)healthy snacks</li> <li>• signalling function</li> <li>• execute management decisions in their own way</li> <li>• need to work together with, and be supported by, parents/family at home/ managers</li> </ul>
Management <i>significant influence/very influential; critical player</i>	<p>Makes policy on healthy living:</p> <ul style="list-style-type: none"> <li>• food (preparation)</li> <li>• available time and money for cooking and exercising</li> <li>• provides guidelines to daily caregivers on healthy lifestyles</li> <li>• (lack of) inclusion of healthy lifestyles in individual care plans</li> <li>• (lack of) inclusion of healthy lifestyles in their vision statement</li> </ul>
Daily caregivers in day-activity care <i>significant influence; critical player</i>	<ul style="list-style-type: none"> <li>• activities often involve cooking and physical activity</li> </ul>
Board of self-advocates <i>significant influence; critical player</i>	<ul style="list-style-type: none"> <li>• signalling function</li> </ul>
Counsellor <i>moderate influence; critical player</i>	<ul style="list-style-type: none"> <li>• advise on a healthy lifestyle</li> </ul>
Person with ID him/herself <i>moderate influence; significant importance</i>	<ul style="list-style-type: none"> <li>• preferences</li> <li>• needs</li> <li>• motivation</li> <li>• self-regulation</li> </ul>
Parents/other family/or legal representatives at home <i>moderate influence; significant importance</i>	<ul style="list-style-type: none"> <li>• role modelling</li> <li>• provide food at home</li> <li>• (lack of) stimulation to exercise</li> <li>• signalling function</li> <li>• need to work together with, and be supported by, daily caregivers</li> </ul>
Group of people with ID lived with <i>moderate influence; significant importance</i>	<p>Group pressure and culture:</p> <ul style="list-style-type: none"> <li>• group preferences</li> <li>• current group lifestyle</li> </ul>
Friends Acquaintances <i>moderate influence; significant importance</i>	<ul style="list-style-type: none"> <li>• increase awareness of a healthy lifestyle</li> <li>• by eating together you take more time to eat, which is healthier</li> <li>• being physically active together gives more pleasure and enhances adherence</li> </ul>
Allied health professionals such as nutritionists, physiotherapists, movement specialists, and behavioural specialists <i>some influence; significant importance</i>	<ul style="list-style-type: none"> <li>• provide correct information on healthy lifestyles</li> <li>• provide tips on healthy food and physical activities adapted to personal capability</li> </ul>

Stakeholders, influence and importance	Why are these persons seen as stakeholders?
ID physician <i>some influence; significant importance</i>	<ul style="list-style-type: none"> <li>include healthy living in individual care plan</li> <li>provide correct information on healthy lifestyles</li> <li>use their superiority in changing a patient's lifestyle</li> </ul>
General practitioner (GP) <i>some influence; significant importance</i>	<ul style="list-style-type: none"> <li>provide opportunities for semi-independently living patients with ID to live healthily</li> </ul>
Teaching staff of daily caregivers <i>little/no influence; significant importance</i>	<ul style="list-style-type: none"> <li>supporting a healthy lifestyle must be incorporated in daily caregivers' education</li> </ul>
Caterer <i>little/no influence; moderate importance</i>	<ul style="list-style-type: none"> <li>provides food for many service providers for people with ID</li> <li>their selection of foods can be (un)healthy</li> </ul>
Those who cook for people with ID in group settings <i>little/no influence; moderate importance</i>	Need to (be instructed to) cook healthily: <ul style="list-style-type: none"> <li>meal composition</li> <li>method of preparation</li> </ul>
Everyone who has contact with a person with ID*	<ul style="list-style-type: none"> <li>role modelling</li> <li>inspire to live healthily</li> <li>provide food</li> <li>healthy living must be on everyone's agenda</li> </ul>

\*This stakeholder group is not included in the other analyses, as it was considered too broad to be a specific stakeholder group and was already represented across the other stakeholder groups.

During the third workshop, identified stakeholders were mapped for influence/importance (Table 5.2). Each stakeholder's influence depended on: dependence on others, decision capacity, closeness of contact with people with ID, knowledge on health promotion, and involvement in health promotion policy. The influence of teachers of daily caregivers in residential and day-activity care especially can be limited by the timeframe in which their influence becomes apparent. They educate the most important and influential stakeholders, but their influence only becomes apparent in the long run.

Daily caregivers in residential care are ranked highest on level of influence and importance, followed by caregivers at day-activity care and those in a management position. In residential care, daily caregivers are the people who decide on the daily menu and on whether or not to stimulate physical activity. Caregivers in day-activity care are thus ranked because people with ID often have lunch at the day-activity centre, and many lifestyle-related activities can be offered. There was disagreement on management's level of influence: regarding policymaking, they are very influential; regarding implementation of their policy, they depend on daily caregivers and have 'only' significant influence.

### 5.3.2 Phase 2: stakeholder interviews

#### 5.3.2.1 Participants

Forty-four stakeholders were approached to participate in phase 2, of which 29 participated. Reasons for declining were: non-response to invitation, no time, or not meeting inclusion criteria. Twenty-one females and eight males participated, their age ranging from 25 to 66 years. Their background is shown in Figure 5.1. Following the inclusion criteria, all

participants were involved with people with mild to moderate ID. Several participants (had) also worked with people with severe and profound ID.

#### 5.3.2.2 Facilitating and hindering factors for a healthy lifestyle for people with ID

The analysis of facilitating and hindering factors described by the stakeholders resulted in two major subcategories: factors relating to *the person with ID him/herself* and factors relating to *support from the social network*.

*The person with ID him/herself:* Stakeholders ascribed mainly hindering factors to the person with ID him/herself. Frequently mentioned hindering factors were dependence/need for support, cognitive ability, motivation, and physical disabilities. The interviewees stated that living healthily would be easier if the focus was on the *person* with ID. However, currently the focus is on *the problems* of a person with ID:

Interviewer: *So is it the same for everyone, the things required [to live more healthily]?*

Behavioural specialist: *That's hard to say, because they need to have a certain motivation to start living more healthily, you know. And they often don't have that, and with that group you also see that if there are problems, they are quick to fall back into their old patterns.*

This quote shows that opinion and experience are intertwined. Stakeholders are convinced of the benefits of person-centred health promotion efforts; their experience, however, reflects the problem-centred approach. They also indicated that the person with ID is not involved in solving the problem, making the person with ID more dependent.

*Support from the social network:* Support and role modelling by caregivers, volunteers, peers, family, and friends was often mentioned as a facilitator; a lack of these, or certain types of support and role modelling were regarded as hindering:

Dietician: *So they would go off to swimming lessons. But then we discover that they're only in the water for 20 minutes. The rest of the time they are getting dressed and all that... And when they leave there is someone at the door dishing out almond biscuits.*

A lot is asked from daily caregivers, but they are not adequately trained to meet these demands. This and the prevailing culture hinder the promotion of healthy behaviour by daily caregivers:

Senior manager: *I think it's still very much entrenched in the way caregivers think. They don't come up with ideas about what you can do with the group, everyone just drinks coffee in the evening, right? Add a biscuit, and you're all set...*

The independence of people with ID in routine activities of daily living is not stimulated, and daily caregivers often define 'a nice day' as a day when unhealthy food is consumed.

In contrast, daily caregivers themselves (as well as other stakeholders) ascribed many hindering factors to the organisational level. Examples are a lack of time, money, and health-promoting activities provided by the service provider, and a lack of continuity in daily caregivers.

### 5.3.2.3 Expectations of health promotion

To improve the health of people with ID, the two most commonly expressed needs were *an increase in physical activity* and *more healthful eating*. The analysis of stakeholders' expectations of health promotion in aiming for these resulted in three central, interconnected subcategories: *autonomy of people with ID*, *a culture change in care for people with ID*, and *facilitation of (supporting) health behaviour*.

*Autonomy of people with ID:* The autonomy of people with ID should be the basic principle of health promotion. Their disabilities do not discharge people with ID from thinking about their own health behaviour and ways to improve it. Living healthily is a shared responsibility of the person with ID and the people surrounding him/her. Letting people with ID take the lead in this will make them feel proud of themselves. Moreover, being supported to make their own choices will increase their feeling of wellbeing:

*Physiotherapist: I think you can feel good about yourself if you can make your own decisions a bit more, if you can do your own thing.*

Stimulating autonomy implies placing the person with ID in the centre, adapting health promotion efforts to his/her wishes and capacities instead of to the (possibilities in the) environment. Health behaviour should also be fun and there should be something in there for people with ID:

*Daily caregiver in day-activity care: Imagine bringing something to your clients... They want to get something out of... It's because for them it's not in their frame of reference. They ask me: "What's the pay" (laughs), you know? So, there has to be something in it for them.*

Stimulating and facilitating such initiatives by people with ID is essential according to the stakeholders. The social network should set the right example and inform people with ID about healthy choices, but should leave room for them to choose.

*Culture change in care for people with ID:* Living healthily should be a normal routine in everyday life, requiring a change of culture. Small things, like bringing their own coffee cup back to the kitchen or having fruit with their coffee/tea instead of a cookie, can already make a big difference. If healthy options are incorporated into daily routines, living healthily becomes self-evident:

*Teacher of daily caregivers: It doesn't have to be anything grand, something small might do as well, but you have to look at the possibilities... Someone could just take the dog for a walk, you know? Or the neighbour's dog, so they meet other people (...) Look for*

*things they can do in everyday life, perhaps some sort of club... As long as it fits their daily routine...*

Integrating healthy living into daily routines requires a shared vision and mindset among stakeholders on what is healthy. This includes feeling free to address a colleague/client/caregiver/roommate etc. if they are not supporting a healthy lifestyle. The social network can act as a role model by demonstrating, doing things together, and showing that it is fun to live healthily. They can emphasize the positive aspects of change, instead of the negative things in the current routines, and encourage by rewarding with positive attention. Support must be adapted to the individual needs of the person with ID: some need advice; others need some more enforcement or just a reward to look forward to. The group of people with whom one is living or working has a great influence, and this can be an advantage. Doing new things as a group is encouraging and helps to form new routines.

*Facilitation of (supporting) health behaviour:* Not only can people with ID be facilitated to live more healthfully; daily caregivers and managers can also be facilitated in their roles. For people with ID, nudging towards healthier choices while respecting autonomy was an important facilitator. To enable managers to do so, health promotion needs to be integrated in organisational policy; more attention on health promotion for people with ID in public policy is also mentioned as helpful. Finally, managers need organisational resources such as time, money, and hands-on facilities to be able to facilitate daily caregivers in their supporting role:

*Behavioural specialist: Well, facilitating too, I think. You can put a lot of effort into informing and encouraging, but if there are no real opportunities, that's quickly the end of that. So, providing the means to create opportunities. Whether that's money or more supervision or whatever... just the things that are needed.*

#### 5.3.2.4 Roles and responsibilities

Stakeholders' roles and responsibilities are described according to the sequential phases of health promotion – *planning, implementation, and sustained implementation* – followed by *needs and hindering factors related to these roles*.

*Planning health-promoting initiatives:* Stakeholders who perceive a role for themselves in planning are daily caregivers in residential and day-activity care, physiotherapists, ID physicians, GPs, and parents/members of the board of self-advocates. Roles in planning health promotion initiatives are *taking the initiative, building contacts, and generating awareness of the need for a lifestyle change and promotion of this*. These stakeholders *advise and coach* colleagues as well as people with ID. Other stakeholders, such as a participating brother, said that they do very little during the planning phase and do not feel that it is their responsibility to do more during this phase. They feel that they are doing their best from their position in this phase.

*Implementation of health-promoting initiatives:* In the implementation phase, stakeholders see a large role for people with ID themselves. Others should *offer facilities to live healthily* but people with ID must be willing to, and must, 'do' it themselves:

ID physician: *Yes, I think that people mainly need to do it themselves. Even if you're the doctor, the patients also have to do things themselves... They have to become motivated and have to want it, and you should provide the means to make that possible.*

Roles and responsibilities mentioned as part of this facilitation in the implementation phase were *goal setting, guiding, coaching, and stimulating people with ID and colleagues*. Not all stakeholders see a role for themselves in this phase, because they feel that they are not in the right position to be a facilitator of a healthy lifestyle, or simply do not know what their role is. A physiotherapist, weight consultant, ID physician, quality of care advisor, father/member of the board of self-advocates, behavioural specialist, counsellor, and daily caregiver in residential care all stated that *someone else has a more important role*, or they *don't feel like it is their responsibility to be involved*. Reasons for this were not being involved in initiatives, not having direct contact with people with ID, or having only occasional contact in a treatment setting with people with ID. Different stakeholders were indicated as *having a more important role*, but mostly those who work with people with ID on a daily basis were mentioned:

Senior manager: *The immediate caregiver is in the best position to tie in with the client in their local community and with those initiatives.*

*Sustained implementation of health-promoting initiatives:* To ensure sustained implementation, *monitoring, evaluating, keeping in touch, and regularly putting it on the agenda of (management) meetings* are described as roles and responsibilities by daily caregivers in residential and day-activity care, managers, ID physicians, quality of care advisor, father/member of the board of self-advocates, sister, brother, behavioural specialist, GP, and a teacher of daily care professionals. However, many other interviewees said that they *do not have a role or responsibility to keep an initiative implemented, do not know what their role is, or that someone else has a more important role*. Sustainable implementation was often described as being difficult:

Senior manager: *In particular, safeguarding those subsequent steps. At (name of organisation) we're very good at initiatives and projects and at embarking on something enthusiastically. The roll-out goes well too, but making it sustainable is something different. (.....) It disappears again because the next initiative comes along, which is suddenly more interesting, shifting everyone's enthusiasm...*

To keep the health-promoting spirit alive and facilitate sustained implementation, it was for example suggested that the service provider should link a special day to this theme.

*Needs to fulfil roles:* Service providers/organisations can provide almost all needs stated as necessary for stakeholders to fulfil their roles. Examples are *time, money, means, support within the organisation, and education/knowledge on health promotion*. All these organisational needs come under one overarching, important, frequently mentioned need: *prioritizing healthy living in organisational policy*. A healthy lifestyle should be part of every service provider employee's job. It should be propagated throughout the organisation and be part of its mission and vision:

Dietician: *Well, in that sense I think it involves policy, something being decided from above: everyone simply has to go along with it...*

*Resistance from others* – colleagues as well as family or other people from the informal network – was often mentioned as a factor that hinders stakeholders from fulfilling their roles. Interviewees thought that the education and personal lifestyle of daily caregivers in both residential and day-activity care was partly to blame for this. To overcome this, stakeholders mentioned that promoting a healthy lifestyle should be part of daily caregivers' education. Some of them (behavioural specialist and daily caregiver in day-activity care) pointed out that it was not only others that needed education on this topic; they themselves needed it as well. Other hindering factors that stood out were *health-promoting activities that were stopped by the service provider, organisational structure and goals, and health promotion not being within the stakeholder's sphere of influence*:

GP: *In some groups they cook their own meals, but there are also some groups where meals are simply provided, and I have absolutely no influence over that.*

Besides the GP, daily caregivers in day-activity care, a counsellor, and a dietician mentioned their lack of influence or not being involved in current health-promoting activities as hindering. One physiotherapist stated that, from her position, nothing hinders her from promoting a healthy lifestyle for people with ID.

## 5.4 Discussion

This study shows that health promotion for people with ID takes place in a complex system with many different stakeholders surrounding the person with ID. Stakeholders closest to the person with ID are said to be responsible for supporting behaviour change, but those further away are the ones who possess the required knowledge, skills, and power. These stakeholders do not take responsibility for facilitating the closest people, or do not know how to do so.

The stakeholders in this study agree with people with ID (Kuijken et al., 2016) about the need for support to be able to live healthily, but feel ambiguous about whether or not this support interferes with the autonomy of people with ID and about who is responsible for providing this support. They doubted whether it is *their* role to support a healthy lifestyle, whether they *have* a role in this, or whether they are *in the right position* to be supportive, or whether another stakeholder was better placed. Hindering factors were mainly ascribed to the person with ID him/herself. Previous research also found that professional caregivers of people with ID perceive the main barriers to a healthy lifestyle – and perhaps responsibility for change – within the person with ID (Melville et al., 2009). This focus on hindering factors was also found in a study on perceptions and beliefs about self-management in stroke rehabilitation (Satink et al., 2015). People with ID stated that they need positively framed support from others to change health behaviour (Kuijken et al., 2016), and so it is important to address stakeholders' focus on barriers to health promotion and to change it into a focus on resources. This links well with assets-based approaches to health promotion and salutogenesis (Antonovsky, 1996).

Next to people with ID themselves, daily caregivers were described as being most responsible for behaviour change but do not have the appropriate knowledge and skills to promote a healthy lifestyle. This was also found to be a barrier to healthy lifestyles among residents in community residences (Elinder et al., 2010; Ruud et al., 2016). Those stakeholders who do have these skills and knowledge and want to promote the health of people with ID (allied health professionals) feel they do not get the chance because they are not involved in everyday care and health promotion initiatives and work mainly from a health-problems perspective.

There is evidence of a lack of a health promotion ethos in the culture of housing/care organisations (Emerson and Hatton, 2013; O’Leary et al., 2017). Culture has a key influence on an initiative’s long-term success (Spasiani et al., 2016), and previous research with people with ID has been criticized for not considering the culture that surrounds this group, as it limits research effectiveness (Ferguson and Ferguson, 2001). Our study clearly shows that a culture change is needed, in which new social norms must be created. According to the expectations of stakeholders in this study, these new social norms should include stimulating autonomy as a guiding principle and, in line with the concept of positive health (Huber et al., 2011), offering opportunities to adapt to physical, social, and emotional challenges. Interviewed stakeholders perceived a tension between autonomy and dependence of people with ID on others. However, when interpreted with an emphasis on the empowerment of people with ID to act so as to take control of their own health behaviour, autonomy is not at odds with dependence (Takala, 2007).

Besides the identified need for changes in culture and social norms, a change in a complex system also requires attention on existing routines, structures, resources, and power relations (Naaldenberg et al., 2009). As pointed out in The Ottawa Charter For Health Promotion (WHO, 1986), health promotion demands coordinated action by all concerned to reorient health services and create supportive environments for health promotion. Unfortunately, there is no attention for health promotion in *kwaliteitskader gehandicaptenzorg* (Landelijke stuurgroep kwaliteitskader gehandicaptenzorg, 2017), the quality framework for care for people with ID which serves as a national standard for practice, helping professionals to improve care and guiding managerial accountability. In line with the Ottawa Charter For Health Promotion (WHO, 1986), our results show that a system change is needed in order to acknowledge people as the main health resource. To support and enable them to keep themselves and the people they care for healthy, changes are needed on interpersonal level (supporting a healthy lifestyle while maintaining autonomy), organisational level (new routines, structures, resources, power relations) and environmental level (culture change, new social norms). Possible ways to accomplish this are the use of health goals in individual support plans, training opportunities for daily care professionals jointly with the people whom they support, and changed job descriptions and responsibilities incorporating health promotion efforts.

#### **5.4.1 Strengths and limitations**

We performed a broad network analysis starting close to the person with ID. The combination of two steps in this study’s stakeholder analysis has provided a unique view of health promotion support from the network around people with ID in the Netherlands,

highlighting those stakeholders who are important and influential, yet not aware of, or facilitated to enact, their roles and responsibilities. The research team took several steps to increase methodological rigour: a two-phase approach that supported data triangulation; a summary at the end of each interview to facilitate participant check; indication of data saturation; independent coding of the data by two researchers; and discussion of all steps of the coding process among all authors.

The perceived personal role and responsibilities in health promotion for people with ID was a potential source of recruitment bias for phase 2 participants, as those who felt that they had a large role in health promotion could have been more eager to participate. However, as we found that many stakeholders actually feel ambiguous about who is responsible for promoting healthy lifestyles and encountered data saturation, this does not seem to have been a problem in our study. Although we think we discovered the most relevant factors using this qualitative approach, future research could avoid recruitment bias by taking a random sample from a record of existing stakeholders in the field.

Social desirability could lead to a potential bias where respondents answer questions in a way that is thought of as acceptable. Our study yielded a wide variety of answers, including social undesirable answers, and we therefore think this bias is minimal. Future studies could further minimize this bias by explicitly stating social undesirable answers are okay and by indirect questioning (Dodou and de Winter, 2014).

This study was tailored to the situation in one country, included local stakeholders and was adapted to the local organisation of care. However, due to the extensive analysis of stakeholders from various settings, the findings are likely to have (inter)national applicability. Literature shows that similar culture problems were met in, e.g., the UK (Emerson and Hatton, 2013; O'Leary et al., 2017). We therefore feel that using similar stakeholder analysis to identify key stakeholders in other countries, based on local organisation of care, might improve the effectiveness of health promotion internationally as well. These studies could increase generalizability by taking an international perspective.

#### **5.4.2 Conclusion**

Our stakeholder analysis identified daily caregivers as the most important and influential stakeholders. All stakeholders see the importance of, and are willing to support, healthy behaviour. They are hindered by a lack of a shared vision and united system in which all stakeholders know their roles and responsibilities. Promotion of a healthy lifestyle should be part of every service provider employee's job and propagated throughout the organisation as part of its mission and vision. Therefore, it should be incorporated into job descriptions and the individual support plan of every person receiving care from a service provider. Because of the large influence of, and variance in, contexts, initiatives should be adjusted to variable contexts, at both behavioural and system level; this requires a whole system approach.

