EMBEDDING HEALTH PROMOTION IN SUPPORT SETTINGS FOR PEOPLE WITH INTELLECTUAL DISABILITIES

An innovative adoption of the settings approach

Kristel Vlot- van Anrooij

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Colofon

Dit proefschrift is mogelijk gemaakt door het ZonMw-programma Gewoon Bijzonder (80-84500-98-118), de Academische Werkplaats Sterker op eigen benen en de overige partners uit het kernteam en gebruikersnetwerk van het project 'Ondersteunen van een gezonde leefstijl van mensen met een verstandelijke beperking; de krachten gebundeld' (zie afbeelding).

Cover:	Stefanie van den Herik, Herikmedia
Layout & Print:	Dennis Hendriks ||ProefschriftMaken.nl
ISBN:	978-94-6423-377-3

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

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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
woensdag 6 oktober 2021
om 16.30 uur precies

door

Dirkje Elisabeth Kristine (Kristel) van Anrooij

geboren op 9 mei 1992
te 's-Hertogenbosch

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CHAPTER

1

General introduction

People with intellectual disabilities (ID) experience a multitude of factors that impact healthy living. The settings in which people with ID engage can stimulate the physical activity and healthy nutrition of people with ID because environmental factors have an important influence on lifestyle. Settings constitute the "place or social context in which people engage in daily activities in which environmental, organizational, and personal factors interact to affect health and wellbeing" [1]. Most people with moderate to profound ID in the Netherlands spend a lot of time in ID support-organization settings where they are offered day activities and residential support. Various stakeholders in these settings can play a role in health promotion. This thesis aims to: 1) gain an overview of stakeholders in health promotion practice and find ways to involve them in research, 2) gain insight into contextual factors that support the physical activity and healthy nutrition of people with ID engaging in ID support settings, and 3) develop a tool for asset mapping and for identifying actionable knowledge to improve the health-promoting capacities of ID support settings. This chapter provides an overview of the (health) characteristics of people with ID and the context in which they engage, the importance of contextual factors for lifestyle behavior, health promotion efforts for people with ID, and the settings approach adopted in this thesis. Lastly, the research questions, the research setting, and the outline of the chapters in this thesis are presented.

Characteristics and health problems of people with ID

Intellectual disabilities are defined as significant limitations that originate before the age of 18 in both intellectual functioning and adaptive behavior, which covers everyday social, practical, and conceptual skills [2]. The degree of disability is expressed in IQ and developmental age. People with moderate to profound ID, the population on which this thesis focuses, have an IQ score of ≤ 50 and a developmental age of ≤ 7 years [3]. Disabilities have an impact on all areas of life, including health literacy, communication skills, knowledge on healthy living, dependence on others, and the ability to live healthily [4-7]. ID prevalence worldwide is approximately 1–3% [3]. For the Netherlands, it is estimated that there are 142,000 people with an IQ below 70, of which 68,000 have an IQ <50 [8].

More and different health problems are experienced by people with ID compared to the general population [9,10]. Common health problems among people with ID include mobility problems, sensory impairments, epilepsy, diabetes, skin disease, osteoporosis, obesity, constipation, and cardiovascular disease [9-12]. Determinants that relate to the health problems faced by people with ID include their low socio-economic status [13,14] and difficulties with access to prevention and health promotion [15-19]. Many health problems such as diabetes, obesity, constipation, and osteoporosis are (partly) related to an unhealthy lifestyle [9].

The lifestyle of people with ID, including diet, sedentary behavior, and physical activity, is unhealthier than that of people without disabilities [9,16,20-30]. Although there is a

lack of research on the dietary intake of people with ID in the Netherlands, Humphries and colleagues' review study provides international insight into the dietary intake of people with ID. They conclude that people with ID have diets that lack fruit, vegetable, and dairy intake and are excessive in the food groups fats, sweets, and junk food [22]. Furthermore, people with ID have more sedentary time than people without ID [31]. Looking at physical activity, a review of 15 studies on the physical activity of 3,159 persons with ID revealed that only 9% of the participants met the minimum physical activity guidelines of at least 150 minutes of moderate to intense physical activity per week [25]. Two Dutch studies show that older adults with ID have extremely low levels of physical activity and also a below average or impaired physical fitness level [17,32].

Care provision and national trends influencing the context of lifestyle support for people with ID

Support for people with ID in the Netherlands ranges from ambulatory support for several hours a week, mostly provided to people with mild ID, to day-activity support and long-term residential support and care in facilities provided by ID support organizations, mostly provided to people with moderate to profound ID [33]. For 2020, it was estimated that 77,000 people with ID received residential support [34]. Residential support for people with ID in the Netherlands is provided in facilities that range from clustered group homes to small-group living in apartments or single-family homes in neighborhoods [8,34]. At these facilities, people with ID receive support with personal, daily, social, and home-health tasks, mainly provided by daily care professionals trained in behavior aspects and/or assisted nursing [35]. Many ID support organizations also employ a general practitioner, an ID physician (medical specialist with three years of postgraduate training), and allied health professionals. As people with ID engage a lot in these settings, ID support organizations and their employees have a considerable influence on the everyday life and support of the physical activity and healthy nutrition of people with ID.

Dutch national trends in the period of this project (2017–2021) that influenced the context of support for a healthy lifestyle for people with ID include legislative changes and the National Prevention Agreement *(Nationaal Preventieakkoord)*. From 2015 onwards, municipalities were given additional responsibilities for supporting people with ID as a result of legislative changes (including the Social Support Act, the Long-term Care Act, and the Participation Act) and ratification of the convention on the rights of people with ID in 2016 (a human rights instrument for protection against deprivation of liberty and provisions related to autonomy and integration in healthcare) [36].

The responsibilities include stimulating (semi)-independent living for people with ID, inclusive education, participation of people with ID in 'regular' jobs, and accessibility for people with disabilities. As a result, intramural support provided by ID support organizations became more focused on people with moderate to profound ID and on

people with mild ID and complex support needs. There are doubts about the extent to which these changes, which were introduced along with budget cuts, indeed realized the aim to stimulate the inclusion and participation of people with ID in society [37,38].

Another change that impacts municipalities is the Environment and Planning Act introduced in 2021. This obligates municipalities to formulate a plan for spatial planning in which one of the main goals is a safe and green environment that protects citizens against health risks and fosters health and healthy living. This provides opportunities for municipalities to integrate public health policy in their environmental plans [39].

On the national level, the National Prevention Agreement was developed and signed by more than 70 parties in 2018. Due to high levels of overweight and smoking and alcohol abuse in the general population, these parties agreed to put prevention efforts into practice in future years. Several agreements focus on physical activity and healthy nutrition: better accessibility to sport clubs for people who are physically inactive, improvements in food logos, education on the food-guide pyramid, and healthier food options in sport clubs, schools, and hospitals [40]. Although the agreement does not include a specific focus on people with ID, the resulting changes can lead to better accessibility to sport clubs for people with ID and a healthier food environment.