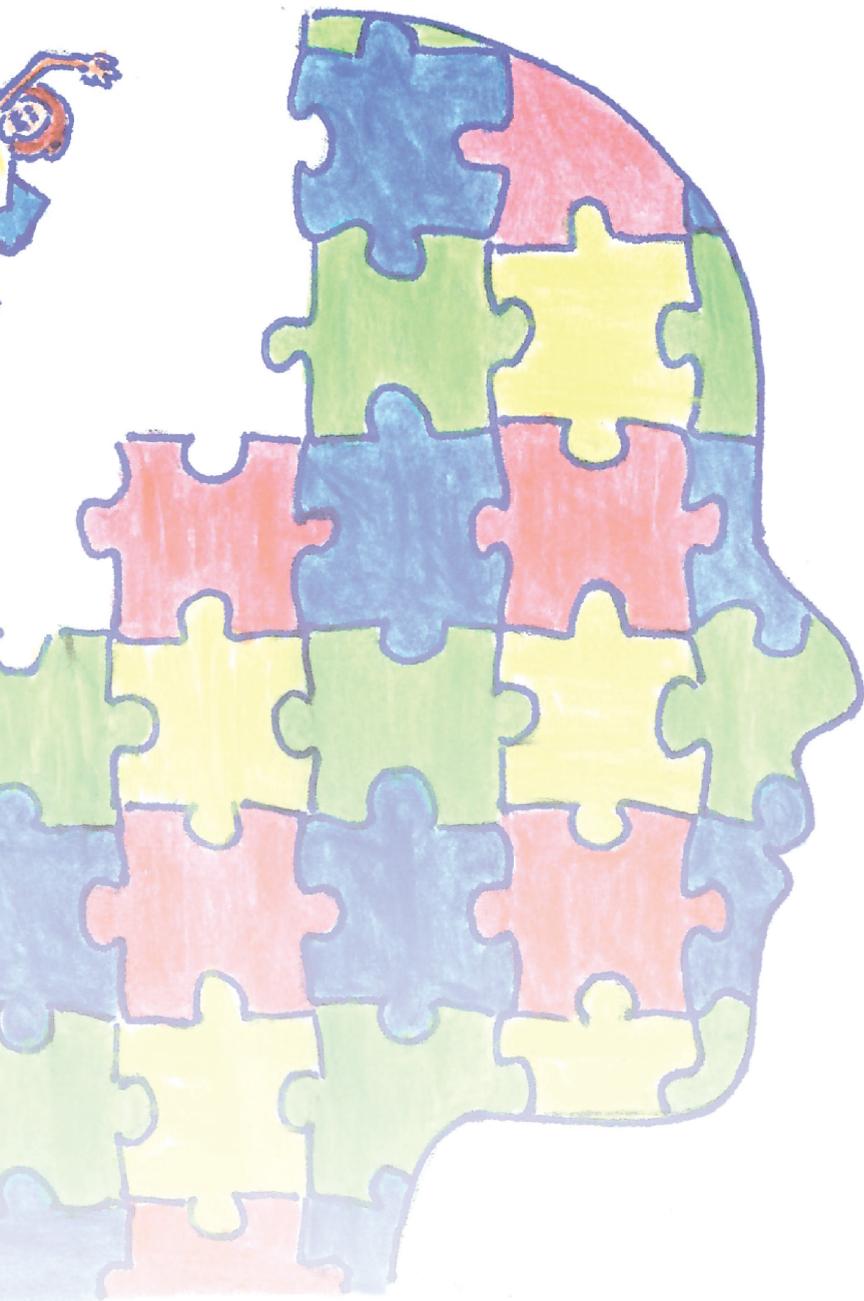
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# Dream, discover, and do! Increasing physical activity in everyday life: a feasibility study

**Submitted as:**

Kuijken, N.M.J., Nijhuis-van der Sanden, M.W.G., van Schrojenstein Lantman-de Valk, H.M.J., Naaldenberg, J., Leusink, G.L. Dream, discover, and do! Increasing physical activity in everyday life: a feasibility study.

**Background:** Supporting people with intellectual disabilities (ID) to lead a more physically active and less sedentary everyday life contributes to their improved health and quality of life.

**Aims:** This study assesses aspects of feasibility for 'Dream, discover, and do! Increasing physical activity in everyday life' (*DDD*).

**Methods and Procedures:** Five group homes, 47 people with ID, 20 daily caregivers, and three physiotherapists participated in a feasibility study with a mixed-methods pre-post-test design with measurement by means of questionnaires and accelerometers. *DDD* consisted of a 90-minute group session, during which a physical activity poster was filled out, and an intermediate evaluation after one week.

**Outcomes and Results:** At post-test, self-reported physical activity and awareness, especially of possible activities in and around the house, increased. Professionals reported that people with ID were more active. Implementation of *DDD* was feasible. Evaluation among people with ID by means of questionnaires and accelerometers was challenging.

**Conclusions and Implications:** This study assessed the feasibility of *DDD* positively and identified small adjustments to increase feasibility. Future evaluation studies should be sensitive to the complex context of health promotion for people with ID.

## 6.1 Introduction

Sedentary lifestyles are common among people with intellectual disabilities (ID) (Hsieh, Hilgenkamp, Murthy, Heller, & Rimmer, 2017; Melville et al., 2018). Supporting people with ID to be more physically active contributes to improving their health and quality of life (Heller & Sorensen, 2013; Melville et al., 2017; Naaldenberg, Kuijken, van Dooren, & van Schrojenstein Lantman-de Valk, 2013). Few current lifestyle approaches for people with ID focus at activities in everyday life, even though this could prove to be much more beneficial than, e.g., regular exercise groups or the use of educational components (Naaldenberg et al., 2013; Steenbergen, Van der Schans, Van Wijck, De Jong, & Waninge, 2017). People with ID are aware that an active lifestyle is important, but they point out that they need facilities and support from others to put this into practice (Caton et al., 2012; Kuijken, Naaldenberg, Nijhuis-van der Sanden, & van Schrojenstein Lantman-de Valk, 2016). Furthermore, stakeholders in care for people with ID point out that promoting physical activity requires continuous attention, especially in everyday life (Kuijken et al., 2018). Health education by mainly 'sending' information alone is therefore not sufficient; the dynamics of everyday life must also be considered (van Woerkum & Bouwman, 2014).

*Dream, discover, and do! Increasing physical activity in everyday life*, hereafter referred to as *DDD*, is a positive approach based on appreciative inquiry (AI) (Cooperrider, 2005; Cooperrider, Whitney, & Stavros, 2005), which includes the everyday group context in which people with ID live, work, and recreate. As awareness is an important step in behaviour change (de Vries et al., 2003), *DDD* aims to increase awareness in people with ID and their daily caregivers about possible physical activities in everyday life and how to incorporate activities into everyday routines. *DDD* includes a group session based on *listening* to people with ID, making the autonomy of people with ID an important element of the approach. People with ID share preferences and ideas for being more physically active in everyday life. Using the existing group context stimulates both positive example-setting by group members and social interaction in physical activity, making it easier to incorporate new physically active habits into the group members' everyday life (Bossink, van der Putten, & Vlaskamp, 2017; Heller, Fisher, Marks, & Hsieh, 2014; Kuijken et al., 2016; van Schijndel-Speet, Evenhuis, van Wijck, & Echteld, 2014). This feasibility study assesses the research question: Can *DDD* work and is it feasible to implement and evaluate?

## 6.2 Methods

### 6.2.1 Design

This feasibility study used a mixed-methods pre-post-test design with baseline measurement and post-test after 2.5 to 4 weeks. To assess whether *DDD* can work and is feasible to implement and evaluate, feasibility objectives as defined by Orsmond and Cohn (2015) were used (Table 6.1).

### 6.2.2 Participants

Participants were purposively sampled from eight service providers that provide residential care to people with ID. Inclusion criteria were: age  $\geq 18$  years; being able to provide informed consent; being able to participate in a group meeting on physical activity; and having a mild to moderate ID. Dependence on a wheelchair was an exclusion criterion. We intended to include four to five residential groups of people with ID, each consisting of 10–12 persons with ID (40–60 persons with ID in total) and at least one daily care professional and one physiotherapist per group.

### 6.2.3 Study Procedure

The accredited Medical Research Ethics Committee (MREC) of the Arnhem-Nijmegen region approved the study (registration number 2016-2737). After receiving easy-to-read information on the content and procedure of the study and stating their interest to an independent contact person, group homes and physiotherapists were contacted by the first author. To obtain informed consent, the researcher talked the participant with ID through the procedures, after which the participant filled out a checklist to see whether he/she correctly understood the study to which he/she would consent. In the event of any inconsistencies, the researcher again explained the procedure until this was clear to the participant.

The general procedure is illustrated in Figure 6.2. The pre-test, the group session, and the post-test were scheduled with help from the daily caregivers in each group home. At post-test, all participants received a pedometer to thank them for participating. With permission, the interview at pre- and post-test was recorded digitally for backup and reference.

### 6.2.4 Approach

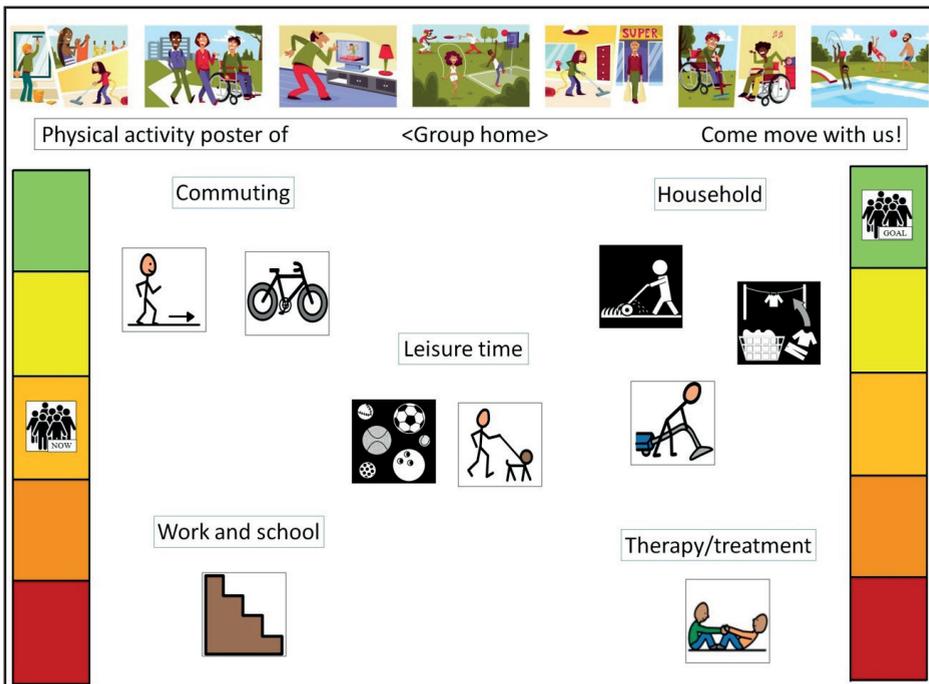
*DDD* consisted of three elements: 1) a group session in which a physical activity poster was filled out, 2) an individual user schedule, and 3) an intermediate evaluation of the use of the poster.

Each group participated in a 90-minute group session during which they filled out a physical activity poster. The sessions were moderated by the first author and took place at the group home. Each participant introduced him/herself with a favourite physical activity that was placed on the poster using pictograms and sorted into five categories: 1) commuting activities, 2) activities at work and school, 3) household activities, 4) leisure-time activities, and 5) activities during therapy/treatment. Next, the current level of physical activity of each group was determined by sticking a group pictogram on a coloured vertical ladder (ranging from red – not very active – to green – very active) on

the left side of the poster. The group discussed where they would like their group level of activity to move towards and placed a pictogram on the ladder on the right side of the poster. The group discussion was used to explore all possible kinds of physical activities in everyday life to climb the ladder, moving from their level of physical activity *now* to the level they *desired to have*. These ideas were placed in the middle of the poster in pictures, pictograms, or photographs. An example of the poster is included in Figure 6.1. The attending daily caregivers and physiotherapists were asked to take a listening role. At the end of the group session, the participants chose a central place on the wall in the group home to hang the poster. The pilot test resulted in removal of the category *activities during therapy/treatment* from the poster, as this category was considered not to be part of everyday life.

For each participant, an individual user schedule was drawn up, consisting of the days of the week on which participants could select one *extra* physical activity per day. The user schedule served as an individual reminder to use the poster to keep track of the extra physical activities undertaken by a participant and as a motivation.

Daily caregivers were instructed to conduct an intermediate evaluation one week after the group session, discussing the use of the poster with the help of the following questions: What do you think of the poster? What activities on the poster did you do last week? Which activities were easy to do? Which activities didn't you do? Which activities were difficult to do? How can we make these activities easier to do? The daily caregiver reported back to the first author by e-mail and included a photo of the poster to record any changes made to it.



**Figure 6.1** Example of physical activity poster

### 6.2.5 Measures

Table 6.1 provides an overview of the measures used per element of the research question and corresponding feasibility objectives (Orsmond & Cohn, 2015). Each of these measures is described below.

#### 6.2.5.1 Measures used to answer Q1: Can DDD work?

To answer Q1, structured questionnaires and accelerometers were used at T0 and T1. The questionnaires are available upon request.

Awareness of possibilities to be physically active in everyday life was assessed at T0 and T1 by asking all participants to mention as many ways as possible to be physically active in everyday life. Answers were categorized as: commuting activities, activities at work and school, household activities, and leisure-time activities (Wendel-Vos, Schuit, Saris, & Kromhout, 2003). This question was also used to provide context for participants with ID for the questions on self-reported level of physical activity.

**Table 6.1** Measures used and corresponding feasibility objectives

Element of research question	Feasibility objective <sup>2</sup>	Used measures	Type of data	Resources of information
Q1. Can DDD work?	Preliminary evaluation of participant responses to DDD	Structured questionnaire	Quantitative and qualitative	People with ID, daily caregivers, physiotherapists People with ID
		Accelerometers	Quantitative	
Q2. Is the implementation of DDD feasible?	Evaluation of acceptability and suitability of DDD	Structured questionnaire	Quantitative and qualitative	People with ID, daily caregivers, physiotherapists
	Evaluation of resources and ability to manage and implement DDD	Recurring reflections	Qualitative	Research team
Q3. Is the evaluation of DDD feasible?	Evaluation of recruitment capability	Recurring reflections	Qualitative	Research team
	Evaluation of resources and ability to manage and implement the study	Recurring reflections	Qualitative	Research team
	Evaluation of acceptability and suitability of the study procedures and outcome measures used	Structured questionnaire Recurring reflections	Quantitative and qualitative Qualitative	People with ID Research team

Subsequently, at T0 and T1, participants with ID answered questions on self-reported level of physical activity and self-reported health, both assessed by means of a coloured, vertical ladder, as used on the poster (Figure 6.1) (Kuijken et al., 2016). Participants filled out four ladders: two representing their current level of physical activity and health, and two representing their desired level of physical activity and health. Their physical activity score at T1 minus T0 was used as a subjective measure of difference in physical activity. Lastly, at T1, all participants answered open-ended questions on the perceived benefits of *DDD*.

Difference in actual activity was measured by accelerometers. All participants with ID were invited to wear accelerometers for four days at both baseline (T0) and approximately three weeks after the group session (T1). Actigraph wGT3X-BT accelerometers (Actigraph, Pensacola, FL, USA) were chosen for this study (Melville et al., 2017). They were worn at the hip, attached to a belt worn round the waist. Instructions were given to wear the accelerometer during all waking hours, except when showering, bathing, or swimming. Group homes were contacted by telephone every morning to check on the use of the accelerometers. The accelerometers sampled the acceleration in three planes at 30 Hertz with low-frequency extension enabled (user determined). This allows for measuring actigraphy data for people who move slowly or take very light steps. Activity intensity was measured by recording activity over 15-s intervals (epochs), with activity counts of four consecutive epochs summed to give activity counts per minute (cpm). In addition, number of steps per day was recorded.

#### 6.2.5.2 Measures used to answer Q2: Is the implementation of *DDD* feasible?

To answer Q2, structured questionnaires and recurring reflections among the research team were used.

At T1, people with ID answered open-ended and closed questions regarding their opinion on different elements of *DDD*. For this, an easy-read questionnaire with visual aids, such as a picture of the poster, was constructed together with co-researchers with ID. Daily caregivers and physiotherapists filled out open-ended and closed questions on the acceptability and suitability of the different elements of *DDD*, its implementation, and risks involved.

Before, during, and after data collection, the research team recurrently reflected on several aspects of feasibility. To answer Q2, resources and *DDD* management were assessed by looking at the administrative capacity, expertise, skills, space, and time of the research team to conduct *DDD*; whether *DDD* can be conducted in an ethical manner and within the designated budget; and whether the technology and equipment is sufficient to implement *DDD*.

#### 6.2.5.3 Measures used to answer Q3: Is the evaluation of *DDD* feasible?

To answer Q3, structured questionnaires and recurring reflections among the research team were used. At T1, by means of open-ended and closed questions, people with ID were asked their opinion on the questionnaire questions and the use of the accelerometer. In the recurring research reflections, recruitment capability, resources to implement the

study, and the acceptability and suitability of the procedures and outcome measures were discussed.

### 6.2.6 Data Analyses

Analyses were performed using SPSS version 22.0 (quantitative data) and ATLAS.ti software 7.1.4 (qualitative data).

For *self-reported physical activity*, the score on the coloured ladders was translated into a score of 0–100 (0 = the lower, red end of the ladder and 100 = the upper, green end of the ladder). Mean, standard deviation, difference score between T0 and T1, and the 95% confidence interval of the difference score were calculated. For the mentioned number of possibilities to be physically active, the mean number of each respondent group's physical activity possibilities at T0 and T1 was calculated per activity category. The answers to the open-ended questions on the structured questionnaires were summarized and described descriptively.

In keeping with guidelines on the validity of accelerometer data, the minimum data requirement for the accelerometers was set at six hours of data on at least three days (Tudor-Locke et al., 2005). If this requirement was not met, the accelerometer data were not included in the analysis. Based on recommendations from previous studies (Freedson, Melanson, & Sirard, 1998; Melville et al., 2017), three categories of activity intensity were defined:

- Sedentary behaviour 0–499 cpm
- Light-intensity activity 500–1,951 cpm
- Moderate to vigorous-intensity activity  $\geq 1,952$  cpm.

Mean time (minutes) per day spent on each level of activity was calculated. Mean, standard deviation, difference score between T0 and T1, and the 95% confidence interval of the difference score were analysed descriptively for:

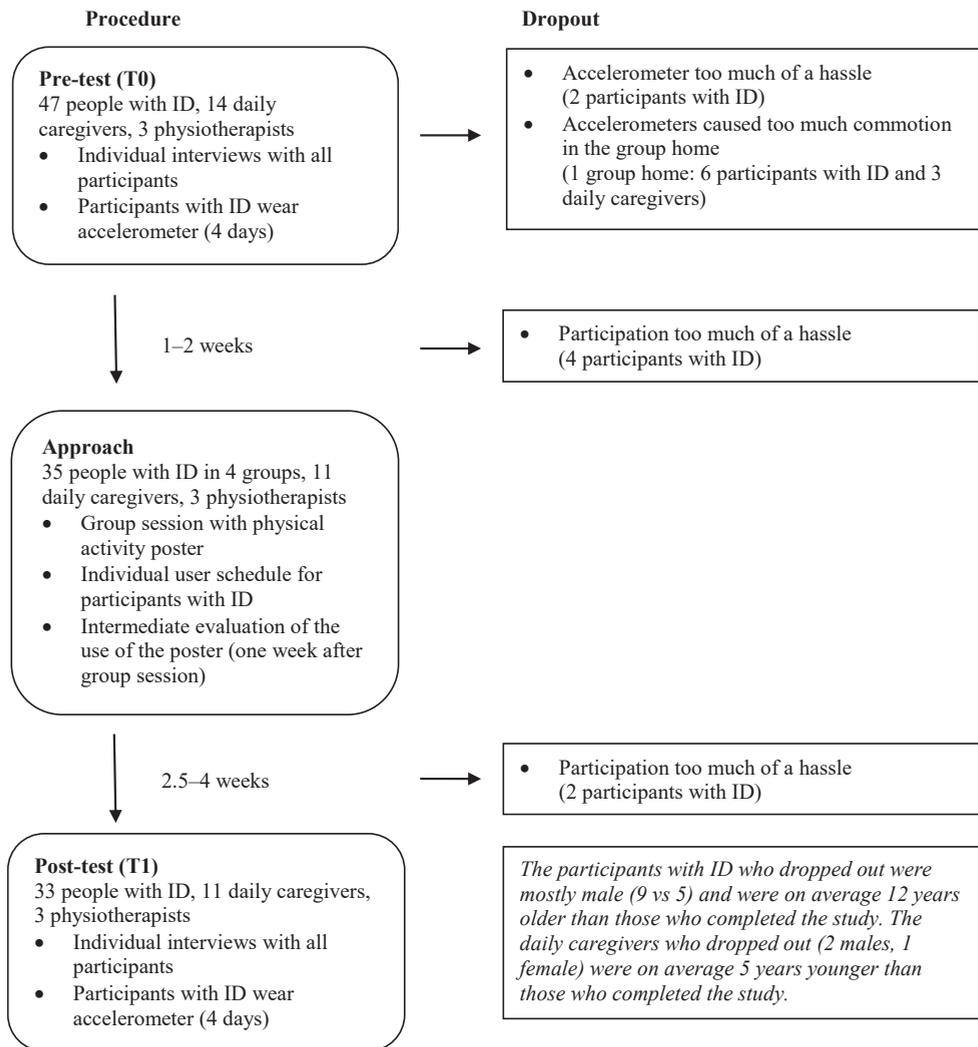
- number of steps
- mean time in minutes per day spent sedentarily
- mean time in minutes per day spent in light-intensity physical activity
- mean time in minutes per day spent in moderate to vigorous-intensity physical activity.

To answer Q2 and Q3, the answers to the questions on the structured questionnaires and the results from the recurring reflections among the research team were summarized and described descriptively.

### 6.3. Results

#### 6.3.1 Participants

In total, five people homes, 47 people with ID, 20 daily caregivers, and three physiotherapists participated in the study. Two wheelchair-dependent people with ID were included as they were very eager to participate. The participants with ID (20 males, 27 females) were on average 46 years old and lived independently without roommates and with support at home (n=13) or in a group home in a neighbourhood (n=34). The daily caregivers and physiotherapists (5 males, 18 females) were on average 44 years old. Over the course of the study, 14 people with ID and three daily caregivers dropped out of the study (timing and reason depicted in Figure 6.2). Six daily caregivers participated only in the group session.



**Figure 6.2** Overview of procedure and dropout

### 6.3.2 Q1 – Can DDD Work?

Reactions to *DDD* in the open-ended questions were positive, and participating daily caregivers and physiotherapists stated that *DDD* had benefits for the participating people with ID and the group home. In their experience, participation in *DDD* led mostly to more awareness among people with ID and daily caregivers: awareness of possibilities to be physically active in everyday life, but also of the activities already undertaken and of the importance of physical activity. *DDD* motivated participants with ID to be more physically active, and participants motivated one another. Daily caregivers stated that people with ID took short walks more often, for example to the supermarket or the doctor. People with ID also talked about physical activity more frequently and were eager to try other physical activities. Because people with ID were invited to think about what they want and can do, they engaged in activities they liked. They needed quite some encouragement from daily caregivers – especially about wearing the accelerometer, which seemed to act as a reminder. Daily caregivers reported that participants with ID were preoccupied about how many steps they had taken already and checked whether other group members were also wearing the accelerometer.

Table 6.2 shows the mean and standard deviation of objectively measured physical activity and sedentary behaviour (accelerometers) and self-reported physical activity (ladders), the corresponding difference scores, and the 95% confidence interval of the difference score. At T0, a relatively high level of physical activity was already measured by the accelerometers, and the difference at T1 was minimal. Time spent sedentarily decreased on average by 23 minutes per day. Self-reported physical activity (Physical activity ladder (now)), increased about 8 points on a scale of 0 to 100 (95% confidence interval 0.1; 15.7) to 74, almost reaching the goal of 75 set at T0.

**Table 6.2** Objectively and subjectively measured physical activity and sedentary behaviour

Outcome variable	T0 Mean (SD)	T1 Mean (SD)	Difference score	95% CI of difference score
Steps per day	13381.4 (3602.5)	13649.9 (4101.7)	268.5	-792.7; 1329.7
Time spent sedentarily (minutes per day)	463.8 (97.0)	440.4 (103.3)	-23.4	-55.3; 8.6
Time spent doing light-intensity PA (minutes per day)	230.2 (51.3)	242.3 (60.1)	12.1	-5.3; 29.5
Time spent doing moderate to vigorous PA (minutes per day)	92.5 (48.7)	91.7 (50.0)	-.8	-10.7; 9.0
Physical activity ladder (now)	66.4 (26.0)	74.3 (18.5)	7.9	0.1; 15.7
Physical activity ladder (goal)	75.7 (19.4)	80.9 (18.6)	5.2	-2.0; 12.4

Table 6.3 shows the mean number of physical activity possibilities mentioned by people with ID, daily caregivers, and physiotherapists at T0 and T1 per activity category. The difference between the number of possibilities mentioned at T0 and T1 is minimal for all respondent groups. Physiotherapists overall mentioned more activities than daily

caregivers and participants with ID, but mentioned fewer activities at T1 compared with T0. Both people with ID and daily caregivers mentioned more household activities at T1, with the difference being larger for daily caregivers, who mentioned almost twice as many activities in and around the house at T1.

**Table 6.3** Awareness of possibilities to be physically active in everyday life

Activity category	People with ID		Daily caregivers		Physiotherapists	
	T0 Mean	T1 Mean	T0 Mean	T1 Mean	T0 Mean	T1 Mean
Commuting activities	0.6	0.5	0.8	1.1	1.7	2.0
Work and school	0.2	0.2	0.6	0.2	0.3	0.3
Household activities	2.0	2.7	4.0	7.6	10.0	7.3
Leisure-time activities	4.1	4.9	11.5	12.8	11.3	9.0
Total	6.9	8.2	16.9	18.6	23.3	18.7

### 6.3.3 Q2 – Is the Implementation of DDD Feasible?

#### 6.3.3.1 Evaluation of acceptability and suitability of DDD

Participants with ID were positive about the group meeting and the poster. The professionals considered the group meeting, poster, individual user schedule, intermediate evaluation, and gift pedometer to be essential elements. All elements, with the exception of the intermediate evaluation, were considered useful. The group meeting was mostly described as being fun, good, and interesting by people with ID, with few participants finding the group meeting either too difficult or too much. The poster was well used by the participants with ID, and they described it as beautiful, good, and fun. Those who had not used it had for example forgotten about it or did not use it because it was hanging at an inconvenient place. Frequently mentioned easy-to-do activities took place in and around the house, such as doing laundry, cleaning, taking out garbage, grocery shopping, walking, and exercising on the Wii and the home trainer. Activities that were difficult to do were characterized by practical barriers, for example *not having a dog to walk* and *it being too cold outside to wash the car*, or by personal barriers, such as *not being able to vacuum due to being wheelchair dependent*, *not being able to iron because it takes too much energy*, or *not being motivated to do something such as swimming or walking up and down stairs*. For people with ID, the purpose of the intermediate evaluation was not always clear, and it did not lead to increased use of the poster.

DDD fitted quite well in existing routines according to the professionals. There was enough room for adaptation of DDD to the group home, the needs of professionals, and the people with ID for whom they care. Participation involved no risks, and the instructions included in DDD were clear. DDD did not always receive enough attention from the team during implementation, despite being written down in the team instructions. Reasons were, e.g., that not all team members were present when the instructions were given, not all daily caregivers instructed participants to use DDD, and daily caregivers needed a motivation to continuously support physical activity. About half of the participating

physiotherapists and daily caregivers felt supported by colleagues and their manager in implementing the programme. Participants felt less supported by other disciplines, such as the ID physician and the behavioural therapist. Most participating professionals felt responsible for implementing *DDD* and felt they possessed enough skills and knowledge for successful implementation.

The majority of the participants with ID expressed the intention to keep using the poster after the project ended, as did the majority of the professionals, who also stated that they would recommend *DDD*. Awareness of current lifestyles in the group and motivation to continuously support physical activity were mentioned as prerequisites by the professionals. Daily caregivers asked for more appropriate activities and ideas for exercising with people in wheelchairs, accessible facilities such as a gym and a swimming pool, and employment of a movement teacher. Other tips included emphasizing that physical activity is normal and that it should not be medicalized but rather built into everyday-life activities. Improvements could be made by having an individual poster per client for a better overview, involving family, prolonging the time that *DDD* is offered to the group homes, and elaborating on it more.

#### *6.3.3.2 Resources and ability to manage and implement DDD*

The research team discussed the resources and the ability to manage and implement *DDD*. To achieve the administrative capacity needed to conduct the approach, a research assistant was added to the research team who helped in preparing and conducting the group sessions. The first author possessed the expertise, skills, and time needed to conduct *DDD* and to instruct the daily caregivers on their role within *DDD*. The participating group homes provided the space needed for the implementation. *DDD* could be conducted in an ethical manner, as participation was voluntary, *DDD* did not include any invasive techniques, and when a person chose not to participate this did not influence the care he/she received. *DDD* itself was not costly and the materials needed were easily accessible: A0-size posters, printed pictograms, and a digital photo printer that could be linked to a smartphone for instant printing of photos taken during the group session.

### **6.3.4 Q3 – Is the Evaluation of *DDD* Feasible?**

#### *6.3.4.1 Recruitment capability*

All inclusion criteria were feasible and suitable. However, the inclusion criterion 'being able to provide informed consent' was found to be difficult to assess. The exclusion criterion 'being dependent on a wheelchair' was suspended so as not to exclude wheelchair-bound group home members who were eager to participate. Two participants in wheelchairs were included in the study and wore the accelerometer on their wrist, but their accelerometer data could not be included in the analysis.

Colleagues and local organizations were very willing to assist with recruitment but, in some cases, local agreement procedures delayed the start of the project. Reasons given for non-interest by people with ID were that participation was seen as too much of a hassle and they did not think that they needed to be more physically active.

DDD is relevant for the intended population, as eleven group homes of four different organizations showed interest in participating in the study. Six of these groups did not enter the study for the following reasons: potential participants did not meet the inclusion criteria (two groups); only two or three people with ID living at the group home were interested in participating (two groups); daily caregivers were only interested in other ways to promote physical activity (one group); and unknown (one group). In all five groups together, 60 people with ID stated their interest in participating.

#### 6.3.4.2 Resources and ability to manage and implement the study

The research team, including the research assistant, possessed the skills, space, and time needed to conduct the study. A statistician was consulted to discuss the appropriate analyses. The study could be conducted in an ethical manner, as there was no control group, no invasive evaluation techniques were used, and participation was voluntary. The only technology and equipment needed to conduct the study were the accelerometers, two digital voice recorders, and paper questionnaires, which were all easily accessible. Although the purchase of 24 accelerometers and the software needed to analyse the data was quite costly, the study could be conducted within the designated budget.

#### 6.3.4.3 Evaluation of acceptability and suitability of the study procedures and outcome measures

Overall, the majority of the participants with ID who completed the post-test stated that the questions on the structured questionnaire were clear and that the researchers explained everything calmly and clearly. For some participants, the question *In what ways can you be physically active in everyday life?* was too difficult. It was hard for them to think of several ways to be physically active, or the language was too difficult to understand. Regarding the questions with the ladders, asking them to score their *current* and *desired* level of physical activity and health, particularly the questions regarding their *desired* level were difficult to answer. It is difficult to think of what one desires; and one participant for example stated that she wished to be as healthy as she used to be, but she did not know how to score that on the ladder. Moreover, the use of the ladders for two different topics (physical activity and health) was confusing for participants with ID, leading to invalid answers on the health ladders that participants filled in after the physical activity ladders. Questions on demographic information, such as age and living arrangements, also contained many missing values and had to be checked with, and completed by, daily caregivers. Filling out the questionnaires face-to-face with people with ID, including the informed consent procedure, took about 20 minutes. Towards the end of these 20 minutes, several participants had difficulty keeping their attention on the questions.

Before the data collection started, the research team discussed the use of a translated and simplified version of the Sedentary Behavior Questionnaire (SBQ), which aims to measure the amount of time spent on nine different sedentary activities. In a study on the suitability and reliability of self-reported measures for people with ID, many missing and non-quantifiable answers were reported for the SBQ, and the question format was considered too difficult because it requires activities to be remembered over a week's time, awareness of time, and numeracy skills (Vlot-van Anrooij, Tobi, Hilgenkamp, Leusink, & Naaldenberg, 2018). The team therefore decided not to include this questionnaire.

Most participants with ID could put on and take off the belt with the accelerometer by themselves. When asked what they thought of wearing the accelerometer, overall participants reacted positively. They said that it was good and fun to do and that it did not bother them. Some even said that they wanted to wear it for a longer period of time and that from now on they were going to wear the pedometer they received as a gift. Some participants found it difficult to get used to wearing it and described it as a bit weird and not fun to do. It was difficult to remember to put it on in the morning, and they did not like asking help from a daily caregiver. Several participants would have liked to be able to see their step count on the accelerometer, which was not possible.

The optimal location of the accelerometer to measure sedentary behaviour is the hip (on a belt around the waist) (Actigraph, 2014); this was found to be challenging for measuring among people with ID. Several participants did not like the lump underneath their shirt or did not like it when the belt with the accelerometer moved upwards on their body. Despite clear instructions on paper and on the belt of the accelerometers themselves and daily reminders by phone, several times the accelerometer was put on upside down, thereby interfering with the measurement.

## 6.4 Discussion

This study assessed whether *DDD* can work and is feasible to implement and evaluate. The results indicate that the group approach has benefits for people with ID individually and for the group as a whole. It was feasible to implement *DDD* within group homes for people with ID, but some adjustments can be made to increase its effect and feasibility. Future evaluation studies should be sensitive to the complex context of health promotion for people with ID.

### 6.4.1 Can *DDD* Work?

Participating professionals reported that the approach led to more awareness among people with ID and daily caregivers on possibilities to be physically active in everyday life. The outcomes showed that the physical activity ideas especially concerned activities in and around the house, and awareness increased most in daily caregivers. Both professionals and people with ID reported more activity by people with ID at T1. Easy-to-do physical activities on the poster took place mostly in and around the house, such as doing laundry, cleaning, taking out garbage, grocery shopping, walking, and exercising on the Wii. In accordance with previous research (Bodde & Seo, 2009; Messent, Cooke, & Long, 1999; Steenbergen et al., 2017; Temple & Walkley, 2007), these results underline the merit of the *DDD* focus on physical activities in everyday life and the need to incorporate health behaviour within the daily routine schedule of activities.

Reactions to the group meeting, poster, and individual user schedule were positive, and the poster was well used by participants with ID, especially when the daily caregivers reminded them individually to use the poster. This dependence on others and the need for an individualized supportive context has been described in previous research (Bergstrom, Elinder, & Wihlman, 2014; Frey, Buchanan, & Rosser Sandt, 2005; Kuijken et al., 2016; Temple, 2009). In *DDD*, the individual user schedule can be used for this purpose,

for example by incorporating a short (five-minute) daily slot in which a caregiver looks together with each group member at the individual user schedule. Providing pictograms or other (visual) cues to specify these goals is helpful. This daily feedback slot could replace the intermediate evaluation, which was the only element that participants considered not to be useful. Many participants with ID did not take part in the intermediate evaluation and those who had did not use the poster more afterwards.

#### 6.4.2 Feasibility of Implementation

Most professionals felt responsible for implementing *DDD*, thought they possessed enough skills and knowledge for implementation, and felt they could succeed in it. Even so, *DDD* did not receive enough attention from the team during implementation. This indicates that integrating *DDD* was not a priority within their routines and other tasks in the group home; this was also encountered in another physical activity health promotion programme for the group home setting (Dixon-Ibarra, Driver, Nery-Hurwit, & VanVolkenburg, 2018; Dixon-Ibarra, Driver, VanVolkenburg, & Humphries, 2016). Integrating the promotion of health behaviour in caregivers' daily routines is not possible without support from the organization through policy and management. The lack of policies on physical activity promotion in residential and day activity care is a known barrier to physical activity (Bodde & Seo, 2009; Messent et al., 1999; Temple, 2007). Although *DDD* does not interfere at policy level, this feasibility study indicates that policy-level changes are essential prerequisites. Important next steps are education of daily caregivers and allocation of resources to help daily caregivers and people with ID to increase physical activity.

#### 6.4.3 Feasibility of Evaluation

Co-researchers with ID were involved in the formulation of the questions, and data collection took only 20 minutes. Participants with ID found several questions too difficult to answer, and the data collection might have taken too long for them. It is hard to design appropriate questionnaires for people with ID (Melville et al., 2015), and collaboration with co-researchers is advisable (Frankena et al., 2016). An open-ended question asking participants to come up with as many answers as they can, such as used in the current study, might be too difficult for people with ID. Posing this question at both the pre- and the post-test resulted in invalid answers among the physiotherapists as well, who were reluctant to list for a second time all possible ways to be physically active.

The use of the ladder for two different topics (i.e. activity and health) and the lack of a clear introduction to the second topic could explain why the questions on subjective health were difficult for participants to answer, although this questioning technique was successfully used regarding subjective health in a previous study of people with ID (Kuijken et al., 2016).

Accelerometers have been previously used to study physical activity and sedentary behaviour in studies involving adults with ID and proved to be well utilized by this group (Melville et al., 2015; Nordstrom, Hansen, Paus, & Kolset, 2013; Spanos, Hankey, & Melville, 2016). In the current study, several challenges were encountered in the use of accelerometers. Dropout resulted mainly from the involvement of accelerometers, which were seen as a hassle. The use of the low-frequency extension, which allows for measuring

actigraphy data for people who move slowly or take very light steps, appeared to be unnecessary for the participants in this study and might have led to an overestimation of the number of steps taken and the time spent doing moderate to vigorous-intensity physical activity. Compared with the results of other studies using accelerometers to measure physical activity among people with ID (Chow, Choi, & Huang, 2018; Melville et al., 2015), our study revealed that the participants took more steps and spent more time doing moderate to vigorous-intensity physical activity at baseline, and time spent sedentarily and doing light-intensity physical activity was comparable. Given the reasons for dropout and the burden of wearing the accelerometers, in hindsight it was a good decision to reduce the number of wearing days from the recommended seven days (Tudor-Locke et al., 2005) to four days. With four days, the chances of collecting at least three days of valid data are quite high, and participants are more likely to complete the pre- and the post-test.

The subjective increase in physical activity reported by both professionals and people with ID was difficult to objectify by means of the accelerometers. People with ID reported that wearing the accelerometers stimulated them to be more active; this indicates that pedometers that display the number of steps taken could be used as a motivation for this group. Although the changes are in the expected direction with an increase in the number of steps and a shift from time spent sedentarily to doing light-intensity physical activity, these changes were small. This could be because the *DDD* effect was too small, the use of the low-frequency extension resulted in high scores on steps taken and time spent doing moderate to vigorous-intensity physical activity at pre-test, or the use of accelerometers was too simple a way of evaluating effect in the complex system of a group home. Many different stakeholders and contextual factors influence the success of an initiative in such complex settings (Naaldenberg et al., 2009). Other outcome measures, such as norms and values, dynamics in and habits of the group, or participatory and reflexive evaluation designs (Smith & Petticrew, 2010) might be more appropriate or complementary for evaluating the effect of an approach that aims to change behaviour in the complex system of a group home for people with ID.

#### **6.4.4 Conclusions and Future Directions**

This study indicates that *DDD* is feasible to implement and has benefits for people with ID individually and for the group home as a whole. It underlines the merit of the *DDD* focus on physical activities in everyday life and the need to incorporate health behaviour within daily routines. Participants were more aware of possibilities to be physically active in everyday life at post-test, especially activities in and around the house. Self-reported physical activity increased, and professionals reported that people with ID were more active and motivated one another. The current study is not, however, designed and powered to measure effect. No clear inferences regarding effectiveness or generalizability can be made. The study indicates that *DDD* has promise and that further research into the effect of *DDD*, using a trial with control groups and longer follow-up, is desirable. Overall, it was feasible to implement *DDD*,

The current study showed that people with ID found it challenging to use questionnaires and accelerometers. Future research, including an effect evaluation of *DDD*, should 1)

take into account the limited timespan over which people with ID can focus on answering questions; 2) be aware of questionnaires that are not validated for people with ID; 3) avoid the repeated use of measures for different purposes, as this might be confusing; 4) be careful with the use of low-frequency extension for the accelerometers; and 5) consider shortening the wearing time of the accelerometer from seven to four days.

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## CHAPTER 7

# General discussion



This thesis aimed to gain a broad perspective on the current situation in health promotion for people with ID and to identify the actions that can help to better tailor health promotion initiatives to the needs, interests, and capabilities of people with ID. It takes into account the context of current health promotion efforts in both literature and everyday-life practice and the perspectives of a large variety of stakeholders, including people with ID themselves. These insights were used to co-create such a specifically tailored health promotion approach. Testing aspects of the feasibility of this approach provided valuable information on the implementation and evaluation of health promotion approaches in everyday-life settings.

This research included the following three areas:

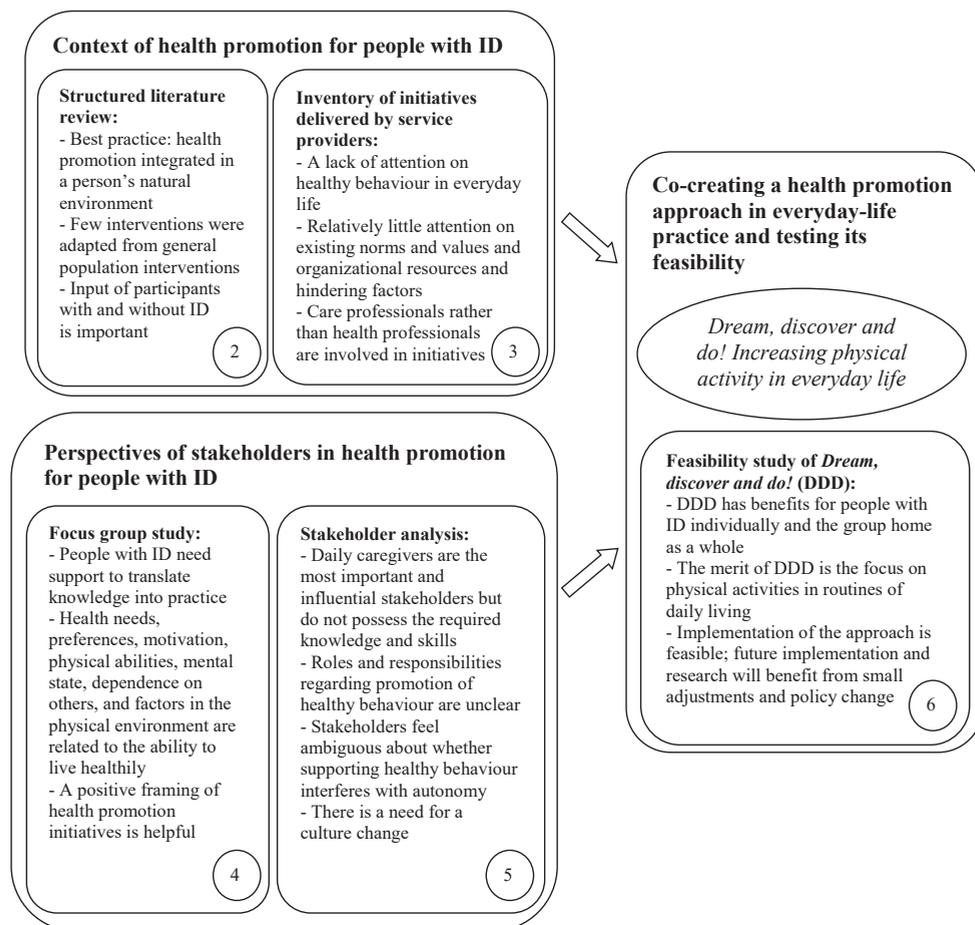
1. the context of existing health promotion initiatives for people with ID
2. the views and perspectives of different stakeholders, including people with ID
3. co-creating a health promotion approach in everyday-life practice and testing its feasibility.

The findings are summarized and reflected on in this chapter. Subsequently, the methodological considerations and recommendations for future research are addressed, followed by recommendations for health promotion practice.