Health promotion

Health promotion for people with ID can enable them to be physically active and eat and drink healthily, and it can foster health and wellbeing. The terms health promotion, health protection, health education, and disease prevention have been used interchangeably in the past, however each has a specific focus [41]:

- Disease prevention: focused on reducing individual disease risk factors, such as smoking [42]
- Health protection: offering resources for risk reduction in the socio-ecological environment, such as hygiene rules to prevent food contamination [42]
- Health education: communicating information to individuals as well as fostering the skills, motivation, and confidence necessary for people to take action to improve their health [1]
- Health promotion: a process that provides people with resources and enables them to gain control over their health determinants, thereby improving their health, wellbeing, and quality of life [43].

So, taking a health promotion approach implies focusing on positive health and resources that keep people healthy and living healthily. The health development model visualizes this focus of health promotion on positive health and individual and contextual resources, see Figure 1 [42].

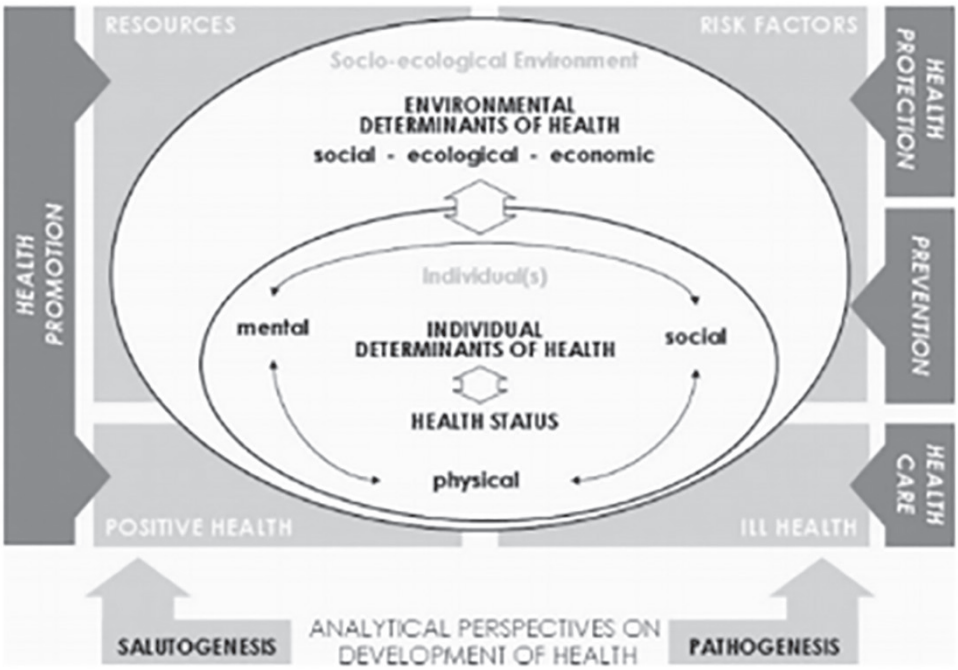

Figure 1: The health development model [42].

The notion that lifestyle behavior is not just the result of individual decision making, but also strongly influenced by the context of environmental determinants, has become strongly supported by the growing amount of evidence in recent decades [44-55]. A model that clearly describes the various layers of environmental influence on lifestyle is the Dahlgren-Whitehead model of health, see Figure 2. The model introduces three environmental layers of health determinants consisting of: 1) social and community networks, 2) living and working conditions, and 3) general socio-economic, cultural, and environmental conditions [56]. So, when health promotion interventions are being developed, these layers of environmental influences should be considered.

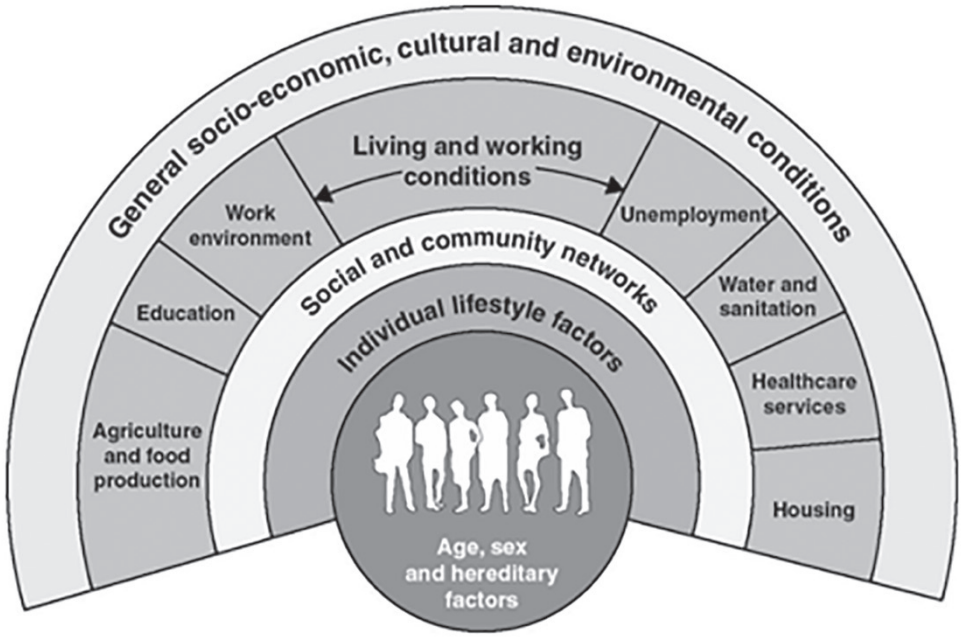

Figure 2: Dahlgren-Whitehead model of health [56].

Health promotion interventions for the general population often do not reach people with ID, because many of them do not have the required independence, money, and literacy skills to participate [15,57]. Furthermore, people with moderate to profound ID do not spend much time in settings where environmental interventions are implemented.

Existing research on people with ID tends to focus on program-based interventions aimed at individual lifestyle behavior and often does not take environmental health determinants into account [58-61]. The same applies to efforts in practice to support healthy living. Two Dutch reviews on health promotion efforts among ID support providers have revealed that they focus mainly on individual behavior change, group behavior change, and interpersonal support [62,63]. Although these efforts are provided in the daily-life settings of people with ID, they are often short term and not embedded in organizational policy after the program ends, and this impedes sustainable health benefits over time [62,63]. Also, the organizational culture and education of support staff in ID support organizations are centered mainly on treating health problems [64].