## 7.1 Summary of main findings

Figure 7.1 provides an overview of the main findings per chapter and the way in which results contributed to the co-creation of *Dream, discover and do! Increasing physical activity in everyday life* (DDD). A structured literature review of published health promotion interventions for people with ID (Chapter 2) and an inventory of everyday-life initiatives delivered by service providers (Chapter 3) were used to study the context of health promotion for people with ID. A focus group study among people with mild to moderate ID (Chapter 4) and a stakeholder analysis (Chapter 5) were used to provide insight into perspectives of various stakeholders in health promotion for people with ID. The results of Chapters 2–5 informed the co-creation of DDD, of which aspects of feasibility were tested in Chapter 6 (chapter number is indicated within a circle in each case).

Throughout this thesis, the socio-ecological model (SEM) (McLeroy, Bibeau, Steckler, & Glanz, 1988) was used to obtain an overview of factors influencing health behaviour across multiple environmental levels, while emphasizing the central role of the person with ID. Below, the findings in this thesis are related to the five levels of the SEM and to the resulting development of DDD.



**Figure 7.1** Summary of main findings in Chapters 2–6

### 7.1.1 Individual level

The results of the focus groups in Chapter 4 indicate that people with ID have a good understanding of what being healthy and keeping themselves healthy entails; they can identify (un)healthy foods, are aware of the benefits of exercising regularly, cooking healthily, and taking enough rest, and know the potential harms of alcohol and smoking. When translating these concepts into behaviours, however, they are aware that they need support from others. Merely knowing what is (un)healthy is not sufficient to be able to live healthily; people with ID emphasize that some autonomy is important for them to make choices, and they prefer a personalized approach to empowering them to make healthy lifestyle choices. They also prefer a positive framing, focusing on what *is* possible, instead of what *is not* possible. Chapter 5 showed that other stakeholders have a rather negative mindset when it comes to promoting healthy behaviour and attribute barriers mainly to

the person with ID, e.g., dependence/need for support, cognitive ability, motivation, and physical disabilities.

### **7.1.2 Interpersonal level**

Other stakeholders in this thesis confirm the need to support a healthy lifestyle for people with ID and are willing to support healthy behaviour, but who is responsible for this support and how this could take shape is unclear (Chapter 5). Besides the barriers attributed to people with ID themselves, another barrier perceived by stakeholders is the fear of violating the autonomy of people with ID.

In Chapter 5, daily caregivers were identified as the most important stakeholders. Although they are in a good position to support people with ID in everyday life, daily caregivers have challenging, multi-faceted roles. According to multiple stakeholders in this study, supporting a healthy lifestyle is not prioritized within these roles, or in their education. They are hindered not only by a lack of knowledge and skills, but also by the absence of a shared vision among service providers and a united system in which all stakeholders' roles and responsibilities regarding supporting a healthy lifestyle are clearly described. Health professionals such as physiotherapists and dieticians, who do have the necessary knowledge and skills to activate people and support good dietary habits, focus mainly on curative therapy and are only marginally involved in the prevention of health problems by means of health promotion (Chapters 3 and 5).

### **7.1.3 Organizational level**

Organizational resources and hindering factors for health promotion for people with ID, such as time, money, and information for employees dedicated to health promotion initiatives, received relatively little attention in the initiatives identified in Chapter 3, as also confirmed by the stakeholders in Chapter 5. Furthermore, stakeholders voiced the requirement for new social norms and an accompanying change towards an organizational culture with a greater focus on health promotion in the care for people with ID.

### **7.1.4 Physical environment and community level**

The literature study (Chapter 2) identified best practices to facilitate a healthy lifestyle for people with ID, with important points such as integrating health promotion in a person's natural, everyday-life environment: the place where they live, work, and engage in recreational activities. The stakeholders in Chapter 5 also pointed out that it would be helpful if living healthily was a normal routine in everyday life. However, an exploration of 47 identified initiatives in practice (Chapter 3) showed that most initiatives were individually oriented and consisted of stand-alone activities, indicating a lack of attention on healthy behaviour in everyday routines of people with ID.

The study in Chapter 3 revealed that health promotion initiatives paid relatively little attention to existing group norms and values related to a healthy lifestyle. As Chapter 4 indicated that group norms and values with regard to healthy living are an important motivation for people with ID, it is essential to pay attention to existing norms and values among peers and professionals in these groups.

### **7.1.5 Public policy level**

Of the 25 studies included in the literature review in Chapter 2, only three used interventions adapted from general population interventions, indicating that valuable links and partnerships with mainstream providers of health promotion and sports activities are hardly utilized.

### **7.1.6 The co-created health promotion approach**

Although the SEM was very useful for getting an overview of the opportunities and pitfalls of health promotion for this group across different environmental levels and for helping to incorporate these findings into a co-created health promotion approach, focusing on individual factors on each level has a pitfall too. It can lead to a narrowed view in which the focus is too much on one SEM level. When focusing on changing one level, or even one single factor in a level, it is important to recognize and act upon the fact that this change brings about change in other factors and levels as well. To prevent researchers and stakeholders from losing sight of the bigger picture, we opt for also using a settings approach to health promotion (Paton, Sengupta, & Hassan, 2005).

The above-described results relating to the SEM levels were incorporated into DDD. The approach was developed to increase awareness about possible physical activities in everyday life and to help incorporate activities into everyday-life routines, including, e.g., activities provided by the municipality for the general population. DDD is based on listening to people with ID instead of sending information, thereby paying attention to their preferences, motivation, and physical abilities. In this way, the autonomy of people with ID is respected. DDD provides a practical tool for the network of people with ID, in which the desired support is made explicit. It is a positive approach that instructs daily caregivers to focus on, and put into practice, physical activities that are possible, despite individual barriers.

In DDD, daily caregivers play an important role supporting people with ID to be physically active. Physiotherapists are involved as well, to support both people with ID and daily caregivers. By involving existing groups in a group approach, their group norms and values regarding a healthy lifestyle are also targeted. DDD can help care providers for people with ID to reify their mission statements on promotion of a healthy lifestyle by providing a tool that takes little time and effort to implement and that can be easily integrated in existing everyday-life routines.

The DDD feasibility study (Chapter 6) showed that awareness increased among participants with ID and even more among daily caregivers, especially regarding household activities. It was feasible to implement DDD in the everyday-life routines in the group homes, and participants with ID found physical activities in and around the house the easiest to do, underlining the importance of integrating healthy behaviour in daily activities.

## **7.2 Discussion of main findings**

Comparison of the results of the various studies in this thesis identifies three important preconditions for successful health promotion for people with ID:

1. an everyday-life perspective in health promotion;
2. a supportive environment; and
3. facilitation of change in health promotion for people with ID.

### 7.2.1 An everyday-life perspective in health promotion

This thesis highlighted the importance of taking into account the complex realities of everyday living. It confirms the results of another study involving perspectives of people with ID themselves and of other stakeholders on health-related lifestyle choices (Young, Chesson, & Wilson, 2007). In current lifestyle approaches for people with ID however, little attention is paid to integrating healthy behaviour into everyday routines of people with ID (Steenbergen, Van der Schans, Van Wijck, De Jong, & Waninge, 2017). As people with ID know quite well what living healthily entails and are aware of the benefits of a healthy lifestyle, but request support to put this into practice in everyday-life reality (Caton et al., 2012; Young et al., 2007), taking an everyday-life perspective can help to bridge this gap between good intentions and unhealthy behaviour (van Woerkum & Bouwman, 2014). This perspective is based on the assumption that healthy behaviour consists of a chain of routines embedded in social practices, which require social changes.

An example of a chain of these routines related to healthy eating is: planning to buy food (or not), selecting food in the supermarket, planning when and what to eat in which proportions, preparing the meal, and deciding to finish your plate (or not). Similarly, increasing physical activity means changing routines around such things as going to and returning from work, gardening, household activities, shopping, and spending one's leisure time (van Woerkum & Bouwman, 2014). A practical example of taking an everyday-life perspective on increasing physical activity could be to incorporate the current norm of at least 150 minutes of moderate to vigorous activity per week (Commissie beweegrichtlijnen, 2017) in these everyday-life routines (van Woerkum & Bouwman, 2014). In the current research, people with ID pointed out several examples of how to increase physical activity by changing a chain of routines (Chapters 4 and 6): going to and returning from work by bike, or by using a bus stop a little further away from work and home so that you can walk the last part of your journeys; vacuuming the house; or walking to the shop to run errands. Consequently, increasing physical activity becomes more tangible and doable in everyday life; this will help people (with and without ID) to put good intentions into practice. These chains of routines have taken a central place in the further development of DDD for people with ID who live (semi)-independently with ambulatory support (Kuijken, 2018).

Changing individual health behaviour implies that the social system in which the person with ID lives, including the shared lifestyle and prevailing norms and values, must be changed as well (van Woerkum & Bouwman, 2014). Beyond standard solutions, tools can focus on a fit with the context in the everyday life of people with ID. For people with ID, everyday life in residential and day-activity settings often takes place in groups (Ras, Verbeek-Oudijk, & Eggink, 2013). Intervening at organizational and group level instead of at individual level benefits from modelling and social support, making it easier to change health behaviour and daily routines (Heller, Fisher, Marks, & Hsieh, 2014; van Schijndel-Speet, Evenhuis, van Wijck, & Echteld, 2014).

### 7.2.2 A supportive environment

The Ottawa Charter for Health Promotion already advocated in 1986 creating a supportive environment and the use of a settings approach for this, with a strong focus on everyday-life settings (World Health Organization, 1986). A settings approach uses initiatives focused on the context in which individuals live, work, and recreate, rather than solely attempting to change the individuals themselves (Paton et al., 2005). Creating a supportive environment by using a settings approach has been successfully applied in contexts other than health promotion for people with ID. Well-known examples are Healthy School projects, Healthy Universities, and Healthy Cities, all of which resulted in policy change, altered organizational structures, and community action to facilitate a healthy lifestyle (Mukoma & Flisher, 2004) (Mark Dooris, Doherty, Cawood, & Powell, 2012; Schwab et al., 2015).

In our research as well as in other studies, people with ID themselves confirmed that support from others, who empower them to make healthy lifestyle choices, is an important factor in this supportive environment (Bollard, 2017; Caton et al., 2012; Young et al., 2007). In this support, daily caregivers play an essential role: Chapter 5 identified them as the most important and influential stakeholders, and other studies underline the potential of daily caregivers to influence the health behaviours of people with ID (Leser, Pirie, Ferketich, Havercamp, & Wewers, 2018; Melville et al., 2009; O’Leary, Taggart, & Cousins, 2018; Young et al., 2007). The way in which daily caregivers can be facilitated to support a healthy lifestyle provides an example of the complexity of health promotion for people with ID and the usefulness of a settings approach in this.

In Chapter 5, the role of daily caregivers with regard to health promotion was shown to be both essential and challenging. At organizational level, it would be helpful to further prioritize the promotion of healthy behaviour as part of daily caregivers’ roles and responsibilities (Leser et al., 2018; Melville et al., 2009; O’Leary et al., 2018). Moreover, it is important for service providers to make these roles and responsibilities more explicit, as daily caregivers and other stakeholders reported that their roles and responsibilities regarding health promotion are unclear (Young et al., 2007). Furthermore, increasing the health-promoting capacity of service providers for people with ID goes beyond assigning and clarifying roles and responsibilities; staff, daily caregivers in particular, need resources and time to invest in promoting healthy behaviour, as well as proper training to increase their knowledge and skills to do so (Cardol, Rijken, & van Schroyen Lantman-de Valk, 2012; Caton et al., 2012; Leser et al., 2018; O’Leary et al., 2018; Sundblom, Bergstrom, & Ellinder, 2015; Young et al., 2007). Health promotion should therefore also be prioritized as part of the training given to daily caregivers. Strong health promotion policy and leadership is indispensable to ensure that professionals from all layers of the organization are committed to health promotion (Dixon-Ibarra, Driver, VanVolkenburg, & Humphries, 2016; Durlak & DuPre, 2008) and to ensure intervention fidelity and sustainable outcomes for participants (Humphries, Traci, & Seekins, 2009; van Schijndel-Speet et al., 2014).

The current lack of health-promoting capacity and inadequate staffing in service providers can restrict people with ID in their activities, food choices, and mobility, impacting their autonomy (Caton et al., 2012). On the other hand, daily caregivers in our and other research fear that, with their greater involvement in health-promoting activities, they will violate

the autonomy of people with ID (Leser et al., 2018; Young et al., 2007). This indicates that daily caregivers interpret autonomy as being free from interference, which is referred to as 'negative freedom' or 'negative autonomy' (Berlin, 1969). Therefore, in addition to the previously described organizational level changes that can help to support daily caregivers, on the interpersonal level daily caregivers can be encouraged to interpret and act upon autonomy as 'positive'. In positive autonomy, the emphasis is on empowering people with ID to take control of their own health behaviour, making autonomy compatible with the dependence of people with ID on their environment (Dekkers, 2001; Takala, 2007). In this view, daily caregivers are advised to focus on the type of support that can help to strengthen people with ID's autonomy, instead of on whether or not their interference violates the autonomy of people with ID (Benaroyo & Widdershoven, 2004).

This research adopted a positive framing towards creating a supportive environment, thereby focusing mainly on enforcing factors that facilitate a healthy lifestyle. However, if attention is not simultaneously paid to eliminating barriers detected at the different SEM levels, the supportive environment created may not reach its full potential. When someone for example wants to eat more fruit but finds it a lot of work and a messy job to peel and cut fruit (Chapter 4), simply providing them with fruit at home or at work will not lead to a higher fruit intake. The personal barrier must be removed, for example by providing them with tips on how to prepare fruit in a quick, less messy way, trying fruits that are less difficult to prepare, or helping them to prepare the fruit. Again, listening to the needs, interests, and capabilities of every individual is key; without this, in the study in Chapter 4, the true barrier to low fruit intake would not have been identified and the supportive environment would have been ineffective, with lots of available but uneaten fruit.

### 7.2.3 Facilitation of change in health promotion for people with ID

Taking an everyday-life perspective and using a settings approach can be useful in a complex setting such as health promotion for people with ID. To further facilitate change and do justice to this complexity, a systems approach such as the system failure framework may be useful, as it helps to identify current failures and facilitate the corresponding required changes (Klein Woolthuis, Lankhuizen, & Gilsing, 2005). In a complex system like the support system of people with ID, actors from different backgrounds share a collective goal, but also have different routines, norms, and values, as well as different reasons for being part of the system. Addressing system failures will make the actors in such a system more susceptible to change (Naaldenberg et al., 2009), thereby facilitating change.

Routines, norms, and values and the prevailing culture are examples of soft system failures (Klein Woolthuis et al., 2005) that could be addressed to facilitate health promotion for people with ID. Chapter 3 showed that current health promotion initiatives pay relatively little attention to existing group norms and values relating to a healthy lifestyle. Chapter 4, however, indicated that such group norms and values are an important motivation for people with ID to live healthily. Attention on norms and values is also an important part of the everyday-life perspective as described by van Woerkum and Bouwman (2014) (van Woerkum & Bouwman, 2014). The stakeholders in Chapter 5 voiced the urgency for *new* social norms and an accompanying change towards an organizational culture that has a greater focus on health promotion. O'Leary et al. (2018) also found that the promotion

of regular physical activity and a healthy diet for people with ID was not valued within the ethos of service providers for people with ID (O’Leary et al., 2018), limiting possible change in this setting. Daily caregivers go so far as to contend that *“they [daily caregivers] have rights themselves (e.g., being able to eat what they want), which should not be violated while they are working”* (Leser et al., 2018).

A different mindset among the actors caring for people with ID can also facilitate change. The stakeholders in the study in Chapter 5, as well as in other studies (Leser et al., 2018; Melville et al., 2009), had a rather negative mindset regarding the promotion of healthy behaviour and attributed barriers mainly to the person with ID. Even GPs have a negative mindset regarding the promotion of healthy behaviour for people with ID, questioning its value because of the complexity surrounding changing their lifestyle behaviour (Walmsley, Price, & Hoghton, 2011). This negative mindset runs against the request of people with ID for a supporting environment and a positive framing of health promotion efforts (Chapter 4), indicating the urgency for a culture change towards a more positive mindset of stakeholders in the support system of people with ID.

### **7.3 Methodological considerations**

A major strength of this thesis lies in the inclusion of perspectives of all relevant stakeholders in health promotion for people with ID. In mainstream health promotion research and the development of new initiatives, taking into account the views of those who will likely implement and benefit from the initiatives is considered indispensable (Bartholomew, Parcel, Kok, Gottlieb, & Fernández, 2011; Green & Kreuter, 2005). It ensures that attention is given to individual, interpersonal, and environmental factors that are important in planning, implementing, and evaluating health promotion initiatives. The importance of involving people with ID in health research has also been acknowledged (Frankena et al., 2018; Walmsley, Strnadova, & Johnson, 2018). In Chapter 4, the perspectives of people with ID themselves were extensively studied, as these are of great value for shaping initiatives to fit their needs, interests, and capabilities. In Chapter 5, a broad network analysis was performed around the person with ID, combining two steps: firstly, identifying all relevant stakeholders and, secondly, interviewing these stakeholders. This analysis provided a unique view of health promotion support from the network around people with ID and how participants in this network view their own roles and responsibilities in this.

However, including a large variety of stakeholders – including people with ID – in research also poses difficulties. As the research concerned a vulnerable group, i.e., people with ID, service providers sometimes required local ethical clearance apart from the clearance already obtained from the medical ethics committee, leading to a long delay in recruitment and subsequently the start of data collection. Another difficulty was experienced in meetings with the participatory planning group which included people both with and without ID. Participants without ID indicated that they found it difficult to deliberate with people with ID about the content and implementation of the research plans. This resulted in the use of wording that was too difficult and less attention on the input of people with ID. The researcher juggled between giving all participants an audience and reaching consensus on the topics discussed. For this purpose, at some points in the research it was

decided to split the meetings with the participatory planning group into one group of people with ID and one group of people without ID. In order to fully utilize the assets of all participants and the interaction in such a heterogeneous group, it would be valuable to use insights from research on inclusive health research (Frankena et al., 2018).

In this thesis, we confined ourselves to people with mild to moderate ID, as respondents with ID required a certain level of comprehension. For example, they had to be able to participate in group interviews and discuss concepts like healthy living. Given the differences in communicative functions between people with different levels of ID, research into health promotion for people with more severe ID requires a very different approach, which did not fall within the scope of this thesis. As the needs, interests, and capabilities of people with more severe ID might differ from those of people with mild to moderate ID, the results of this thesis might not be generalizable to the entire group of people with ID.

To appreciate the diversity in viewpoints, increase the validity of our results, and reduce researcher bias, several strategies were used. We utilized *methods and data source triangulation* as follows: in Chapter 2, a qualitative literature review of scientific literature was performed; in Chapter 3, a qualitative inventory of initiatives was compiled, using grey literature and stakeholder information; and to study opinions and experiences of various stakeholders including people with ID, in Chapters 4 and 5, semi-structured (group) interviews and, in Chapter 6, quantitative and qualitative methods were used. Furthermore, we used *researcher triangulation* in all chapters, and in Chapters 4 and 5 we used *participant checks* by providing a summary at the end of the interview and giving the participants the opportunity to confirm, correct, or add to this. We continued data collection and analyses in the interview studies (Chapters 4 and 5) until almost no new information came up in the interviews, indicating the *achievement of data saturation*. The *involvement of the participatory planning group* throughout our research was an extremely valuable link to everyday-life practice. It helped to shape our research, which drew on real questions from those involved with health promotion for people with ID, separate from the researchers' point-of-view.

In addition to the above-described strategies, the research team used *continuous reflection* to shape our subsequent research based on results of our previous studies. In Chapter 4, people with ID indicated that they preferred a positive framing of health promotion efforts, so in Chapters 5 and 6 we adopted an assets-based approach. Questions and data analyses focused mainly on what works well and on positive examples, facilitating open conversations. DDD, whose feasibility was tested in Chapter 6, was based on appreciative inquiry (AI) (Cooperrider, 2005; Cooperrider, Whitney, & Stavros, 2005). The positive AI cycle was adapted by letting people with ID *Dream* about how active they would like to be, helping them to *Discover* how they could do this in everyday life, and facilitating them to *Do* this in practice. The assets-based focus in the interviews and data analyses could have led to bias. However, as barriers to health promotion for people with ID were also discussed by the stakeholders and were included in the analyses, we assume that this bias was small.

In Chapter 6, accelerometers were used to quantify difference in actual activity of people with ID before and after participating in a health promotion approach. During this part of data collection, the complexity of real-world settings such as the everyday life of people with ID was hard to reduce to a daily step count. The qualitative evaluation in the same study provided the required context to appreciate the positive change in physical activity. Therefore, we would advise against the sole use of quantitative methods to evaluate programmes in complex settings.

## **7.4 Recommendations for future practice and research**

In the discussion of the main findings, three important preconditions of successful health promotion for people with ID were described. Below, an elaboration follows on the specific recommendations for *health promotion practice, policy, education of daily caregivers, and future research* that follow from taking an everyday-life perspective in health promotion, creating a supportive environment, and facilitating change in health promotion for people with ID.

### **7.4.1 Health promotion practice**

To empower people with ID to live healthily, it is recommended to use a systems approach to create a supportive environment – a healthy setting – in which healthy behaviour is positively framed and incorporated into everyday-life routines. This healthy setting facilitates the support of healthy behaviour on various environmental levels. One of the most important barriers to supporting healthy behaviour experienced by stakeholders – the fear of violating the autonomy of people with ID – is largely mitigated by a healthy setting. The majority of choices in a healthy setting are healthy choices, lessening the tension between making one's own choice and a healthy choice. It then comes down to empowering people with ID to take control of their own health behaviour by strengthening their autonomy: providing them with good examples of healthy behaviour by yourself and other stakeholders, helping them to focus on healthy behaviour that they can and like to do, encouraging them to do it together with others and to ask for support where desired.

### **7.4.2 Policy**

To acknowledge the importance of supporting a healthy lifestyle and to facilitate daily caregivers in doing so, it is recommended to change organizational structures in service providers for people with ID. A change in a complex system such as the care for people with ID requires attention on, and a change to, existing routines, structures, resources, and power relations (Naaldenberg et al., 2009). A clear organizational vision and mission that acknowledge health promotion as a key part of everyday-life support to people with ID, and a resulting lifestyle policy, can help to make these changes happen. In such a policy, it is advised to include at least the amount of time and money (resources) assigned to health promotion efforts, the use of health goals in personal support plans and specific role descriptions for different professionals (structures), and health promoting norms and values that are appreciated throughout the organization. This will help to prioritize health promotion in daily support and to secure the embedding of health promotion within the organizational structures of service providers for people with ID. Attention to norms

and values regarding (the promotion of) health behaviour in such a policy facilitates a change in organizational culture, and this makes daily caregivers and people with ID more susceptible to behaviour change.