People with ID themselves have acknowledged the need for a supportive context for healthy living, as they have identified support from their social environment and facilities in the physical environment as necessary for them to be able to make healthy choices [65]. Studies on barriers to, and facilitators of, healthy living, as perceived by stakeholders that support people with ID, also identify environmental facilitators of healthy living such as

support from others, sense of safety, facilities for physical activity and healthy eating, and the embedment of health promotion policies of ID support organizations [5-7,65-72]. However, these studies lack a holistic view on how multi-facetted factors in ID support settings support a healthy lifestyle.

So, the focus of health promotion on addressing resources and the context of positive health is limited in efforts to promote healthy living for people with ID. To improve the effects of ID support organizations' efforts toward health promotion, health promotion should be embraced on a multi-level basis, whereby it is normalized in organizational culture [64,70,73,74]. Targeting environmental determinants in care settings where people with ID live, work, and engage is expected to be beneficial for the health and wellbeing of people with ID, thereby potentially adding to the current health promotion research and practice for this population.

Settings approach

A major development in health promotion is the so-called 'settings approach' initiated after the Ottawa charter for health promotion [75]. In this charter, creating supportive environments for health was defined as an action area. In the settings approach a setting is defined as: "The place or social context in which people engage in daily activities in which environmental, organizational and personal factors interact to affect health and wellbeing"[1]. Often, a setting has physical boundaries, a range of people with defined roles, and an organizational structure [76]. As a health promotion strategy, the settings approach adopts a salutogenic perspective on health and focuses on environmental determinants of health [75] – for example, better access to healthy food choices in everyday-life settings [77,78]. The Healthy Cities, Healthy Universities, and Healthy School projects are well-known examples where the settings approach resulted in transformed policies, organizational structures, and community action to facilitate healthy living and participation [79-81]. This settings approach has not yet been implemented in ID support settings. Developing healthy settings for people with ID can contribute to goals of the United Nations (UN) and the World Health Organization (WHO). Working toward healthy settings for people with ID aligns with the UN sustainable development goals on reducing inequities and promoting health and wellbeing and with the UN convention on the rights of people with disabilities [82,83]. This approach contributes also to the WHO goals on increasing health equity and developing enabling environments for people with disabilities [84].

A key benefit of a settings approach is that it includes dynamics and interactions within the setting. This is in line with systems thinking, which is also often applied in settings approaches. Systems thinking addresses problems as part of a system in which all components should be considered to change a situation. Therefore, it is useful for studying the complex context of health promotion to facilitate social change [85]. Three

main principles of the settings approach and systems thinking adopted in this thesis are discussed below.

Firstly, stakeholder involvement in research and co-designing and implementing health promotion actions is key to facilitating system-wide change in practice. Stakeholder analysis can be used to get an overview of stakeholders in a certain setting and provide insight into their importance, influence, interests, values, knowledge, and perceptions [41,86]. In research, stakeholders can contribute by sharing experiential knowledge in the development of appropriate data collection, data quality and relevant outcomes [87,88]. In practice, stakeholders can share their insights on systemic problems and resources and relationships between actors in a setting [85]. This can help to identify what actions are needed and assess whether or not an action is systemically desirable and culturally feasible, that is, relevant to the situation and meaningful to those involved [89]. Also, stakeholders can contribute to implementing actions as they have the insight into the system's network and inter-personal relationships that is necessary for planning, obtaining resources, and mobilizing change [90].

Secondly, the settings approach embraces a whole-system perspective. This implicates that, in organizational settings such as ID support settings, attention should be paid to the macro, meso, and micro level of social, cultural, environmental, and economic determinants [91-94]. Furthermore, the settings approach considers reciprocal relationships within the system and between subsystems, as well as relationships with the wider environment [Chapter 16 in 95]. This implicates that health promotion actions are not isolated from their context but, rather, addressed as part of a system in which all components should be considered to change a situation [96]. So, a good overview of a setting is needed before actions can be designed and taken.

Thirdly, settings are viewed as complex adaptive systems, implicating interaction of the system with the wider environment of inputs, throughputs, outputs, and impact [75,92]. To create change in a setting's health-promoting capacities, organizational change is needed to target the nucleus of the setting, the structures, the culture, and the core processes relevant for the health of people engaging in the setting [77]. Also, as systems keep changing, the current situation within a setting should be considered to develop actions that can be added in the system to promote healthy living. Stakeholders can be given this capacity to implement actions to address behavioral and environmental factors and embed health within the routines and the culture of a setting [97,98]. In sum, guiding principles for this thesis are stakeholder involvement, a whole-system perspective, and viewing settings as complex adaptive systems.

Research questions

The overall aim of this thesis is to gain insight into the contextual factors that support the physical activity and healthy nutrition of people with ID and to develop an asset mapping

tool for practice to improve the health-promoting capacities of ID support settings. This thesis focuses on residential and daytime support settings of ID support organizations for people with moderate to profound ID in the Netherlands. The three main research questions are:

1. Who are the stakeholders in health promotion practice for people with ID and how can they be involved in research and practice involving the settings approach?
2. What concepts and environmental assets are important for conceptualizing healthy settings for people with ID?
3. Can the asset mapping tool provide a comprehensive view of available assets in ID support settings and does it provide actionable knowledge for stakeholders to improve the health-promoting capacities of a setting?

Research setting

This thesis is part of the research project *Ondersteunen van een gezonde leefstijl van mensen met een verstandelijke beperking; de krachten gebundeld*, funded by ZonMw and a large network of Dutch research groups, ID support organizations, and knowledge centers. Four research groups were involved that each collaborate with ID support organizations through their own sub-networks: Academic Collaborative 'Stronger on Your own Feet' (*Sterker op eigen benen*), center of expertise 'Active Ageing of people with ID, research center on profound disabilities', and academic collaborative 'GOUD'. Through these sub-networks, the following 19 ID support organizations were involved in this project; De Zijlen, Talant, Sprank, Cosis, 's Heerlenloo, Koninklijke Visio, Siza, Pluryn, De Swaai, De Trans, Vanboeijen, Philadelphia, Dichterbij, Driestroom, ORO, Koraal, Abrona, Amarant, and Ipse de Bruggen. Also, knowledge centers were involved: Knowledge center for sport and physical activity, VG Belangenplatform Drenthe, Vitale Zorgverlener, Platform EMG (knowledge center for parents and caregivers of people with profound and multiple disabilities), and Vilans.