### **7.4.3 Education of daily caregivers**

Daily caregivers play a key part in supporting people with ID to live healthily, but they currently cannot take on this role; their health promotion role is underestimated and not prioritized, and their capacities regarding supporting a healthy lifestyle are overestimated. To increase their capacities, it is advised to incorporate health promotion into the education of new daily caregivers and to provide current daily caregivers with on-the-job courses on health promotion. In these courses and in the daily practice of supporting healthy behaviour, collaboration with health professionals caring for people with ID, such as physiotherapists and dieticians, is desirable. It is also recommended to pay attention to adopting a positive mindset towards supporting healthy behaviour and to educate daily caregivers on what type of support contributes to strengthening autonomy in making lifestyle choices.

### **7.4.4 Future research**

This thesis identified the importance of a supportive environment that empowers people with ID to incorporate a healthy lifestyle into their everyday-life routines. Future research could adopt a settings approach to health promotion (Paton et al., 2005) to study the creation of healthy settings for people with ID that take into account the characteristics of the population, their specific support needs, their living environment, and the core business of the setting (M. Dooris, 2016). To appreciate the complexity of the setting – i.e., the everyday life of people with ID – it is recommended to include both qualitative and quantitative evaluations that complement each other in this research.

To unravel the important barrier to health promotion experienced by daily caregivers in the current research as well as in other studies (Leser et al., 2018; Young et al., 2007) in relation to violating the autonomy of people with ID, and possibly to find ways to overcome it, it might be helpful to study this further from an ethical point of view. Does currently practiced health promotion for people with ID indeed interfere with autonomy and in what way? From an ethical point of view, how can the social environment of people with ID be supported to strengthen the autonomy of people with ID in making healthy choices?

Although the research presented in this thesis is of limited generalizability to the entire group of people with ID because we confined ourselves to studying health promotion for people with mild to moderate ID, our research could act as a basis for research into health promotion for people with more severe ID. It is therefore recommended to study further the creation of a supportive environment to empower people with more severe ID to live healthily as well.

Future health promotion studies could also benefit from conducting inclusive health research, in which people with ID are included not only as study participants, but also as

co-researchers. The work of Frankena et al. (2018) provides researchers with guidelines for designing and conducting such research (Frankena et al., 2018).

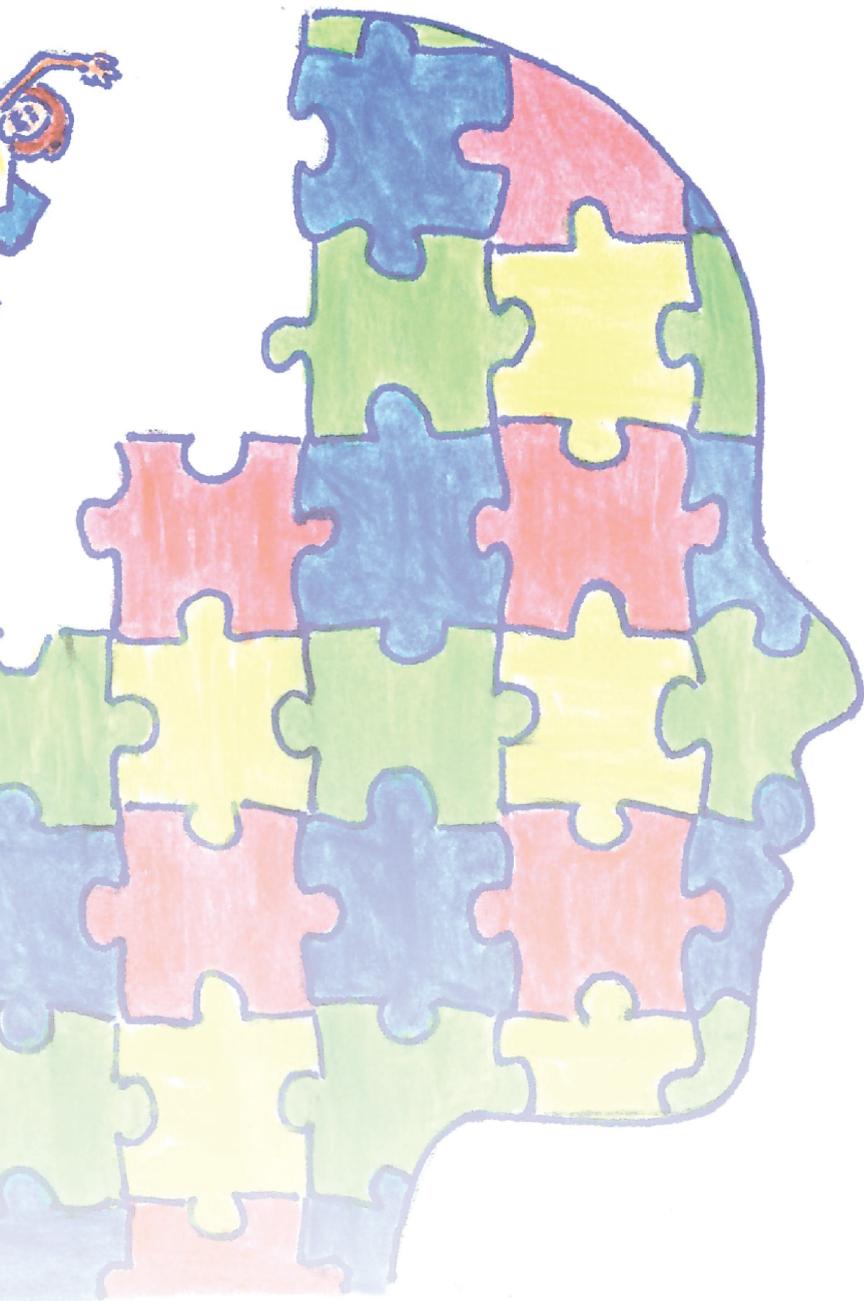
This thesis focused on the perspectives of people with ID and their network in the Netherlands only. It would be interesting to perform similar stakeholder analyses to identify key stakeholders and their perspectives on health promotion for people with ID in other countries also, thereby contributing to international generalizability.

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## CHAPTER 8

# Summary



A healthy lifestyle is important for one's health and wellbeing. This accounts for people with intellectual disabilities (ID) as well. They know what living healthily entails and why this is important. Engaging in health behaviour is, however, not self-evident, especially for people with ID. Many people with ID have unhealthy lifestyles characterized by extremely low levels of physical activity, high levels of sedentary behaviour and an unhealthy diet. Unsurprisingly, people with ID experience many lifestyle-related health problems, such as diabetes, cardiovascular disease and obesity. Effective and accessible health promotion could contribute to a healthier lifestyle for people with ID, thereby reducing and preventing the above-described health problems. However, researchers and governments worldwide have pointed out that the international focus on health promotion for people with ID is inadequate and requires more attention. This thesis aims to better tailor health promotion initiatives to the needs, interests, and capabilities of people with ID. To guide the analysis of stakeholders' perspectives on, and the context of, current health promotion for people with ID, the following research questions were formulated:

What can be learned from:

1. the context of existing health promotion initiatives for people with ID?
2. the views and perspectives of different stakeholders, including people with ID?
3. co-creating a health promotion approach in everyday-life practice and testing its feasibility?

## Chapter 1

Chapter 1 provides a general introduction to the topic of health promotion for people with intellectual disabilities. It discusses the health disadvantage of people with ID and the importance of the social and physical environment for promoting the health of this group. The objective and the research questions for this thesis are formulated from this perspective.

## Chapter 2

Chapter 2 describes a structured, qualitative literature review that looks at the key characteristics of, and best practices and challenges in, studies that report on health-promoting initiatives for people with ID (*research question 1*). Most of the 25 included studies were aimed at promoting physical activity (11) or a combination of physical activity and healthy nutrition (8). Many studies did not report how they had recruited their participants. Other challenges were related to the implementation of interventions, the selection of suitable measuring instruments and the suitability of used outcome measures. The results of this study suggest that there are still many inconsistencies and methodological weaknesses within this field of research, making it difficult to compare the results of studies. One of the main recommendations is that the views of people with ID and their network should be consulted more in health promotion research. It can be helpful to build on existing knowledge and theories from research into mainstream health promotion, to adapt mainstream projects to the needs of people with ID and to make the methods more inclusive.

### Chapter 3

Chapter 3 describes the range of health-promoting initiatives within Dutch service providers for people with ID. Using telephone interviews, 44 employees were questioned about existing initiatives in the field of healthy nutrition and exercise, looking into the characteristics of these initiatives and to what extent these initiatives take into account known factors that impede or promote healthy living (*research question 1*). The 47 initiatives found focused mainly on exercise and consisted of standalone activities that are offered regularly (e.g. once a week). The initiatives were often carried out by daily caregivers; health professionals were relatively little involved. Initiatives took into account many factors that make healthy living easier or more difficult, such as the level of the participants. Relatively little attention was given to organizational factors. This study shows that there is a lack of continuous attention for a healthy lifestyle in the daily lives of people with ID. Health promotion for people with ID benefits from a mission that is aimed at creating a living environment that supports healthy living, in which 1) more attention is paid to exercise and nutrition in the daily structure, 2) health professionals such as physiotherapists and dieticians become more involved in health promotion and 3) daily caregivers are better trained in the field of health promotion.

### Chapter 4

Chapter 4 examines in detail what people with ID think of healthy living and which personal and environmental factors they consider relevant for the realization of a healthy lifestyle (*research question 2*). Twenty-one people with a mild to moderate ID from the Netherlands participated in five semi-structured focus group interviews. The discussions focused on three main themes: 1) perception of their own health, 2) what participants consider as healthy living and 3) factors experienced to be related to the ability to live healthily. The interviews were thematically analysed. For the participants, healthy living is more than just healthy nutrition and exercise: feeling healthy, experiencing happiness and being independent are also important. A positive approach is important; focus on what you can do. In addition, living healthily is made easier/more difficult, according to them, by (a lack of) motivation, support from others, and environmental factors such as available health education, (a lack of) facilities and a favourable (or unfavourable) living and/or work location. This qualitative research shows that adults with mild to moderate ID have a good understanding of what it means to be healthy and to live healthily. They can be helped to live healthier by adapting existing health-promoting programmes for people with ID to their individual preferences, motivations and physical limitations. Given the dependence of people with ID on others, it is important that these adjustments also focus on the factors in their physical and social environment that make living healthily easier or more difficult.

### Chapter 5

In addition to people with an ID themselves, many other stakeholders were also asked about their ideas of health promotion. The research described in Chapter 5 consisted of two phases, in which we first identified all major stakeholders using four stakeholder

workshops. In the second phase, 29 individual interviews were conducted with various stakeholders such as managers, daily caregivers, family, physiotherapists and dieticians. We asked them what they expect from health promotion for people with an ID, how they view their own role and responsibilities, and what they believe to be impeding and facilitating factors (*research question 2*). Daily caregivers were designated as the most important and influential stakeholders, while they are not trained in health promotion. Hindering factors for a healthy lifestyle were mainly ascribed to the person with ID him/herself, and although the participants indicated that people with ID need support to live healthily, there was a lack of clarity about the (own) role and responsibilities of the stakeholders. There is a need for a cultural change in which (supporting) healthy living in everyday life becomes the norm. This requires a facilitating context in which the social network supports the autonomy of people with ID and offers them opportunities to adapt to physical, emotional and social challenges. This requires a shared vision and a system in which all stakeholders know their roles and responsibilities.

## Chapter 6

Based on the results of previous studies, *Dream, discover, and do! Increasing physical activity in everyday life (DDD)* was developed. This method consists of a group discussion with a positive approach, in which people with ID, together with their daily caregiver and physiotherapist, look for ways to exercise more in everyday life. Together they make an exercise poster, on which they indicate what they are already doing to exercise in daily life and what they would like to do more. Chapter 6 describes this final sub-study that investigated whether this method is feasible, whether it could work and whether it can be properly investigated (*research question 3*). To this end, the method was tested within four residential groups of people with a light to moderate ID. With the help of accelerometers and questionnaires, it was examined whether, after the group discussion, participants became more active, sat less, and were more aware of possibilities to exercise in daily life. The results show that the method is easy to implement, but evaluation among people with ID by means of questionnaires and accelerometers was challenging. Questions are often difficult to answer, the attention span is short, and it asks a lot from the participants to wear an accelerometer for a few days. Self-reported physical activity and awareness of exercise possibilities, particularly in and around the house, scored higher at post-test. Awareness of daily exercise options was most increased among the daily caregivers. Professionals also reported that people with ID were more active. This study indicates that *DDD* is feasible and offers advantages to both people with ID individually and to the residential group as a whole. Small adjustments to *DDD*, as well as a policy change that creates favourable preconditions, can increase feasibility and effect.

The research emphasizes the importance of focusing on more exercise in everyday life and integrating healthy behaviour into daily routines. It is important that future evaluation studies address the complex context of health promotion for people with ID.

## Chapter 7

Chapter 7 contains a general discussion of the main findings of the studies from Chapters 2 through 6. Comparison of the results of the various studies in this thesis identifies three important preconditions for successful health promotion for people with ID:

1. an everyday-life perspective in health promotion;
2. a supportive environment; and
3. facilitation of change in health promotion for people with ID.

These conditions are explained below.

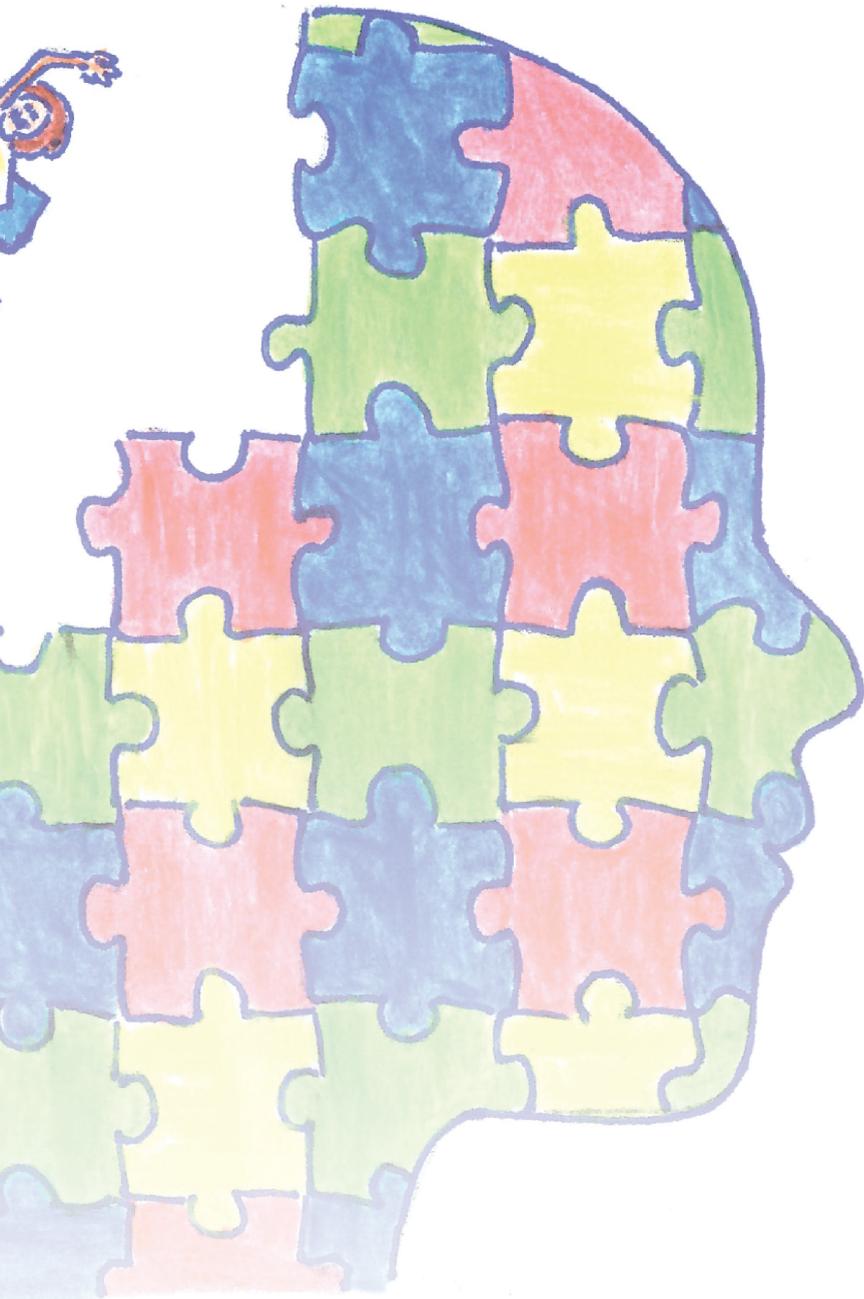
This thesis highlighted the importance of taking into account the complex realities of everyday living. Literature on current lifestyle approaches for people with ID however, shows that little attention is paid to integrating healthy behaviour into everyday routines of people with ID. As people with ID know quite well what living healthily entails and are aware of the benefits of a healthy lifestyle, but request support to put this into practice in everyday-life reality (Chapter 4), taking an everyday-life perspective can help to bridge this gap between good intentions and healthy behaviour. This perspective is based on the assumption that healthy behaviour consists of a chain of routines embedded in social practices, which require social changes. A practical example of taking an everyday-life perspective on increasing physical activity could be to incorporate the current norm of at least 150 minutes of moderate to vigorous activity per week in these everyday-life routines. In this thesis, people with ID pointed out several examples of how to increase physical activity by changing a chain of routines (Chapters 4 and 6): going to and returning from work by bike, or by using a bus stop a little further away from work and home so that you can walk the last part of your journeys; vacuuming the house; or walking to the shop to run errands. Consequently, increasing physical activity becomes more tangible and doable in everyday life; this will help people (with and without ID) to put good intentions into practice.

The World Health Organization already advocated in 1986 creating a supportive environment and the use of a settings approach for this, with a strong focus on everyday-life settings. A settings approach uses initiatives focused on the context in which individuals live, work, and recreate, rather than solely attempting to change the individuals themselves. Creating a supportive environment by using a settings approach has been successfully applied in contexts other than health promotion for people with ID, for example Healthy School projects, Healthy Universities, and Healthy Cities. All of these resulted in policy change, altered organizational structures, and community action to facilitate a healthy lifestyle. In this thesis as well as in other studies, people with ID themselves confirmed that support from others, who empower them to make healthy lifestyle choices, is an important factor in this supportive environment. In this support, daily caregivers play an essential role: Chapter 5 identified them as the most important and influential stakeholders, and other studies underline the potential of daily caregivers to influence the health behaviours of people with ID. This thesis showed that the role of daily caregivers with regard to health promotion is both essential and challenging. The

way in which daily caregivers can be facilitated to support a healthy lifestyle provides an example of the complexity of health promotion for people with ID and the usefulness of a settings approach in this.

Taking an everyday-life perspective and using a settings approach can be useful in a complex setting such as health promotion for people with ID. To further facilitate change and do justice to this complexity, a systems approach may be useful. In a complex system like the support system of people with ID, actors from different backgrounds share a collective goal, but also have different routines, norms, and values, as well as different reasons for being part of the system. Addressing changes at system level will make the actors in such a system more susceptible to change, thereby facilitating change. Routines, norms, and values and the prevailing culture can be identified which will facilitate health promotion for people with ID. This thesis and other research showed that current health promotion initiatives pay relatively little attention to existing group norms and values relating to a healthy lifestyle, while such group norms and values are an important motivation for people with ID to live healthily.

This thesis identified the importance of a supportive environment that empowers people with ID to incorporate a healthy lifestyle into their everyday-life routines. A clear organizational vision and mission that acknowledge health promotion as a key part of everyday-life support to people with ID, and a resulting lifestyle policy, can help to make these changes happen in organizations that provide support to people with ID. To increase the health promoting capacities of daily caregivers, it is advised to incorporate health promotion into the education of new daily caregivers and to provide current daily caregivers with on-the-job courses on health promotion. It is also recommended to pay attention to adopting a positive mindset towards supporting healthy behaviour and to educate daily caregivers on what type of support contributes to strengthening autonomy in making lifestyle choices. Future research could adopt a settings approach to health promotion to study the creation of healthy settings for people with ID that take into account the characteristics of the population, their specific support needs, their living environment, and the core business of the setting.





## CHAPTER 9

# Nederlandse samenvatting (Dutch summary)



Gezond leven is belangrijk voor je gezondheid. Dit geldt ook voor mensen met een verstandelijke beperking (VB). Zij weten wat gezond leven inhoudt en waarom het belangrijk is. Het in de praktijk brengen van gezond leven is moeilijk, zeker voor mensen met een VB. Velen van hen hebben een ongezonde leefstijl die gekenmerkt wordt door weinig beweging, veel zitten en een ongezond voedingspatroon. Het is dan ook niet verwonderlijk dat mensen met een VB veel leefstijlgerelateerde gezondheidsproblemen ervaren, zoals diabetes, hart- en vaatziekten en obesitas. Gezondheidsbevorderende initiatieven kunnen helpen om deze problemen te verminderen en te voorkomen. Echter, onderzoekers en beleidsmakers vanuit de hele wereld hebben aangegeven dat de focus op gezondheidsbevordering voor mensen met een VB internationaal onvoldoende is en meer aandacht nodig heeft.

Dit proefschrift heeft als doel handvaten te bieden om gezondheidsbevordering beter aan te laten sluiten op de behoeften, mogelijkheden en interesses van mensen met een VB, door de perspectieven van alle betrokkenen en de context van huidige gezondheidsbevordering voor mensen met een VB te analyseren. Daartoe zijn de volgende onderzoeksvragen geformuleerd:

Wat kunnen we leren van:

1. de context van bestaande gezondheidsbevorderende initiatieven voor mensen met een VB?
2. de perspectieven van verschillende betrokkenen, inclusief mensen met een VB?
3. het samen ontwikkelen van een gezondheidsbevorderend initiatief in het dagelijks leven en het testen van de praktische uitvoerbaarheid van dit initiatief?

## Hoofdstuk 1

In hoofdstuk 1 wordt een algemene introductie gegeven op het onderwerp gezondheidsbevordering voor mensen met een verstandelijke beperking. Er wordt ingegaan op de gezondheidsachterstand van mensen met een VB en het belang van de sociale en fysieke omgeving voor het bevorderen van de gezondheid van deze groep. Vanuit dit perspectief worden het doel en de onderzoeksvragen voor dit proefschrift geformuleerd.

## Hoofdstuk 2

Hoofdstuk 2 beschrijft een gestructureerde, kwalitatieve literatuurstudie waarbij is gekeken naar de belangrijkste karakteristieken van, en best practices en uitdagingen in studies die rapporteren over gezondheidsbevorderende initiatieven voor mensen met een VB (*onderzoeksvraag 1*). De meeste van de 25 geïncludeerde studies waren gericht op het bevorderen van lichamelijke activiteit of een combinatie van lichamelijke activiteit en gezonde voeding. Veel studies rapporteerden niet hoe ze hun deelnemers hadden geworven. Andere uitdagingen waren gerelateerd aan de implementatie van interventies, de selectie van geschikte meetinstrumenten en de geschiktheid van gebruikte uitkomstmaten. De uitkomsten van deze studie suggereren dat er binnen dit onderzoeksveld nog veel inconsistenties en methodologische zwaktes bestaan,

waardoor het moeilijk is om resultaten van studies te vergelijken. Eén van de belangrijkste aanbevelingen is dat de opvattingen van mensen met een VB en hun netwerk meer betrokken moeten worden bij onderzoek naar gezondheidsbevordering. Het kan behulpzaam zijn om hierbij te bouwen op bestaande kennis en theorieën uit onderzoek naar gezondheidsbevordering voor de gehele bevolking, de daar gebruikte projecten aan te passen naar de behoeften van mensen met een VB en hun methodes meer inclusief te maken.

### Hoofdstuk 3

Hoofdstuk 3 beschrijft het aanbod aan gezondheidsbevorderende initiatieven binnen Nederlandse zorgorganisaties voor mensen met een VB. Door middel van telefonische interviews zijn 44 medewerkers ondervraagd over bestaande initiatieven op het gebied van gezonde voeding en beweging, waarbij is gekeken naar de karakteristieken van deze initiatieven en in welke mate deze initiatieven rekening houden met bekende factoren die gezond leven belemmeren of bevorderen (*onderzoeksvraag 1*). De 47 gevonden initiatieven richtten zich vooral op beweging en bestonden uit op zichzelf staande activiteiten die regelmatig (bijv. 1x per week) aangeboden werden. De initiatieven werden vaak door dagelijks begeleiders uitgevoerd; gezondheidsprofessionals waren relatief weinig betrokken. Initiatieven hielden veel rekening met individuele factoren die gezond leven makkelijker of moeilijker maken, zoals het niveau van de deelnemers. Relatief weinig aandacht werd gegeven aan organisatorische factoren. Deze studie laat zien dat er een gebrek is aan continue aandacht voor een gezonde leefstijl in het dagelijks leven van mensen met een VB. Gezondheidsbevordering voor mensen met VB heeft baat bij een missie vanuit zorgorganisaties gericht op het creëren van een leefomgeving die gezond leven ondersteunt, waarin 1) er meer aandacht is voor beweging en voeding in de dagelijkse structuur, 2) gezondheidsprofessionals zoals fysiotherapeuten en diëtisten meer betrokken worden bij gezondheidsbevordering en 3) dagelijks begeleiders beter worden opgeleid op het gebied van gezondheidsbevordering.

### Hoofdstuk 4

In hoofdstuk 4 wordt uitgebreid ingegaan op wat mensen met een VB zelf vinden van gezond leven en welke persoonlijke en omgevingsfactoren door hen worden gezien als relevant voor het realiseren van een gezonde leefstijl (*onderzoeksvraag 2*). Eenentwintig mensen met een lichte tot matige VB uit Nederland namen deel aan vijf semigestructureerde focusgroep interviews. De discussies waren gefocust op drie hoofdthema's: 1) de perceptie van je eigen gezondheid, 2) wat deelnemers beschouwen als gezond leven en 3) factoren die volgens hen belangrijk waren om gezond te leven. De interviews zijn thematisch geanalyseerd. Voor de deelnemers is gezond leven meer dan alleen gezonde voeding en lichaamsbeweging: je gezond voelen, geluk en mate van onafhankelijkheid zijn ook belangrijk. Een positieve insteek is belangrijk; focussen op wat je wél kunt. Daarnaast wordt gezond leven volgens hen makkelijker/moeilijker door: (een gebrek aan) motivatie, ondersteuning van anderen, en omgevingsfactoren zoals beschikbare gezondheidsvoorlichting, (een gebrek aan) faciliteiten en een (on) gunstige woon- en/of werklocatie. Dit kwalitatieve onderzoek laat zien dat volwassenen

met een lichte tot matige VB een goed begrip hebben van wat gezond zijn en gezond leven inhoudt. Zij kunnen geholpen worden om gezonder te leven door bestaande gezondheidsbevorderende programma's voor mensen met een VB aan te passen aan hun individuele voorkeuren, motivaties en fysieke beperkingen. Gezien de afhankelijkheid van mensen met een VB van anderen, is het belangrijk dat deze aanpassingen ook gefocust zijn op de factoren in hun fysieke en sociale omgeving die gezond leven makkelijker of juist moeilijker maken.

## Hoofdstuk 5

Naast mensen met een VB zelf, zijn ook allerlei andere betrokkenen gevraagd naar hun ideeën over gezondheidsbevordering. Het onderzoek dat beschreven wordt in hoofdstuk 5 bestond uit twee fases, waarbij we eerst alle belangrijke betrokkenen hebben geïdentificeerd met behulp van vier stakeholder workshops. In de tweede fase hebben 29 individuele interviews plaatsgevonden met verschillende betrokkenen zoals managers, dagelijks begeleiders, familie, fysiotherapeuten en diëtisten. We vroegen hen wat zij verwachten van gezondheidsbevordering voor mensen met een VB, hoe zij hun eigen rol en verantwoordelijkheden hierin zien, en wat volgens hen belemmerende en bevorderende factoren zijn (*onderzoeksvraag 2*). Dagelijks woonbegeleiders werden aangewezen als de belangrijkste en meest invloedrijke betrokkenen, terwijl zij niet opgeleid zijn op het gebied van gezondheidsbevordering. Belemmerende factoren voor een gezonde leefstijl werden vooral toegewezen aan de persoon met een VB zelf, en hoewel de deelnemers aangaven dat mensen met een VB ondersteuning nodig hebben om gezond te leven, was er onduidelijkheid over de (eigen) rol en verantwoordelijkheden van betrokkenen hierin. Er is behoefte aan een cultuuromslag waarbij (het ondersteunen van) gezond leven in het dagelijks leven de norm wordt. Hiervoor is een stimulerende omgeving nodig waarin het sociaal netwerk de autonomie van mensen met een VB ondersteunt en hen mogelijkheden biedt om aan te passen aan fysieke, emotionele en sociale uitdagingen. Daarvoor is een gedeelde visie nodig en een systeem waarin alle betrokkenen hun rol en verantwoordelijkheden kennen.

## Hoofdstuk 6

Op basis van de resultaten van voorgaande studies is *Dromen, ontdekken en doen! Meer bewegen in je dagelijks leven (DOD)* ontwikkeld. Deze methode bestaat uit een groepsgesprek met een positieve insteek, waarbij cliënten samen met hun dagelijks begeleiders en hun fysiotherapeut op zoek gaan naar manieren om meer te bewegen in het dagelijks leven. Samen maken ze een beweegposter, waarop ze aangeven wat ze nu al doen aan beweging in het dagelijks leven en wat ze nog meer zouden willen doen. Hoofdstuk 6 beschrijft deze laatste deelstudie waarin is onderzocht of deze methode uitvoerbaar is, effect kan hebben, en of dit goed te onderzoeken is (*onderzoeksvraag 3*). Hiervoor is de methode getest binnen vier woongroepen van mensen met een lichte tot matige VB. Met behulp van accelerometers (geavanceerde stappentellers) en vragenlijsten is onderzocht of deelnemers na het groepsgesprek meer zijn gaan bewegen en minder zitten, en of zij zich meer bewust zijn van mogelijkheden om te bewegen in het dagelijks leven. De resultaten laten zien dat de methode goed uitvoerbaar is, maar dat het doen

van metingen bij deze doelgroep lastig is. Vragen zijn vaak moeilijk te beantwoorden, de aandachtspanne is kort en het vraagt behoorlijk veel van deelnemers om een aantal dagen een accelerometeor te dragen. Bij de nameting was zelfgerapporteerde lichamelijke activiteit en bewustzijn van beweegmogelijkheden, met name in en rond het huis, hoger. Bewustzijn van alledaagse beweegmogelijkheden was het meest verhoogd onder dagelijks begeleiders. Professionals rapporteerden daarnaast dat mensen met een VB actiever waren. Deze studie geeft aan dat *DOD* uitvoerbaar is en voordelen heeft voor mensen met een VB individueel en de woongroep als geheel. Door enkele aanpassingen kan de uitvoerbaarheid en het effect van *DOD* vergroot worden. Het onderzoek benadrukt het belang van de focus op meer beweging in het dagelijks leven en het integreren van gezond gedrag in dagelijkse routines. Het is belangrijk dat in toekomstige evaluatiestudies aandacht wordt besteed aan de complexe context van gezondheidsbevordering voor mensen met een VB.

## Hoofdstuk 7

Hoofdstuk 7 bevat een algemene discussie van de belangrijkste bevindingen van de studies uit de hoofdstukken 2 tot en met 6. Vergelijking van deze resultaten leidt tot het identificeren van drie belangrijke voorwaarden voor succesvolle gezondheidsbevordering voor mensen met een VB:

1. Een alledaags perspectief binnen gezondheidsbevordering;
2. een ondersteunende omgeving; en
3. het faciliteren van verandering binnen gezondheidsbevordering voor mensen met een VB.

Deze voorwaarden worden hieronder toegelicht.

Dit proefschrift benadrukt hoe belangrijk het is dat er binnen gezondheidsbevordering rekening wordt gehouden met de complexe realiteit van het dagelijks leven. Literatuur over huidige leefstijlbenaderingen voor mensen met een VB laat zien dat er weinig aandacht is voor het integreren van gezond gedrag in de dagelijkse routines van mensen met een VB. Omdat mensen met een VB redelijk goed weten wat gezond leven inhoudt en zich bewust zijn van de voordelen van een gezonde leefstijl, maar hulp nodig hebben om dit in het dagelijks leven in de praktijk te brengen (hoofdstuk 4), kan een alledaags perspectief helpen om een brug te slaan tussen goede bedoelingen en gezond gedrag. Dit perspectief is gebaseerd op de veronderstelling dat gezond gedrag bestaat uit een keten van routines die je dagelijks doet en waarbij je vaak in contact bent met anderen. Een praktisch voorbeeld van het toepassen van een alledaags perspectief op het verhogen van fysieke activiteit zou kunnen zijn om de huidige norm van minstens 150 minuten matige tot intensieve activiteit per week te vertalen naar de routines van het dagelijks leven. In dit proefschrift gaven mensen met een VB verschillende voorbeelden van het verhogen van fysieke activiteit door een keten van routines te veranderen (hoofdstuk 4 en 6): op de fiets naar het werk gaan; een bushalte iets verder van huis en werk gebruiken, zodat je een deel van je reis kunt lopen; het huis stofzuigen; of lopend naar de winkel gaan om boodschappen te doen. Hierdoor wordt de toename van fysieke activiteit tastbaarder

en praktisch uitvoerbaar in het dagelijks leven; dit zal mensen (met en zonder VB) helpen om goede intenties in de praktijk te brengen.

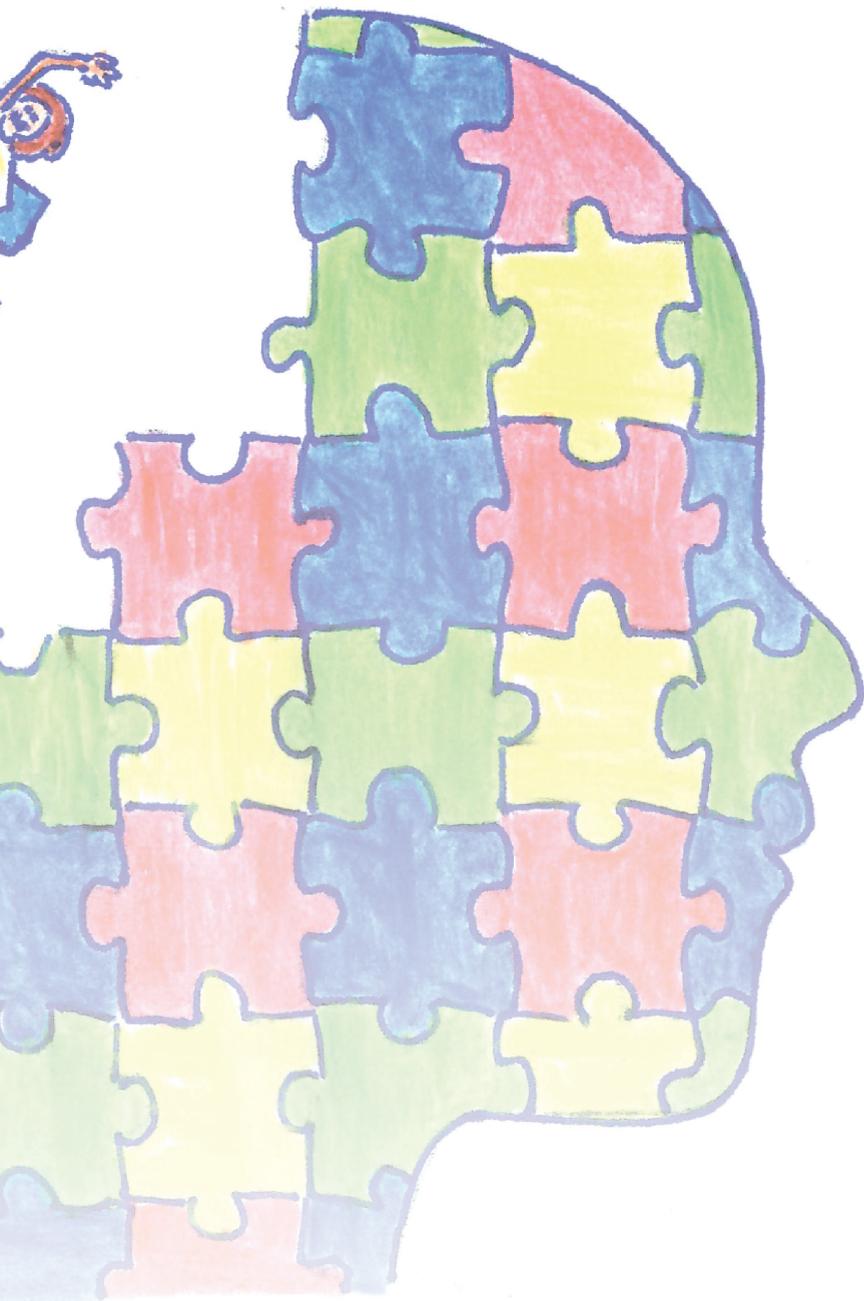
De Wereldgezondheidsorganisatie pleitte al in 1986 voor het creëren van een ondersteunende omgeving en het gebruik van een settingsbenadering hiervoor, met een sterke focus op het dagelijks leven. Een settingsbenadering gebruikt initiatieven die niet alleen gericht zijn op het veranderen van het gedrag van de persoon zelf, maar juist ook op het veranderen van de omgeving waarin mensen leven, werken en ontspannen. Het creëren van een ondersteunende omgeving met een settingsbenadering is met succes toegepast in andere contexten dan gezondheidsbevordering voor mensen met een VB, zoals GezondeSchoolprojecten, Gezonde Universiteiten en Gezonde Steden. Dit resulteerde in beleidsveranderingen, veranderde organisatiestructuren en gemeenschapsacties om een gezonde leefstijl mogelijk te maken. Zowel in dit proefschrift als in andere onderzoeken hebben mensen met een VB zelf bevestigd dat steun van anderen, die hen in staat stellen om gezonde leefstijlkeuzes te maken, een belangrijke factor is in deze ondersteunende omgeving. Bij deze ondersteuning spelen de dagelijks begeleiders een essentiële rol: in hoofdstuk 5 worden zij geïdentificeerd als de belangrijkste en meest invloedrijke betrokkenen, en andere onderzoeken benadrukken het potentieel van dagelijks begeleiders om het gezondheidsgedrag van mensen met een VB te beïnvloeden. Dit proefschrift laat zien dat de rol van dagelijks begeleiders met betrekking tot gezondheidsbevordering zowel essentieel als uitdagend is. De manier waarop dagelijks begeleiders kunnen worden gefaciliteerd om een gezonde leefstijl te ondersteunen is een voorbeeld van de complexiteit van gezondheidsbevordering voor mensen met een VB en het nut van een settingsbenadering hierin.

Een alledaags perspectief en een settingsbenadering kunnen nuttig zijn in een complexe omgeving, zoals bij gezondheidsbevordering voor mensen met een VB. Om veranderingen verder te vergemakkelijken en recht te doen aan deze complexiteit, kan een systeembenadering behulpzaam zijn. In een complex systeem zoals het ondersteuningssysteem van mensen met een VB, delen actoren met verschillende achtergronden een gezamenlijk doel. Zij hebben echter ook verschillende routines, normen en waarden, evenals verschillende redenen om deel uit te maken van het systeem. Het bekijken van veranderingen op systeemniveau helpt actoren in een dergelijk systeem gevoeliger te maken voor verandering. Routines, normen en waarden en de heersende cultuur kunnen zo zichtbaar worden gemaakt om gezondheidsbevordering voor mensen met een VB mogelijk te maken. Dit proefschrift heeft aangetoond dat de huidige initiatieven voor gezondheidsbevordering relatief weinig aandacht besteden aan bestaande groepsnormen en -waarden met betrekking tot een gezonde leefstijl, terwijl dergelijke groepsnormen en -waarden een belangrijke motivatie voor mensen met een VB zijn om gezond te leven.

Voor het onderzoeken van het creëren van gezonde settings voor mensen met een VB, zou toekomstig onderzoek een settingsbenadering met betrekking tot gezondheidsbevordering aan kunnen nemen. In zulke settings is het van belang om rekening te houden met de karakteristieken van de populatie, hun specifieke ondersteuningsbehoeften, hun leefomgeving en de kernactiviteiten van iedere setting.

Dit proefschrift benadrukt het belang van een ondersteunende omgeving die mensen met een VB in staat stelt om gezond leven te integreren in hun dagelijkse routines. Een duidelijke organisatorische visie en missie en daaropvolgend leefstijlbeleid, waarin een gezonde leefstijl erkend wordt als een belangrijk onderdeel van de dagelijkse begeleiding, kunnen helpen om deze veranderingen teweeg te brengen binnen organisaties die mensen met een VB ondersteunen. Om de gezondheidsbevorderende capaciteiten van dagelijks begeleiders te vergroten, wordt geadviseerd om gezondheidsbevordering te integreren in de opleiding van nieuwe dagelijks begeleiders, en om huidige dagelijks begeleiders een training op de werkplek aan te bieden. In dit proefschrift wordt ook aangeraden om aandacht te schenken aan het aannemen van een positieve mentaliteit met betrekking tot het ondersteunen van gezond gedrag. Het is daarbij belangrijk om dagelijks begeleiders te scholen in hoe zij, middels hun begeleiding, de autonomie van mensen met een VB in het maken van leefstijlkeuzes kunnen waarborgen.







## CHAPTER 10

# Makkelijk lezen samenvatting (Easy read summary in Dutch)

**Door:**

Noortje Kuijken, Anneke van der Cruisen en Henk Jansen



## Hoofdstuk 1:

### **Gezond leven makkelijk maken voor mensen met een verstandelijke beperking. Waar gaat dit boek over?**

#### **Wat staat er in dit boek?**

In dit boek staat een onderzoek opgeschreven.

Het onderzoek gaat over hoe we gezond leven makkelijk kunnen maken voor mensen met een verstandelijke beperking.

In dit onderzoek noemen we dit: **gezondheidsbevordering**.

Hiermee bedoelen we: mensen helpen om gezond te eten en meer te bewegen.

#### **Waarom is dit onderzoek belangrijk?**

Mensen met een verstandelijke beperking hebben een slechtere gezondheid dan mensen zonder een verstandelijke beperking.

Veel mensen met een verstandelijke beperking leven niet zo gezond: ze bewegen weinig, zitten veel en eten ongezond.

Door gezond te leven kan je problemen met je gezondheid voorkomen. Of de problemen met je gezondheid verminderen.

Het is belangrijk om te onderzoeken hoe we gezond leven makkelijk kunnen maken voor mensen met een verstandelijke beperking.

Voor mensen met een verstandelijke beperking is het vaak lastiger om gezond te leven.

Aan bestaande activiteiten om gezond te leven kunnen zij niet altijd goed meedoen.

Ook hebben ze vaak anderen nodig om hen te helpen gezond te leven.

Maar anderen weten vaak niet wat mensen met een verstandelijke beperking nodig hebben, leuk vinden en kunnen.

Gezond leven gaat makkelijker als:

- je aan bestaande activiteiten om gezond te leven beter mee kan doen;
- anderen goed weten wat jij nodig hebt, leuk vindt en goed kan;
- anderen goed weten wat zij kunnen en moeten doen om jou te helpen gezond te leven.

### **Wat was het doel van het onderzoek?**

Het doel van dit onderzoek was:

Gezondheidsbevordering beter aan laten sluiten op wat mensen met een verstandelijke beperking nodig hebben, leuk vinden en kunnen.