The research project involved two PhD projects: the project presented in this thesis and Annelies Overwijk's PhD project on training for daily care professionals to support people with ID with physical activity and healthy nutrition. Although these are two separate PhD projects, the researchers collaborated closely to inform each other about preliminary results, inform the network on the progress of their projects, and collaborate in recruitment for the study in which the products for practice were implemented (Chapter 8 in this thesis). The studies presented in this thesis were undertaken within the academic collaborative 'Stronger on Your own Feet' and, in the study presented in Chapter 8, ID support organizations from the center of expertise 'Active Ageing of people with ID' were also involved. Collaboration involved: 1) participation on the advisory board, 2) assistance in the recruitment of study participants, and 3) dissemination of study results.

Stakeholders from ID support organizations and people with ID were actively involved in all studies to facilitate the use of experiential, practical, and research-based knowledge and involve people with ID in matters that affect them. This took the form of engagement of an advisory board and application of an inclusive research approach. The inclusive research approach involved a structural collaboration by the PhD candidate with two co-researchers, that is, two experts-by-experience. For four hours a week, they worked together on the project, combining experiential and research-based knowledge in designing, executing, and interpreting the results of the studies. In each phase, they decided together upon the level of involvement of the co-researchers, which ranged from consultation, to advising and collaboration. In this process, the principles of the consensus statement on inclusive health research were adopted [87]. The advisory board, consisting of clients with ID, daily support professionals, health professionals, and a manager from various ID support organizations, met 2–4 times per year. The board members provided practical advice on the design and execution of the studies and helped in sharing the results with people with ID and with employees of ID support organizations.

Outline of this thesis

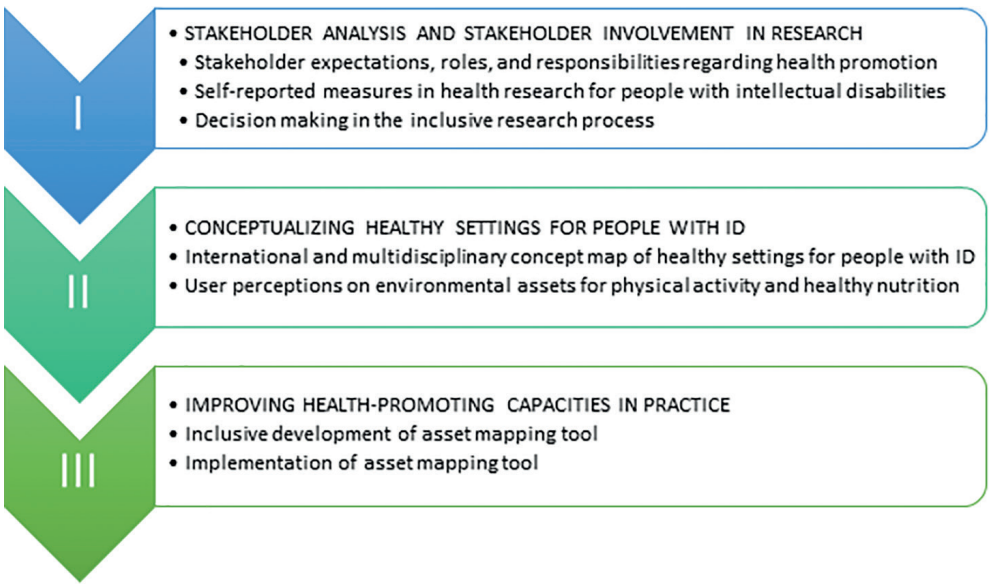

Figure 3: Outline of thesis.

Chapters 2 to 8 of this thesis present the studies that address the three research questions visualized in Figure 3. Part I focuses on stakeholder analysis and stakeholder involvement in research. **Chapter 2** presents a stakeholder study in which stakeholders that support people with ID with healthy living were identified. These stakeholders shared

their expectations of, perceived roles and responsibilities in, and perceived facilitating and hindering factors for, health promotion for people with ID. Four workshops were conducted to identify stakeholders, and 29 semi-structured interviews were conducted with stakeholders. **Chapter 3** describes an inclusive process of adjusting and testing lifestyle questionnaires. The researchers with and without ID adjusted the scales and tested them on suitability (n=40) and test-retest reliability (n=15). **Chapter 4** describes how decision making took place in an inclusive research team of researchers with and without ID. Decision making regarding four studies, described in Chapters 5 to 8, was reflected upon by the research team.

Part II presents the development of the conceptual framework of healthy settings for people with ID. In **Chapter 5**, a concept mapping study, an integrative mixed-methods approach, is used to develop a conceptual framework of healthy settings for people with ID. In the international and multidisciplinary concept mapping study, 41 researchers specialized in either healthcare for people with ID or healthy settings participated. In phase one, participants participated in an (online) brainstorming session and created statements about what a (healthy) setting for people with ID looks like. In phase two, participants sorted these statements into clusters and rated them on level on importance. In **Chapter 6**, the conceptual framework is refined by obtaining perspectives of people with ID. This involved a Nominal Group Technique study on assets supporting healthy nutrition and physical activity in ID care settings. Fifty-one participants – people with mild/moderate ID and proxy respondents for people with severe/profound ID – were involved in two group meetings where ideas were generated and ranked.

Part III focuses on developing and implementing a tool to improve the health-promoting capacities of ID support settings. The results in Chapters 5 and 6 informed the first version of the asset mapping tool, called DIscovering Health-promoting Assets in Settings for people with Intellectual Disabilities (DIHASID). The tool aims to identify perceived environmental assets and points for improvements regarding support for healthy nutrition and physical activity for people with moderate to profound ID in settings where they engage. In **Chapter 7**, the DIHASID tool is developed into a comprehensive, clear, and usable tool for environmental asset mapping that people with ID and other users of ID support settings can use. An iterative process is used, whereby input from expert interviews (n=7), cognitive interviews with end-users (n=7), and pilot-testers (n=16) lead to amendments to the tool. **Chapter 8** involves the implementation of the DIHASID in four ID support settings. Fifty-seven users completed the DIHASID and gave insights into the extent to which the tool can provide a comprehensive view of availability, user-satisfaction, and dreams regarding assets for physical activity and nutrition and the ability of the tool to provide actionable knowledge for improving health-promoting capacities.

Finally, **Chapter 9** includes a reflection on the main findings, strengths and limitations, and recommendations for practice and future research.

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PART

Stakeholder analysis and stakeholder involvement in research

CHAPTER

2

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

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Health Promotion International, doi: 10.1093/heapro/day059

Abstract

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.

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 Schrojenstein 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.

Methods

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

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).

Phase 1: stakeholder identification

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.

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.

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).