### **Wat wilden we weten?**

In ons onderzoek wilden we verschillende dingen weten:

1. Wat wordt er al gedaan aan gezondheidsbevordering voor mensen met een verstandelijke beperking?

We hebben gekeken naar:

- wat zorgorganisaties al doen om gezond leven makkelijk te maken;
- wat er al in onderzoek is geschreven over gezondheidsbevordering.

2. Wat vinden mensen zelf van gezond leven en gezondheidsbevordering?

Dit vroegen we aan:

- mensen met een verstandelijke beperking;
- allerlei andere mensen, bijvoorbeeld begeleiders, familieleden, fysiotherapeuten, diëtisten, artsen voor verstandelijk gehandicapten en managers.

3. We hebben samen een hulpmiddel om gezond te leven gemaakt en getest. Wat kunnen we hiervan leren?

## **Hoofdstuk 2:**

### **Wat hebben andere onderzoekers al geschreven over gezondheidsbevordering voor mensen met een verstandelijke beperking?**

#### **Wat wilden we weten?**

- Wat is er al door andere onderzoekers geschreven over het makkelijk maken van gezond leven voor mensen met een verstandelijke beperking?

#### **Wat hebben we gedaan?**

We hebben gezocht in medische tijdschriften.

We hebben 25 stukken tekst gevonden die gaan over activiteiten om gezond te leven.

Deze hebben we onder elkaar gezet en met elkaar vergeleken.

### **Wat zijn we te weten gekomen?**

- Veel activiteiten om gezond te leven gaan over meer bewegen, of over meer bewegen en gezond eten samen.
- Onderzoek doen naar activiteiten om gezond te leven voor mensen met een verstandelijke beperking is moeilijk:
  - het uitvoeren van de activiteiten is vaak lastig
  - manieren om te meten of iets goed werkt, passen niet altijd goed
  - de uitkomsten die onderzoekers gebruiken zijn niet altijd belangrijk

### **Dit onderzoek laat zien:**

- Mensen met een verstandelijke beperking en hun omgeving moeten meer betrokken worden bij onderzoek naar gezondheidsbevordering.
- Er is meer onderzoek nodig om goede manieren om te meten te vinden.
- We moeten meer samenwerken met onderzoekers die kijken naar gezondheidsbevordering voor mensen zonder verstandelijke beperking.

## Hoofdstuk 3:

### Wat doen zorgorganisaties al om gezond leven makkelijk te maken voor mensen met een verstandelijke beperking?

#### Wat wilden we weten?

- Wat doen zorgorganisaties in het dagelijks leven om gezond leven makkelijk te maken voor mensen met een verstandelijke beperking?

#### Wat hebben we gedaan?

We hebben via de telefoon met 44 mensen gesproken die werken bij zorgorganisaties.

We hebben gesproken met **begeleiders, fysiotherapeuten, diëtisten** en **managers**.

We vroegen of zij activiteiten kennen die helpen om gezond te leven.

Het maakte niet uit of het een uitgebreide activiteit was, of juist iets kleins.

We vroegen naar activiteiten die helpen om meer te bewegen. En naar activiteiten die helpen om gezond te eten.

#### Wat zijn we te weten gekomen?

- We hebben 47 activiteiten gevonden.
- De meesten activiteiten helpen om meer te bewegen.
- Veel activiteiten worden 1x per week aangeboden.
- Er is niet de hele dag aandacht voor gezond leven.
- Vooral dagelijks begeleiders voeren de activiteiten uit.
- De activiteiten houden veel rekening met de deelnemers, bijvoorbeeld wat iemand kan.
- De activiteiten houden minder rekening met de organisatie. Bijvoorbeeld hoeveel tijd en geld er nodig is voor een activiteit. Ook is er weinig informatie voor medewerkers over de activiteiten.

**Dit onderzoek laat zien:**

Gezondheidsbevordering voor mensen met een verstandelijke beperking kunnen we verbeteren door:

- Meer aandacht voor beweging en gezonde voeding in het dagelijks leven.
- Fysiotherapeuten en diëtisten meer betrekken bij gezondheidsbevordering.
- Begeleiders meer les geven over hoe zij mensen met een verstandelijke beperking kunnen helpen om gezond te leven.

## Hoofdstuk 4:

### Hoe denken mensen met een verstandelijke beperking zelf over gezond leven en hoe we dit makkelijk kunnen maken?

#### Wat wilden we weten?

- Wat vinden mensen met een verstandelijke beperking van gezond leven?
- Wat helpt om dit makkelijk te maken en wat niet?

#### Wat hebben we gedaan?

We hebben 5 groepsgesprekken gehouden met mensen met een verstandelijke beperking.

In iedere groep zaten 4 of 5 mensen.

In totaal hebben er 21 mensen meegedaan.

We hebben gepraat over:

1. Hoe gezond vind je jezelf?
2. Wat is gezond leven volgens jullie?
3. Wat maakt het makkelijk of moeilijk om gezond te leven?

Alles waar we over hebben gepraat, is uitgetypt.  
We hebben alle antwoorden uitgezocht.

### **Wat zijn we te weten gekomen?**

Bij gezond leven hoort volgens mensen met een verstandelijke beperking:

- gezonde voeding;
- voldoende bewegen;
- je gezond voelen;
- gelukkig zijn;
- sommige dingen zelfstandig kunnen doen (of met een beetje hulp).

Wat het makkelijk of moeilijk maakt om gezond te leven is:

- wel/geen motivatie hebben;
- wel/geen ondersteuning van anderen hebben;
- wel/geen informatie over gezond leven krijgen uit je omgeving;
- wat er bij je woning of werk in de buurt is om gezond te leven, bijvoorbeeld:
  - wel/geen sportschool in de buurt;
  - je moet veel trappen lopen (of niet);
  - je woont te ver van je werk om er naartoe te fietsen en je moet daarom met de bus.

**Dit onderzoek laat zien:**

- Mensen met een verstandelijke beperking weten best goed wat wel en niet gezond is.
- Het is voor hun vaak wel moeilijk om de gezonde dingen echt te gaan doen.
- Ze zijn hierbij vaak afhankelijk van andere mensen.
- De hulp die mensen krijgen om gezond te leven,
- moet aangepast worden op wat zij zelf leuk vinden en graag willen doen.
- Ook moeten we rekening houden met de lichamelijke beperkingen die iemand heeft.
- En met wat iemand nodig heeft in zijn omgeving om gezond te kunnen leven.

## Hoofdstuk 5:

### Wie is belangrijk om gezond leven makkelijk te maken en hoe denken zij over gezondheidsbevordering voor mensen met een verstandelijke beperking?

#### Wat wilden we weten?

- Wie is belangrijk om gezond leven makkelijk te maken?
- Wat zijn de ervaringen van deze mensen om gezond leven makkelijk te maken?

#### Wat hebben we gedaan?

Dit onderzoek bestond uit twee delen:

In **deel 1** hebben we gekeken naar wie belangrijk is om gezond leven makkelijk te maken voor mensen met een verstandelijke beperking.

We hebben daarvoor 4 groepsgesprekken gehouden met de mensen van onze vaste klankbordgroep.

Deze klankbordgroep bestond onder andere uit: mensen met een verstandelijke beperking, familie, begeleiders, een arts, een fysiotherapeut en een diëtiste.

In **deel 2** hebben we 29 gesprekken gehouden met de mensen die we in deel 1 hebben gevonden.

We spraken met onder andere **begeleiders, familieleden, fysiotherapeuten, diëtisten, artsen voor verstandelijk gehandicapten** en **managers**.

We vroegen:

Wat verwachten jullie van gezondheidsbevordering voor mensen met een verstandelijke beperking?

Wat doen jullie zelf binnen de activiteiten en wat wordt er van jullie verwacht?

Wat maakt het makkelijk of moeilijk om mensen te helpen gezond te leven?

**Wat zijn we te weten gekomen?**

- Woonbegeleiders en werkbegeleiders zijn het belangrijkste om mensen te helpen gezond te leven.
- Maar zij leren op hun opleiding niet veel over hoe ze dat moeten doen.
- Deelnemers noemden ook dingen die het lastig maken om gezond leven te ondersteunen. Ze noemden dan vooral dingen die met de persoon met een verstandelijke beperking te maken hebben.
- Bijvoorbeeld wat iemand begrijpt, niet zelf naar de sportschool kunnen en geen motivatie hebben om gezond te leven.
- Volgens de deelnemers hebben mensen met een verstandelijke beperking hulp nodig om gezond te leven.
- Maar de deelnemers weten niet goed wat zij hierin kunnen doen.

**Dit onderzoek laat zien:**

- Mensen uit de zorg moeten anders gaan denken over gezond leven:
- iedereen moet het gewoon vinden dat mensen elke dag gezond leven. En iedereen moet hierbij helpen.
- Mensen met een verstandelijke beperking moeten wel hun eigen keuzes blijven maken.
- Maar de omgeving moet hen zo goed mogelijk helpen om gezonde keuzes te maken.
- Het is daarom belangrijk dat alle betrokkenen weten wat zij kunnen doen.
- Organisaties moeten duidelijk zeggen wie wat moet doen.

## Hoofdstuk 6:

### ***Dromen, ontdekken en doen!* Een hulpmiddel om meer te bewegen in je dagelijks leven.**

#### **Wat wilden we weten?**

- Kan het hulpmiddel helpen om meer te bewegen in het dagelijks leven?
- Kan het hulpmiddel goed gebruikt worden binnen woongroepen van mensen met een verstandelijke beperking?
- Kunnen we goed testen of het hulpmiddel werkt?

#### **Wat hebben we gedaan?**

We hebben de uitkomsten van alle hoofdstukken onder elkaar gezet.

Hiermee hebben we een hulpmiddel gemaakt dat helpt om meer te bewegen in het dagelijks leven.

Dit hulpmiddel heet: *Dromen, ontdekken en doen! Meer bewegen in je dagelijks leven.*

Het hulpmiddel bestaat uit een groepsgesprek waarin een beweegposter wordt gemaakt.

Mensen met een verstandelijke beperking praten met hun begeleiders en fysiotherapeut over wat zij al doen om te bewegen in het dagelijks leven.

En over wat zij meer zouden willen en kunnen doen aan beweging.

Dit vullen ze in op de beweegposter.

We hebben het hulpmiddel getest binnen 5 woongroepen.

In totaal deden **47 bewoners, 20 begeleiders** en

**3 fysiotherapeuten** mee.

We vroegen hen wat ze van het hulpmiddel vonden en wat ze van het onderzoek vonden.

Ook vroegen we of ze konden vertellen op welke manieren je kan bewegen.

Bewoners droegen stappentellers om te kijken hoeveel zij bewogen. Ze droegen de stappentellers voor en na het groepsgesprek.

**Wat zijn we te weten gekomen?**

- De deelnemers vonden het hulpmiddel een goed hulpmiddel.
- De begeleiders en fysiotherapeuten zeiden dat de bewoners meer waren gaan bewegen.
- Bewoners en begeleiders konden na het groepsgesprek meer manieren vertellen om te bewegen in het dagelijks leven.
- Dit waren vooral dingen die je in en om het huis kunt doen.
- De stappentellers lieten zien dat bewoners na het groepsgesprek minder stil zaten.
- We kunnen het hulpmiddel goed gebruiken binnen woongroepen.
- Het doen van onderzoek met vragenlijsten en stappentellers is lastig bij mensen met een verstandelijke beperking.
- Sommige vragen waren te moeilijk.
- Ook duurde het onderzoek voor sommige mensen te lang.
- En sommige mensen vonden het lastig om de stappentellers een paar dagen achter elkaar te dragen.

### **Dit onderzoek laat zien:**

- Het hulpmiddel kan helpen om meer te bewegen in het dagelijks leven.
- Maar we moeten meer onderzoek doen om te testen of het hulpmiddel echt goed werkt.
- Na een paar aanpassingen, kunnen we het hulpmiddel nog beter gebruiken en zal het hulpmiddel nog beter werken.
- Als andere onderzoekers vragenlijsten en stappentellers gebruiken bij mensen met een verstandelijke beperking, moeten ze op de volgende dingen letten:
  - zorg dat het stellen van vragen niet te lang duurt;
  - wees voorzichtig met vragenlijsten die niet speciaal voor mensen met een verstandelijke beperking zijn;
  - 7 dagen een stappenteller dragen is erg lang: 4 dagen is waarschijnlijk ook genoeg.

## Hoofdstuk 7:

### Alle hoofdstukken samen. Wat zijn we te weten gekomen?

#### Wat wilden we aan het begin van het onderzoek weten?

We wilden onderzoeken hoe we gezond leven makkelijker kunnen maken voor mensen met een verstandelijke beperking.

We wilden weten wat er al gedaan wordt aan gezondheidsbevordering voor mensen met een verstandelijke beperking.

In dit onderzoek bedoelen we hiermee: mensen helpen om gezond te eten en meer te bewegen.

Daarnaast wilden we weten wat mensen zelf vinden van gezond leven en gezondheidsbevordering.

Ook hebben we samen een hulpmiddel om meer te bewegen gemaakt en getest. We wilden weten: wat kunnen we hiervan leren?

Dit wilden we weten, omdat het belangrijk is om te gezond leven.

Veel mensen met een verstandelijke beperking leven niet zo gezond:ze bewegen weinig, zitten veel en eten ongezond.

Door gezond te leven kan je problemen met je gezondheid voorkomen. Of de problemen met je gezondheid verminderen.

Daarom wilden we onderzoeken hoe we gezond leven makkelijker kunnen maken voor mensen met een verstandelijke beperking.

## **Wat hebben we geleerd van dit onderzoek?**

**Drie onderwerpen zijn belangrijk om gezond leven makkelijker te maken voor mensen met een verstandelijke beperking:**

1. gezond leven in wat je dagelijks doet;
2. een gezonde leefomgeving;
3. kijken naar het denken en de gewoontes van mensen.

### **1. Gezond leven in wat je dagelijks doet**

Mensen met een verstandelijke beperking weten best goed wat wel en niet gezond is.

Het is voor hun vaak lastig om de gezonde dingen echt te gaan doen.

Het helpt om gezond te leven in wat je dagelijks al doet.

Bijvoorbeeld:

- op de fiets naar je werk gaan;
- uitstappen bij een bushalte verder, zodat je een extra stuk kunt lopen;
- het huis stofzuigen;
- lopend naar de winkel gaan om boodschappen te doen.

### **2. Een gezonde leefomgeving**

Mensen met een verstandelijke beperking hebben vaak hulp van hun omgeving nodig om gezond te leven.

Het is dus belangrijk om niet alleen naar de persoon met een verstandelijke beperking zelf te kijken.

Maar juist ook de omgeving waarin mensen leven.

Dus bijvoorbeeld ook begeleiders en familie helpen.

We kijken naar:

- de omgeving waar je woont;
- de omgeving waar je werkt;
- de omgeving waar je ontspant.

In iedere omgeving kijken we naar:

- om welke mensen gaat het?
- wat doen de mensen in deze omgeving?
- wat voor hulp hebben deze mensen nodig om gezond te leven?
- hoe ziet de omgeving eruit en hoe kan deze omgeving helpen om gezond te leven?

### 3. **Kijken naar het denken en de gewoontes van mensen**

Verschillende mensen zijn belangrijk in het leven van mensen met een verstandelijke beperking.

Veel van hen kunnen mensen met een verstandelijke beperking helpen om gezond te leven.

Maar deze mensen vinden niet altijd hetzelfde belangrijk of 'goed'.

Sommige begeleiders vinden het belangrijk dat je gezond eet.

Andere begeleiders vinden het belangrijker dat je geniet van het eten.

Zij vinden het minder belangrijk of het gezond is of niet.

Ook je familie of je huisgenoten kunnen hier anders over denken.

Of de mensen die de regels maken voor organisaties.

Zij vinden het misschien belangrijker dat het allemaal niet teveel geld kost.

Of dat het eten veilig klaargemaakt kan worden.

Om verandering makkelijker te maken, kunnen we kijken naar wat verschillende mensen belangrijk vinden.

En wat verschillende mensen doen en hoe ze dat iedere dag doen.

Dat noem je normen, waarden en gewoontes.

Als je weet wat de normen, waarden en gewoontes zijn, kun je makkelijker dingen veranderen.

Bijvoorbeeld: als de begeleiding en de bewoners van een woongroep het niet belangrijk vinden dat er gezond eten gekookt wordt, moet je eerst zorgen dat ze dat wel belangrijk vinden.

Daarna kun je makkelijker de gewoontes veranderen: dus het kiezen van het eten, de boodschappen doen en het koken zelf.

### **Tips en adviezen**

We hebben tips en adviezen voor:

- familie en mensen die in de zorg werken;
- mensen die de regels maken voor organisaties;
- de opleiding van begeleiders.

### **Tips voor familie en mensen die in de zorg werken**

Een gezonde leefomgeving helpt om gezond te leven.

Samen kunnen we de omgeving gezonder maken, zodat mensen met een verstandelijke beperking makkelijker gezonde keuzes kunnen maken.

Het is daarbij belangrijk om mensen met een verstandelijke beperking te helpen, zoveel mogelijk zelf te kiezen wat zij willen doen om gezond te leven.

Wat hierbij helpt is, dat familie en mensen die in de zorg werken:

- zelf het goede voorbeeld geven;
- mensen met een verstandelijke beperking helpen om zelf gezonde keuzes te maken;
- mensen met een verstandelijke beperking aanmoedigen om het samen met iemand anders te doen;
- mensen met een verstandelijke beperking aanmoedigen om hulp te vragen als ze dit nodig hebben.

### **Tips voor mensen die de regels maken voor organisaties**

Voor organisaties die mensen met een verstandelijke beperking begeleiden, is het belangrijk dat:

- zij zeggen en opschrijven dat ze het ondersteunen van gezond leven belangrijk vinden;
- zij duidelijke regels maken over het ondersteunen van gezond leven;
- zij zorgen dat het ondersteunen van gezond leven in het persoonlijk plan van iedere cliënt staat;
- zij aangeven wie wat doet in het ondersteunen van gezond leven;
- zij aangeven hoeveel tijd en geld er besteed moet worden aan het ondersteunen van gezond leven;
- zij aandacht geven aan de normen, waarden en gewoontes binnen de organisatie en deze zo nodig veranderen.

### **Tips voor de opleiding van begeleiders**

Mensen met een verstandelijke beperking hebben vaak hulp van hun omgeving nodig om gezond te leven.

Vooraf de begeleiders kunnen daar veel bij helpen.

Op hun opleiding leren ze nog niet goed genoeg hoe ze dit moeten doen.

Dit onderzoek laat zien dat het belangrijk is om begeleiders beter te leren hoe ze gezond leven kunnen ondersteunen.

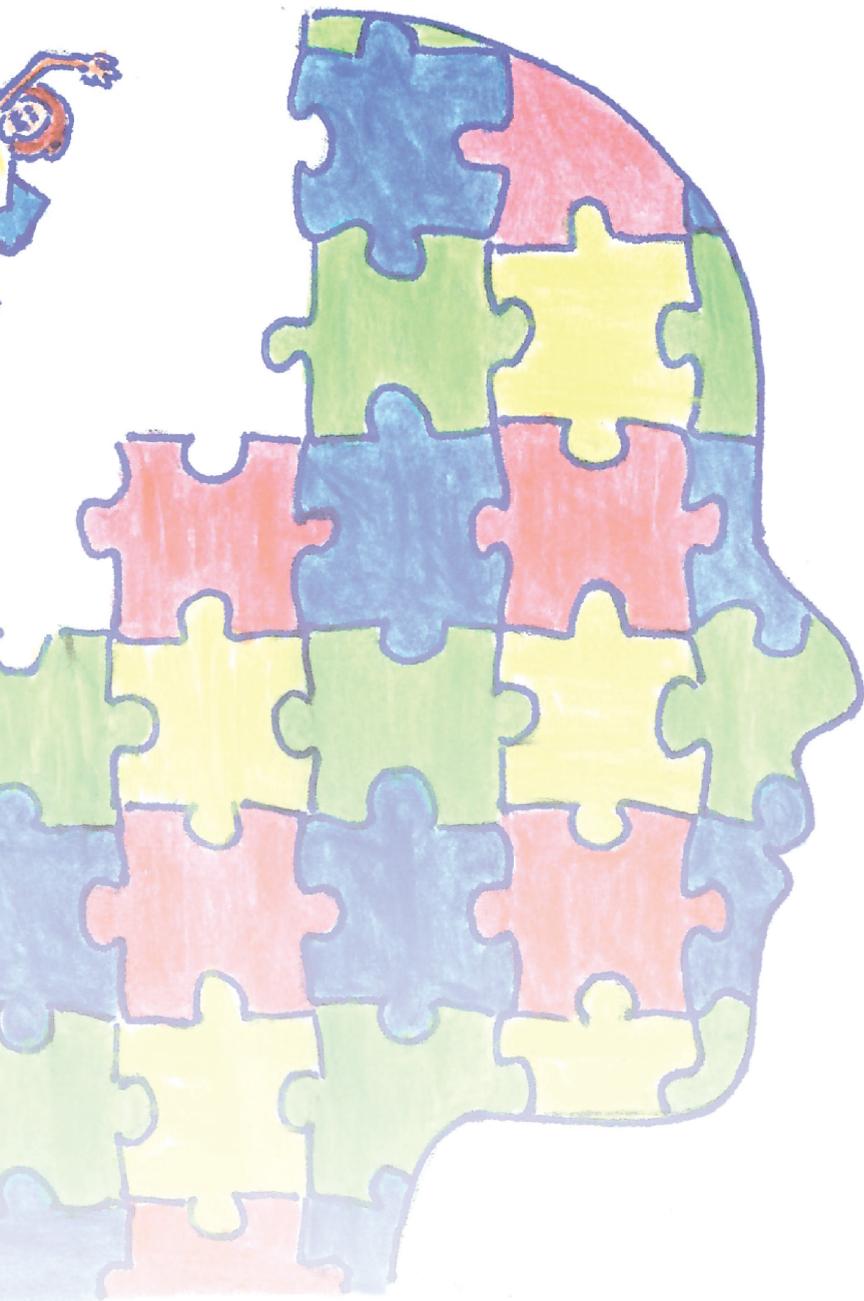
In de opleiding van nieuwe begeleiders moet aandacht zijn voor hoe je gezond leven kunt ondersteunen.