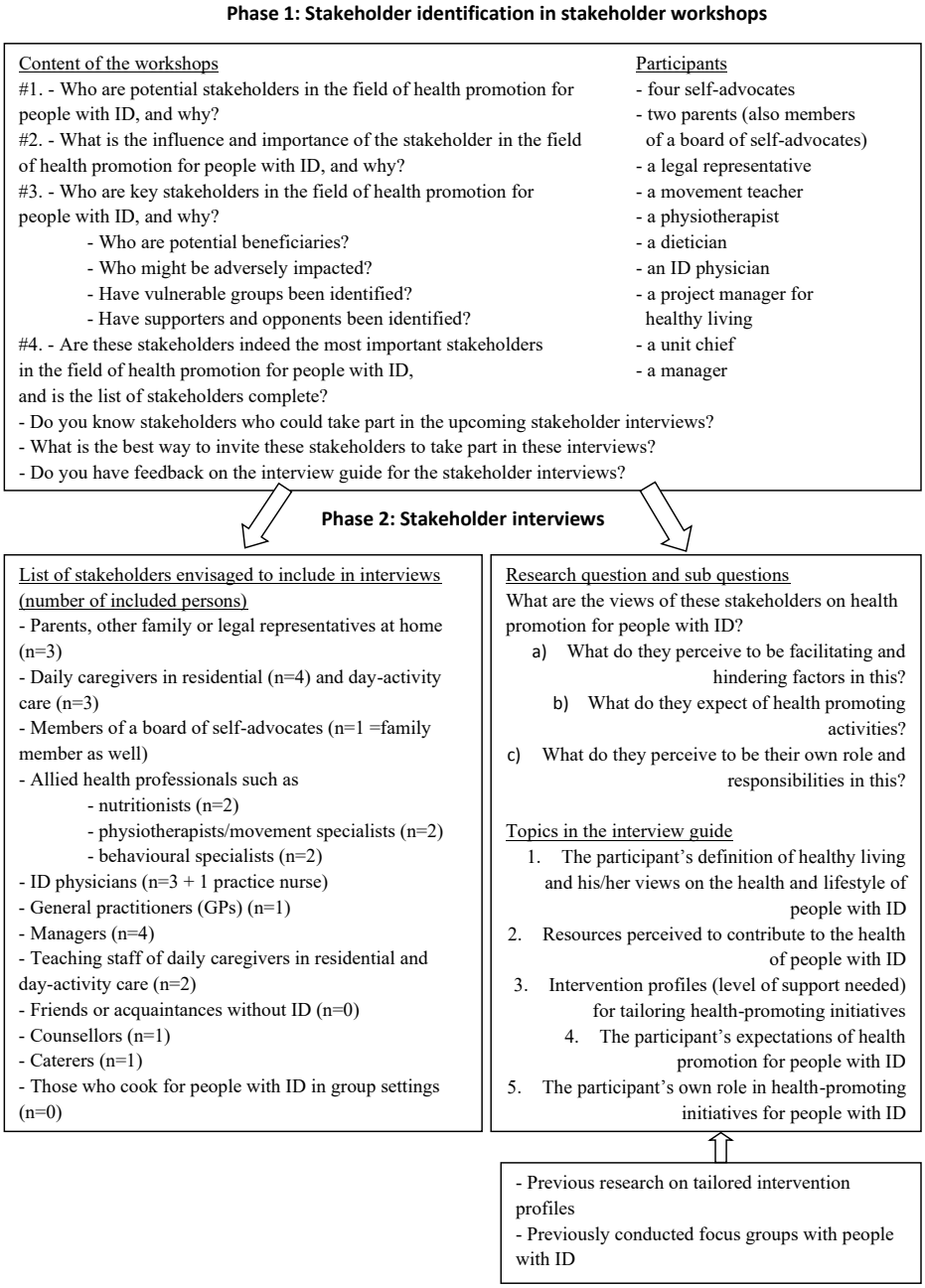

Figure 1: Participants and content of phases 1 and 2.

Phase 2: stakeholder interviews

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 ≥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.

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.

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 (.. and ..): 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 1: Consecutive steps, aims and results of the coding process.

Step	Action	Aim	Result
1	Grouping fragments of the tran-scripts using the five topics of the interview protocol (..)	First, top-down segmenta-tion of data	Raw data divided into five segments: views, resources, profiles, expectations, and own role
2	Selecting respondent perspec-tive keywords from fragments within each of the five segments (..)	Bottom-up coding and focus-ing of data	Coded and focused text frag-ments
3	Arranging the actual text frag-ments into three primary do-mains, each related to one re-search question (.., ..)	Identifying possible subcate-gories within each primary domain	A taxonomy of primary do-mains and possible subcatego-ries
4	Discussing relations between primary domains and subcatego-ries (all authors)	Identifying definite subcate-gories and their mutual rela-tions within each primary domain	Three primary domains and their subcategories as pre-sented 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

Results

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 2: Identified stakeholders, their influence and importance, and reported reasons for being stakeholders.

Stakeholders, influence and im-portance	Why are these persons seen as stakeholders?
Daily caregivers in residential care *very influential; critical player*	• role modelling • provide information on healthy lifestyles • decide on menu, order menu at caterer • support a healthy lifestyle • provide (un)healthy snacks • signalling function • execute management decisions in their own way • need to work together with, and be supported by, parents/ family at home/ managers
Management *significant influence/very influential; critical player*	Makes policy on healthy living: • food (preparation) • available time and money for cooking and exercising • provides guidelines to daily caregivers on healthy lifestyles • (lack of) inclusion of healthy lifestyles in individual care plans • (lack of) inclusion of healthy lifestyles in their vision statement
Daily caregivers in day-activity care *significant influence; critical player*	• activities often involve cooking and physical activity
Board of self-advocates *significant influence; critical player*	• signalling function
Counsellor *moderate influence; critical player*	• advise on a healthy lifestyle
Person with ID him/herself *moderate influence; significant importance*	• preferences • needs • motivation • self-regulation
Parents/other family/or legal representatives at home *moderate influence; significant importance*	• role modelling • provide food at home • (lack of) stimulation to exercise • signalling function • need to work together with, and be supported by, daily caregivers

Group of people with ID lived with *moderate influence; significant importance*	Group pressure and culture: • group preferences • current group lifestyle
Friends Acquaintances *moderate influence; significant importance*	• increase awareness of a healthy lifestyle • by eating together you take more time to eat, which is healthier • being physically active together gives more pleasure and enhances adherence
Allied health professionals such as nutritionists, physiotherapists, movement specialists, and behavioural specialists *some influence; significant importance*	• provide correct information on healthy lifestyles • provide tips on healthy food and physical activities adapted to personal capability
ID physician *some influence; significant importance*	• include healthy living in individual care plan • provide correct information on healthy lifestyles • use their superiority in changing a patient's lifestyle
General practitioner (GP) *some influence; significant importance*	• provide opportunities for semi-independently living patients with ID to live healthily
Teaching staff of daily caregivers *little/no influence; significant importance*	• supporting a healthy lifestyle must be incorporated in daily caregivers' education
Caterer *little/no influence; moderate importance*	• provides food for many service providers for people with ID • their selection of foods can be (un)healthy
Those who cook for people with ID in group settings *little/no influence; moderate importance*	Need to (be instructed to) cook healthily: • meal composition • method of preparation
Everyone who has contact with a person with ID*	• role modelling • inspire to live healthily • provide food • healthy living must be on everyone's agenda

*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.

Phase 2: stakeholder interviews

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.

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.

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 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.*

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.

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 (Spassiani 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 kwaliteits-kader 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.

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.

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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CHAPTER

3

Self-reported measures in health research for people with intellectual disabilities: an inclusive pilot study on suitability and reliability

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BMC Medical Research Methodology, doi:10.1186/s12874-0180539-1

Abstract

The lack of suitable and reliable scales to measure self-reported health and health behaviour among people with intellectual disabilities (ID) is an important methodological challenge in health research. This study, which was undertaken together with co-researchers with ID, explores possibilities for self-reported health scales by adjusting, testing, and reflecting on three self-reported health scales. In an inclusive process, the researchers and co-researchers with ID adjusted the SBQ (sedentary behaviour), SQUASH (physical activity), and SRH (self-reported health) scales, after which a test-retest study among adults with ID was performed. Test outcomes were analysed on suitability and test-retest reliability, and discussed with the co-researchers with ID to reflect on outcomes and to make further recommendations. Main adjustments made to the scales included: use easy words, short sentences, and easy answer formats. Suitability (N = 40) and test-retest reliability (N = 15) was higher for the adjusted SQUASH (SQUASH-ID), in which less precise time-based judgements are sought, than in the adjusted SBQ (SBQ-ID). Suitability and test-retest reliability were fair to moderate for the SRH-ID and CHS-ID. The main outcome from the reflection was the recommendation to use SQUASH-ID answer options, in which less precise time-based judgements were sought, in the SBQ-ID as well. This study served as a pilot of an inclusive process in which people with ID collaborated in adjusting, testing, and reflecting on self-reported health scales. Although the adjusted self-reported measurements may be reliable and suitable to the target group, the adjustments needed may impair measurement precision. This study's results contribute to informed decision making on the adaptation and use of self-reported health scales for people with ID.

Background

In the current patient-centred paradigm, self-reports such as patient-reported outcome measures and health behaviour are highly valued in care and research. Self-reports, often collected via questionnaires, can help to make shared decisions and tailor treatment plans [1,2]. Socially disadvantaged groups, such as people with intellectual disabilities (ID), who have impaired social functioning and limited cognitive ability that developed before the age of 18 [3], are likely to be underrepresented in self-report studies [4-6] because of challenges in all steps of research: (1) sampling; (2) recruitment and gaining consent; (3) data collection and measurement; (4) intervention, delivery, and uptake; and (5) retention and attrition [7]. The present paper focuses on data collection and measurement.

In data collection on health behaviour and patient-reported outcome measures for people with ID, questionnaires are often proxy-administered [8-11]. It may be difficult to find good proxy respondents who have a high level of interaction with the person with ID, have known the person for a long time, and relate to the type of domain being queried [12]. Also, providing high quality answers can be difficult for proxy respondents, as shown in a study by Andresen and colleagues where proxies tended to overestimate impairment and underestimate health-related quality of life [13]. Besides the challenges of proxy-administered questionnaires [12], the need to listen to the views and experiences of people with ID themselves is increasingly acknowledged [14].

Self-reports of people with ID potentially contribute to the improvement of healthcare research for this group and the autonomy of people with ID, and answer their wish and democratic right to be involved in research [15-17]. Furthermore, self-reported instruments may contribute to the growing demand for inclusive research as required by funding bodies and national policies [18-20]. Despite the fact that the active involvement of people with ID in health research, either as respondents or as part of a research team [16], is increasingly popular [18,20,21], suitable and valid scales to collect self-reports on health and health-related behaviour among people with ID remain to be scarce [10,22]. Online questionnaires which allow for data collection among large samples are required as the field of research for people with ID is in need of studies with larger sample sizes. Also, compared with interviews, questionnaires are less prone to acquiescence, social desirability and nterviewer effect, which are important methodological challenges in data collection among people with ID [10,22,23]. So, adjusted versions of questionnaire scales designed for the general population are needed to tackle the methodological challenges of data collection among people with ID [10,12,22]. This pilot study aims to explore the applicability of self-reported health scales in research among people with mild ID, by adjusting, testing, and reflecting on three self-reported health scales together with co-researchers with ID.

Methods

Study context

Important contextual factors for study designs in which people with ID participate are: access to the population, ethical concerns, and the abilities of the target group [22,24].

First, poor access to the population is due to: A) a lack of population-based registries of this population [24,25], and B) organisational barriers to recruitment (e.g. obtaining organisational consent, communication problems, support of employees) when sampling through residential service providers [16,24]. In this study the opportunity was taken to recruit amongst the large group of Special Olympics participants. Second, the burden and potential benefits for this vulnerable participant group should be carefully considered from an ethical point of view. Both researchers and co-researchers with ID assessed the original self-reported health scales as too difficult. They deemed the administration of these scales a probable cause of unnecessary stress, and, therefore, unethical. Hence, this stresses the demand for adapted versions of the scales. Finally, the following characteristics of people with ID ought be taken into account: A) the heterogeneity of the cognitive and linguistic abilities of people with ID [22]; B) the difficulties that people with ID have in making time-based judgements and comparisons [22]; and C) the high tendency towards acquiescence among people with ID [12].

Data collection

This inclusive study on self-perceived health and health behaviours amongst people with ID consisted of three phases: (1) adjusting the three health scales; (2) performing an online test-retest study of the adjusted scales among people with ID; and (3) reflecting on the adjusted scales and the test-retest study results. To facilitate an inclusive approach, people with ID participated actively during the study as co-researchers [21] in phases 1 and 3. Five co-researchers who had been involved in previous studies by our research group were invited to participate in this research project because of their experience in advising on data collection.

Phase 1: inclusively adjusting the health scales

Three health scales frequently used in the general population were selected by the researchers. Adjustments to the scales, the informed consent procedure, and the outline of the online questionnaire for people with ID were discussed by two co-researchers and the principal researcher, resulting in a list of recommendations according to which the researchers adjusted the questionnaire. Then, the adjusted questionnaire was pilot tested by three other co-researchers. Their feedback, together with recommendations from relevant literature [10,12,22,23,26], was used by the researchers to develop the final questionnaire. The recommendations and the adjusted scales are described in the results section.