Begeleiders die al aan het werk zijn, zouden een cursus op de werkplek moeten krijgen.

Begeleiders in dit onderzoek zagen vaak vooral hoe moeilijk het is om gezond leven te ondersteunen.

In deze opleidingen leren de begeleiders ook om positief te denken: wat kun je wél doen om gezond leven te ondersteunen?







## CHAPTER 11

# Dankwoord (Acknowledgements)



Op een hete zomerdag in 2018 vroeg Bas mij, toen ik in de woonkamer zat te schrijven aan mijn discussie: “Als jij klaar bent met pomputeren, mama, gaan we dan wandelen?”

Eindelijk... ben ik klaar. Echt klaar. En kunnen we eindeloos gaan wandelen, mijn lieve schat.

Het laatste stukje proefschrift, maar waarschijnlijk het eerste wat de meeste mensen zullen lezen. Tenminste, dat doe ik altijd. Zo'n promotieonderzoek zie ik als een lange reis waarop je vele mensen tegenkomt. Sommigen reizen vanaf het begin tot eind met je mee. Anderen hoppen even op en weer af, en weer anderen stappen halverwege in, om tot het eind te blijven. Het mooiste vind ik altijd om te lezen hoe al die mensen deze reis hebben verrijkt: je bij hebben gestaan tijdens de moeilijke stukken, met humor of goed advies; en de mooie momenten met je hebben gevierd. Dit moment, het afronden van mijn proefschrift, vier ik graag met jullie allemaal. Dank, dat jullie me hebben bijgestaan.

Dr. Jenneken Naaldenberg, als eerste wil ik jou bedanken voor je dagelijkse begeleiding. Ik had me geen betere copromotor kunnen wensen. Wanneer ik vastliep met een analyse, kon ik na een overleg met jou weer met nieuwe ideeën aan de slag. Je bleef altijd begripvol, ook als mijn focus – om wat voor reden dan ook – minder was. Jouw droge humor hielp om de boel te relativieren, wat erg welkom was tijdens en na een zwaar promotorenoverleg!

Prof. dr. Henny van Schrojenstein Lantman – de Valk, dankjewel voor jouw wens om de zorg voor mensen met een verstandelijke beperking sterker en beter te maken – zonder jouw inzet en leerstoel was dit onderzoek er niet geweest. Dank ook voor je eerlijke kritiek op mijn stukken. En hoe bijzonder is het, als je met je eigen hoogleraar in een gymzaal vol vrouwen staat te bewegen op muziek! Dank dat je mij niet alleen op professioneel gebied ‘aan de hand nam’ in zowel binnen- als buitenland, maar dat ik je ook op vele andere manieren heb mogen leren kennen.

Prof. dr. Ria Nijhuis – van der Sanden, dankjewel voor jouw enthousiasme en passie voor het onderzoeks-vak. Als ik de draad kwijtraakte en verzandde in details, wist jij me feilloos terug te halen naar de grote lijn. Dank ook voor jouw open persoonlijkheid. Met jou erbij begon ieder overleg als een borrel; eigenlijk kon ik de eerste vijf minuten in de agenda standaard reserveren voor een persoonlijk verhaal van jou, want niet zelden kwam je binnen met “Sorry dat ik laat ben, maar wat ik nou toch weer (op het werk of thuis) aan de hand heb...!”. Die vijf minuten kon ik echter makkelijk missen dankzij jouw kernachtige feedback en scherpe blik, waarmee je een lange discussie kon doorbreken.

Prof. dr. Geraline Leusink, dank voor de frisse wind die jij door mijn project liet waaien vanaf het moment dat je als copromotor bij mijn begeleidingsteam kwam. Jouw zakelijke kijk hielp om keuzes te maken als we meer wilden dan we eigenlijk konden met de tijd en middelen die we hadden. Maar je wist mij ook te motiveren als ik het even niet meer zag zitten, en bood een fijn tegenwicht tijdens de overleggen. Ik ken maar weinig mensen met een werkethos zoals dat van jou; als ik, vanwege een deadline, om 02.00u 's nachts met zombie-ogen een stuk naar het team stuurde voor feedback, kreeg ik binnen twee

minuten van jou terug: “Werkt lekker rustig zo hè?”. Hopelijk mag je nog vele mooie onderzoeken opzetten en begeleiden als je straks je eigen leerstoel bekleedt.

De leden van de manuscriptcommissie prof. dr. Kees Noordam, prof. dr. Dick Thijssen en prof. dr. Annette van der Putten en de aanvullende leden van de promotiecommissie prof. dr. Maria Koelen, prof. dr. Koos van der Velden en dr. Dederieke Maes – Festen, dank voor de tijd en energie die u heeft besteed aan het lezen van mijn manuscript en voor de bijdrage die u levert tijdens de verdediging van mijn proefschrift.

Mijn dank gaat uit naar de Academische Werkplaats Sterker op eigen benen, die dit proefschrift mogelijk heeft gemaakt door een samenwerking tussen het Radboudumc en verschillende zorgorganisaties: Dichterbij, Driestroom, 's Heeren Loo, Koraal, ORO, Philadelphia, Pluryn, Siza en de Twentse Zorgcentra. In het bijzonder dank ik alle medewerkers, cliënten en naasten die hebben bijgedragen aan dit onderzoek. Zonder jullie hulp bij de werving van deelnemers en zonder jullie deelname aan het onderzoek, was dit boekje er niet geweest.

Mijn Sterker op eigen benen collega's Mathilde, Lotte, Francine, Esther, Tonnie, Freek, Corine, Cis, Maarten en Monique, dank voor de gezelligheid in zowel binnen- als buitenland en voor de altijd oprechte interesse in elkaar. Ik koester warme herinneringen aan onze lunches waarin de meest hilarische gespreksonderwerpen voorbij kwamen. Het was bijzonder om deel uit te maken van zo'n hechte club collega's. Anja, supersecretaresse, wat ben je toch een lief mens. Dankjewel voor al je hulp en de fijne gesprekken over andere dingen dan onderzoek. Marloes en Tessa, mijn roomies: ik weet niet of ik het zonder jullie had volgehouden! Ik mis onze humor, die soms alleen wij leken te begrijpen. Zo kwamen we die lange analyse- en schrijfdagen wel door! Tessa, we bleken niet alleen matties op werkgebied: ook over andere dingen denken we veelal hetzelfde. Ik vind het bijzonder hoe jij zonder oordeel naar mensen luistert en voor hen klaar staat! Dankjewel dat je als paranimf aan mijn zijde wilt staan. Kristel, tijdens mijn twee zwangerschapsverloven heb je, eerst als stagiaire en later als medewerker, een deel van mijn onderzoek waargenomen. Inmiddels ben je al een heel eind met je eigen promotieonderzoek, een prachtig vervolg op 'mijn' onderzoek. Dankjewel voor jouw kritische blik en enthousiasme voor het onderwerp. Mocht ik een antwoord niet weten, dan weet jij het vast wel; dankjewel dat je als paranimf aan mijn zijde wilt staan.

Co-onderzoekers Henk Jansen en Anneke van der Cruijssen, dank voor jullie hulp bij het aanpassen van teksten. Dankzij jullie konden we deelnemers met een verstandelijke beperking goed uitleggen wat het onderzoek inhield. En mede dankzij jullie is er ook een makkelijk lezen samenvatting van dit proefschrift. Anneke, jij hebt ook deelgenomen aan de klankbordgroep van dit onderzoek. Dank voor je heerlijke lach en waardevolle mening over gezond leven en hoe we dit moeten onderzoeken.

Frank Rutten en Marco Buurman, dank voor jullie bijdrage aan de klankbordgroep en voor onze samenwerking in het project *Dromen, ontdekken en doen!*. Jullie waren degenen die zeiden: “Dit hulpmiddel moet voor iedereen beschikbaar worden, ook voor mensen die zelfstandig wonen!” Ook Daniëlle Groeneveld, San Sperber, Paul Maas, Marion Bulkens

en Kennisplein gehandicaptensector dank ik voor onze samenwerking in het project *Dromen, ontdekken en doen!*. Dankzij jullie is het hulpmiddel nu ook echt beschikbaar voor iedereen!

De andere leden van de klankbordgroep, Miranda van de Pol, Diederik Smit, Henk du Bois, Laurian Alferink, Nenette Bosveld-Hendriks, Jacqueline van Zwieten, Anneke Peters-Burgerjon, Gé Jacobs, Esther Zweden, Juliette Vaal, Mariëtte Verhoeven, Mia Ewalts-Willems, Lonneke Groenen, Luciënne Heerkens-Brunschot, Renske Koordeman en Thea Meeuwse, dank voor jullie kritische blik vanuit de praktijk. Jullie mening en ideeën zijn bijzonder waardevol geweest op vele momenten tijdens het onderzoek!

Charlotte van Corven, Janne van der Heijden, Stephan Hendriks, Mendy Kuipers, Neliza Lubbers en Maaike Muskens, dank voor jullie ondersteuning bij het uitvoeren van verschillende deelonderzoeken.

Impuls collega's Milou, Sara, Nicoline, Judith, Loes, Irene, Linda, Tessa, Marieke, Danielle, Manon, Dorieke, Ragna, Manja, Sandra, Renée, Mariëlle en Jorien, dank voor alle gezelligheid op de gang en tijdens onze gezamenlijke (verjaardags)feestjes, en dank voor de frisse blik op mijn artikelen tijdens de LES.

Catherine O'Dea, thank you for proofreading my papers as well as the introducing and concluding chapter of my thesis. No matter how short my deadline was, you were able to provide me with excellent feedback. Thank you so much!

Mijn collega's bij Fontys, jullie zijn met teveel om iedereen apart te noemen. Dank voor jullie interesse in mijn onderzoek en voor alle mental support tijdens de laatste loodjes. Dit onderzoek hoort al zo lang bij mij, dat ik de uitkomsten vanzelfsprekend ben gaan vinden. Jullie enthousiasme laat me met hernieuwde energie naar het onderwerp kijken; daar maak ik dankbaar gebruik van in de voorbereiding op mijn verdediging!

Mijn vriendinnen Anneke, Edith, Eline en Anne, wat kan ik genieten van onze lunches en saunadates. Even helemaal eruit, gezellig kletsen en lekker eten. Dat was soms hard nodig! Dankjulliewel daarvoor. Ik hoop dat we dit nog lang zullen blijven doen. Esther, dankjewel dat je mijn onderzoeks-mattie was tussen al het doktersgeweld in onze vriendinnengroep. Het was heel bijzonder om bij jouw promotie voor het eerst achter de kathedraal te mogen staan als paranimf. Jammer dat onze wegen nu van elkaar gescheiden zijn. Katherine, we don't see each other very often, but I know I am always in your prayers. Thank you for your wise words in times of difficulty, and for all the fun we have when spending time together!

Lieve pap en mam, jullie hebben mij altijd in mijn keuzes gesteund; of ik nou op mijn 18<sup>e</sup> ging samenwonen, besloot te stoppen met geneeskunde of voor de 10<sup>e</sup> keer ging verhuizen. In alles voel ik jullie trots en onvoorwaardelijke steun, waar ik jullie ontzettend dankbaar voor ben. Dankzij jullie durf ik te kiezen voor wat ik écht wil. Mam, dankjewel voor het mooie ontwerp dat je hebt gemaakt voor de kaft van dit proefschrift.

Coen, Sander, Eefje, Claudia en Maarten: dank voor jullie steun en interesse in mijn onderzoek, en voor jullie blijdschap bij iedere mijlpaal. Emile en Nelly, zonder al die keren 'extra' oppas op vrijdag of in het weekend, was dit boekje nog steeds niet af geweest. Bedankt dat jullie altijd voor ons klaar staan.

Mijn liefste Bas en Suus, toen ik aan dit boek begon, waren jullie er nog niet! Maar wat ben ik blij dat ik jullie mama mag zijn. Ik geniet van jullie grapjes en knuffels. Gelukkig hebben we nu weer meer tijd om samen leuke dingen te doen. Op naar de volgende boswandeling!

Tenslotte, lieve Geert, ik begon deze reis zonder jou. Ergens in het eerste jaar stapte je in, en je bleef tot het eind. Dat was niet altijd makkelijk. Hoe kon het toch dat zo'n onderzoek jaren duurt... Dankjewel dat je in mij bent blijven geloven. Dankjewel voor de keren dat je "Hora est" door het huis scandeerde om me gemotiveerd te houden. Dat je me opvrolijkte na een zwaar gesprek. Dankjewel voor je geduld bij mijn antwoord "het is écht bijna klaar". Nu... is het echt klaar! Je weet naar wie ik kijk bij die twee woorden.. *Hora est!*







## CHAPTER 12

List of publications  
English Curriculum Vitae  
Nederlands Curriculum Vitae  
(Curriculum Vitae in Dutch)  
RIHS PhD Portfolio

## 12.1 List of publications

### Peer reviewed

Naaldenberg J., Kuijken N., van Dooren K. & van Schrojenstein Lantman de Valk H. (2013). Topics, methods and challenges in health promotion for people with intellectual disabilities: a structured review of literature. *Research in Developmental Disabilities, 34*, 4534–45.

Kaal, S.E., Kuijken, N.M., Verhagen, C.A., Jansen, R., Servaes, P., van der Graaf, W.T. (2016). Experiences of parents and general practitioners with end-of-life care in adolescents and young adults with cancer. *Journal of Adolescent and Young Adult Oncology, 5*, 64-68.

Kuijken, N.M.J., Naaldenberg, J., Vlot-van Anrooij, K., Nijhuis-van der Sanden, M.W.G., van Schrojenstein Lantman-de Valk, H.M.J., & Leusink, G.L. (Accepted for publication). Integrating health promotion in everyday life of people with ID - extent to which current initiatives take context into account. *Intellectual and Developmental Disabilities*

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*, 228-241.

Kuijken, N.M.J., Vlot-van Anrooij, K., van Schrojenstein Lantman-de Valk, H.M.J., Leusink, G., Naaldenberg, J., & Nijhuis-van der Sanden, M.W. (2018). Stakeholder expectations, roles and responsibilities in Dutch health promotion for people with intellectual disabilities. *Health Promotion International*. E-publication ahead of print

### Not peer reviewed

Kuijken, N.M.J. (2018) Gezond leven in het dagelijks leven, dat kan iedereen! *Tijdschrift voor Artsen voor Verstandelijk Gehandicapten, 36*, 52-54.

## **12.2 English Curriculum Vitae**

Noortje Kuijken was born in Eindhoven (The Netherlands) on the 7th of December, 1987. After completing her secondary education at the 'Pleincollege Eckart' in Eindhoven in 2006 (Cum laude), she started her medical education at the Radboud University in Nijmegen. During her Bachelor in medical education, Noortje worked as a student-assistant Internal Medicine at the Emergency Room of the Radboud University Medical Center in Nijmegen. During her medical internships Noortje decided to switch to another Master. In 2011 she started the Master Health Education and Promotion at Maastricht University, which she completed in 2012 (Cum laude). Prior to and after this Master, she worked as an administrative / logistic worker at the Radiotherapy department of the Radboud University Medical Center in Nijmegen. In November 2012 Noortje started a full-time PhD trajectory at the Academic Collaborative Stronger on your own feet, in which several service providers for people with intellectual disabilities collaborate with the Radboud University Medical Center in Nijmegen. As of August 2018 Noortje works as a teacher at the Bachelor of Nursing at 'Fontys Hogescholen' in Eindhoven. Noortje lives together with her partner Geert, her son Bas and daughter Suus in Son en Breugel.

## **12.3 Nederlands Curriculum Vitae (Curriculum Vitae in Dutch)**

Noortje Kuijken is geboren in Eindhoven op 7 december 1987. In 2006 behaalde zij Cum laude haar gymnasiumdiploma aan het Pleincollege Eckart te Eindhoven. In hetzelfde jaar startte zij met de opleiding Geneeskunde aan de Radboud Universiteit te Nijmegen. Tijdens de bachelor Geneeskunde werkte Noortje als student-assistent Interne Geneeskunde op de Spoedeisende Hulp van het Radboudumc in Nijmegen. Na het afronden van haar onderzoeksstage als onderdeel van de Master Geneeskunde, besloot Noortje tijdens de co-schappen van Master te veranderen. In 2011 startte zij met de Master Health Education and Promotion (Gezondheidsbevordering- en voorlichting) aan de Universiteit Maastricht, die zij in 2012 Cum laude behaalde. Voorafgaand aan en na deze Master werkte Noortje als administratief / logistiek medewerker op de afdeling Radiotherapie van het Radboudumc in Nijmegen. In november 2012 startte Noortje een voltijd promotietraject bij de Academische Werkplaats Sterker op eigen benen, waarin verschillende zorgorganisaties voor mensen met een verstandelijke beperking samenwerken met het Radboudumc in Nijmegen. Sinds augustus 2018 is Noortje werkzaam als docent en studieloopbaanbegeleider bij de HBO opleiding Verpleegkunde aan Fontys Hogescholen in Eindhoven. Noortje woont samen met haar partner Geert, haar zoon Bas en dochter Suus in Son en Breugel.

## 12.4 RIHS PhD Portfolio

<b>Name PhD candidate:</b>		<b>PhD period: 12-11-2012 – 31-12-2017</b>	
<b>N.M.J. Kuijken</b>		<b>Promotor(s):</b>	
<b>Department:</b>		<b>Prof. dr. H.M.J. Van Schroyen-stein Lantman – de Valk</b>	
<b>Primary and Community Care</b>		<b>Prof. dr. M.W.G. Nijhuis – van der Sanden</b>	
<b>Graduate School:</b>		<b>Co-promotor(s):</b>	
<b>Radboud Institute for Health Sciences</b>		<b>Dr. J. Naaldenberg</b>	
		<b>Prof. dr. G.L. Leusink</b>	
		<b>Year(s)</b>	<b>ECTS</b>
<b>TRAINING ACTIVITIES</b>			
<b>a) Courses &amp; Workshops</b>			
-	<b><i>RUNMC introduction for PhD students</i></b>	2012	0.1
-	<b><i>Endnote introduction course</i></b>	2012	0.1
-	<b><i>Pubmed for advanced users</i></b>	2013	0.1
-	<b><i>RIHS PhD introduction course</i></b>	2013	1.75
-	<b><i>BROK course</i></b>	2013	1.75
-	<b><i>Qualitative Research Methods in Health Care (CaRe)</i></b>	2013	1.75
-	<b><i>Evers Research &amp; Training focus groups course</i></b>	2013	0.8
-	<b><i>Time management course</i></b>	2014	0.4
-	<b><i>RIHS Workshop Poster Design and Presentation</i></b>	2014	0.1
-	<b><i>Advanced academic writing course</i></b>	2014	1.75
-	<b><i>Presentation skills course</i></b>	2016	1.5
-	<b><i>Scientific integrity course</i></b>	2015	0.8
-	<b><i>Refresher course statistics</i></b>	2017	1.75
-	<b><i>Mindfulness-Based Stress Reduction course</i></b>	2017	1.75
-	<b><i>Re-registration BROK</i></b>	2017	0.2

<p>b) <b>Seminars &amp; lectures<sup>^</sup></b></p> <ul style="list-style-type: none"> <li>- <i>Meetings regional network of Intellectual Disability (ID) physicians and ID service providers, oral presentations</i></li> <li>- <i>Symposium GOUD</i></li> <li>- <i>Annual CaRe days</i></li> <li>- <i>Studiedag LVB en leefstijl, oral presentation</i></li> <li>- <i>Congresparade Gezonde Leefstijl Bewegen en Activeren in de VGZ, workshops (2)</i></li> </ul>	<p>2013-2017</p> <p>2014</p> <p>2016</p> <p>2016, 2017</p> <p>2017</p>	<p>0.75</p> <p>0.25</p> <p>0.25</p> <p>0.75</p> <p>0.5</p>
<p>c) <b>Symposia &amp; congresses<sup>^</sup></b></p> <ul style="list-style-type: none"> <li>- <i>Health care beyond medicine – The changing role of the academia</i></li> <li>- <i>Symposium Tranzo: Door co-creatie verbonden</i></li> <li>- <i>Nederlands Congres Volksgezondheid, poster presentation</i></li> <li>- <i>Conference IASSIDD Health Special Interest Group (SIRG), Nijmegen, poster presentation and workshop organisation</i></li> <li>- <i>RIHS conferences, oral presentation</i></li> <li>- <i>IASSIDD Europe congress Vienna, oral presentation</i></li> <li>- <i>IASSIDD World congress, Melbourne, oral presentations (2)</i></li> </ul>	<p>2012</p> <p>2013</p> <p>2013</p> <p>2013</p> <p>2013, 2014</p> <p>2014</p> <p>2016</p>	<p>0.25</p> <p>0.25</p> <p>0.5</p> <p>1.75</p> <p>0.75</p> <p>1.5</p> <p>2.0</p>
<p>d) <b>Other</b></p> <ul style="list-style-type: none"> <li>- <i>Journal club, Department Primary and Community Care</i></li> <li>- <i>Reviewing scientific papers for multiple journals</i></li> </ul>	<p>2012-2017</p> <p>2016-2017</p>	<p>1</p> <p>0.2</p>

<b>TEACHING ACTIVITIES</b>		
<b>e) Lecturing</b>		
- <i>Wageningen University, Master students, guest lecture</i>	2013	0.15
- <i>Radboud University, Bachelor students, workshops</i>	2014-2016	2.4
- <i>Wetenschapsdag AVG-opleiding, workshops</i>	2016	0.2
- <i>Congres Nederlandse Vereniging van Fysiotherapeuten voor Verstandelijk Gehandicapten, workshops (2)</i>	2017	0.2
<b>f) Supervision of internships / other</b>		
- <i>Supervision research internship HAN students</i>	2013	1
- <i>Supervision Bachelor students (Medicine) during the development and implementation of a Plan-Do-Check-Act cycle</i>	2014-2016	1.5
- <i>Meet your PhD, one week supervision Bachelor student</i>	2017	0.1
- <i>Supervision research internship Honours programme HAN</i>	2017	0.2
<b>TOTAL</b>		<b>31.05</b>

^Indicate oral or poster presentation



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