Phase 2: test-retest of the adjusted scales Sampling, recruitment, and informed consent

To test the adjusted scales among adults with mild ID, all adult participants in the Three Day March, part of the Dutch Special Olympics 2016, were invited to participate. The register for the Three Day March included email addresses for the participants' support person only. These support persons, often a family member or professional caregiver, received an invitation by email giving information on the study. They were asked to discuss participation in the study with the person(s) they supported and to discuss whether this person met the inclusion criteria of: having intellectual disabilities, being adult, being able to give informed consent, and being able to answers questions. When a support person served a group of up to five persons, a personalised invitation was sent for each person with ID. Support persons serving a group of more than five persons with ID received a general invitation followed by a phone call from the first author.

Risks of, and objections to, participation were deemed to be negligible in our study, which asks respondents to fill out a questionnaire on health-related behaviour and self-reported health. Potential respondents with sufficient decision capacity according to their support persons were asked to give informed consent, as suggested by Iacono and Murray [27]. After consent was expressed to the support person, the potential participants opened the online questionnaire. The first part of the questionnaire contained study information and concluded with three questions to check whether the respondent understood the study information and the informed consent procedure. Thereafter, informed consent was obtained online. At the end of the questionnaire, respondents were invited to participate in the retest, 2 weeks later.

Measurements

The original scales are the Sedentary Behaviour Questionnaire (SBQ), Short QUestionnaire to ASsess Health-enhancing physical activity (SQUASH), and a single-item scale on self-reported health (SRH). These scales are often used in health research [28–34]. The original scales are explained below. In the results section, the first phase of questionnaire adjustment, the informed consent procedure, and the adjustments to the three scales are reported.

The SBQ aims to measure the amount of time spent on nine sedentary activities: watching television, playing computer/video games, sitting while listening to music, sitting and talking on the phone, doing paperwork or office work, sitting and reading, playing a musical instrument, doing arts and crafts, and sitting and driving in a car, bus, or train. The question asked in the SBQ is: 'On a typical weekday/weekend day, how much time do you spend doing the following?' Answer options are: none, 15 min or less, 30 min, 1h, 2h, 3h, 4h, 5h, or 6h or more. The item, total hours per week spent on sedentary activities, is calculated by

multiplying weekday hours by five and the weekend day hours by two and summing these. Total hours spent on sedentary behaviour per day is calculated by dividing total hours per week by seven. Outcomes higher than 24 h per day are usually truncated to 24 h per day [35].

The SQUASH assesses physical activity levels and may be used to measure compliance with physical activity guidelines [36]. It contains questions about the following sets of activities: (A) commuting activities (walking to/from work school, bicycling to/from school), (B) leisure-time activities (walking, bicycling, gardening, odd jobs, and sports), (C) household activities (light household work, intense household work), and (D) activities at work and school (light work, intense work). For each activity, questions are asked about the number of days per week (open answer box), average time per day (open answer box), and effort (multiple choice: light, moderate, or intense) involved in the activity [36].

Finally, the question 'How would you rate your current general health on a scale from 1 to 10? (score 1=very bad, score 10=perfectly healthy)' aims to measure self-reported health (SRH).

Data analysis

The adjusted scales data, obtained in the online test and retest study, were analysed on suitability and reliability. Prior to analysis, data processing included the transformation of strings into numerical variables for the SBQ-ID according to the following rules: (1) answers such as 'no' and 'never' were given the numeric code '0'; (2) for answers containing a range of values, the middle of that range was used, e.g. 'two–three hours' yielded 2.5; and (3) soft quantifiers, such as 'rarely' and 'sometimes', were regarded as non-quantifiable answers. For the test-retest reliability of the SBQ-ID, missing values were coded as 0 h. Indicators for suitability were response rate and the proportion of non-quantifiable and missing values, respectively. For interval measurements, the test-retest reliability was investigated by means of the Intraclass Correlation Coefficient (ICC) with a 95% confidence interval (CI). For categorical variables, the test-retest reliability was investigated by means of Kappa with a 95% CI calculated using bootstrapping [37]. The ICC and Kappa values were interpreted as follows: 0.00–0.20 as poor, 0.21–0.40 as fair; 0.41–0.60 as moderate; 0.61–0.80 as substantial; and 0.81–1.00 as almost perfect reliability [38]. Convergent validity was estimated through the correlation, Kendall's tau (τ), between the two self-reported health scales (SRH-ID and CHS-ID). The statistical analysis was conducted using SPSS version 22.

Phase 3: reflecting on adjusted scales and results in group discussion

The results of the test-retest study and the adjusted scales were discussed in two separate group discussions with two and three co-researchers respectively, the principal researcher and a moderator experienced in group discussions with people with ID. A PowerPoint presentation and A3 posters were used to show the participants the adjusted questionnaire

and the results of the test-retest study. During the group discussions, the co-researchers reflected for each scale on the adjusted format and the results of the test-retest study and identified recommendations for further improvement. The transcription of the group discussions were thematically analysed [39] on: (1) reflections on adjusted questionnaire, (2) reflections on test-retest results, and (3) recommendations for further improvements to the questionnaire.

Results

Phase 1: inclusively adjusting the health scales

The discussion with the co-researchers with ID and the feedback from the pilot yielded the following general recommendations: (1) include questions to check whether the study information and the meaning of an informed consent is understood correctly, (2) group related questions, (3) depict per page or screen questions on one single theme only, and (4) explicitly allow the participant to ask for, and receive, help from a support person. Specific recommendations for the settings and layout of an online questionnaire were: (1) use of a clear font and large font size, (2) allow for item non-response, and (3) use multiple pages because scrolling down requires more motor skills than a single carriage return does. The co-researchers suggested many adjustments tapping clarity of language, such as use of easy words, easy answer formats, and short sentences. The co-researchers were indecisive on whether or not the SBQ and SQUASH, asking for hours spent on certain activities, had to be adjusted as the time-based judgement sought might be too in-depth. Hence, the SQUASH question format was altered, whereas the SBQ format was maintained, allowing comparison of suitability of both formats.

In the adjusted SQUASH (SQUASH-ID), the physical activities for which judgements were sought were the same as in the original SQUASH. However, the question format was altered from days per week, average time per day, and effort to intensity and days per week. For each activity, respondents were asked to report on (1) the intensity with which they did this activity by choosing one of the tick box options: never, sometimes, often, or always; and (2) days per week, by ticking the days of the week when they normally do this activity (tick box with Monday–Sunday).

For the adjusted SBQ (SBQ-ID), the question phrasing was slightly changed ('How many hours are you sitting on a weekday (Monday to Friday) when you are ...?') and an example was added. The co-researchers suggested changing the original multiple choice answer categories to an open answer box to allow respondents to express the time verbatim. Weekend days were split into Saturday and Sunday because activities on these days varied a lot according to the co-researchers.

The question 'What score between 1 and 10 do you give for your current general health? (score 1=very bad, score 10=perfectly healthy)' was rephrased as: 'What score

do you give your own health? (score 1=very bad, score 10=perfectly healthy)'. As recommended by the co-researchers, one other question was added, namely, the health ladder, which has been used previously [40]. The health ladder consisted of the question 'How healthy do you feel?' with the instruction 'Place the arrow on the health ladder; green is very healthy, red is very unhealthy'. The colours, or answer categories, on the ladder were green, yellow, light orange, dark orange, and red.

These points were all taken into account in the programming of the questionnaire in Limesurvey [41]. Estimated time to complete the questionnaire was between 15 and 30 min.

Phase 2: test-retest of the adjusted scales

Overall response

To pilot test the SBQ-ID, the SQUASH-ID, the Self-Reported Health scale for people with ID (SRH-ID), and the Coloured Health Scale for people with ID (CHS-ID), people with ID were invited to participate in this study (see Fig. 1). Some support persons who had received a personal invitation explained why they would not participate: the person with ID did not want to (N = 16), the person with ID did not meet the inclusion criteria (N = 14), or the support person would be absent during the study period (N = 2). In total, 40 persons filled out the questionnaire of which 31 with help from someone else. The group consisted of 18 males and 22 females and their age ranged from 18 to 76 (mean = 37, SD = 15.5). Participants lived in a community group home (N = 15), independent with ambulatory support (N = 10) or with their parents (N = 7). For daytime activities most participants reported day-care (N = 19), and paid work (N = 13), where few reported voluntary work (N = 3) or school (N = 4). Out of the 40 respondents, 23 were willing to be approached 2 weeks later for the retest. Of these 23 persons, 15 persons answered the questionnaire twice.

Sedentary behaviour questionnaire for people with ID (SBQ-ID)

For the SBQ-ID, missing values varied per question, from 2 to 12 out of 40 respondents. The provisions of non-quantifiable values also varied per question, ranging from 3 to 6 out of 40 respondents. These non-quantifiable answers were: 1) soft quantifiers such as 'sometimes', 'not much'; 2) time frames such as 'in the morning', 'before bedtime'; 3) conditional answers such as 'depends on ….', 'varies every day'; 4) related to the respondents disability such as 'wheelchair bound', 'I cannot do that'; or 5) associative answers such as 'coffee' when hours of sitting while eating and drinking was asked.

Due to missing values, the total hours of sedentary activities could be calculated only for 16 respondents and had a median of 10 h per day (IQR 6.00–15.61). One respondent reported a total time spent on sedentary activities per day that exceeded 24 h. The reliability test of the SBQ-ID showed heterogeneous results (Table 1). The item ICC ranged from poor for Eating or drinking (0.09) and Transport (– 0.14) to substantial for Playing

a musical instrument (0.79). Because of high numbers of non-quantifiable answers, the summary values hours of sedentary activity on a weekday/Saturday/Sunday/per week could be calculated for four to eight respondents: too few to calculate ICC.

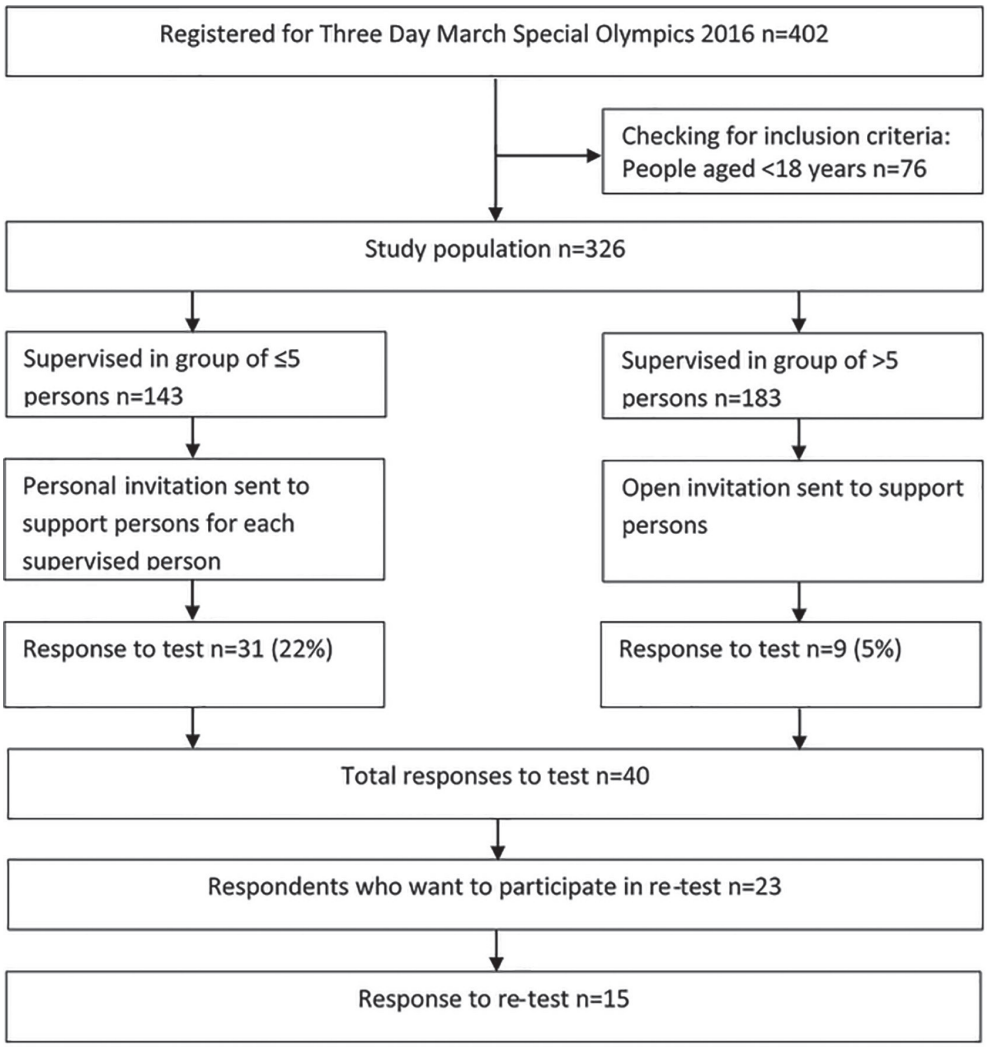

Figure 1: Participation flowchart.

Table 1: SBQ-ID, Test suitability and Test-retest reliability.

Items	Test suitability (n=40)		Test-retest reliability (n=15)	
How many hours are you sitting on a weekday/Saturday/Sunday* when you are	**n non-quantifiable answers**	**n missing answers**	**n**	**ICC (95% CI)**
Eating or drinking	3	5	14	0.09 (-0.45;0.56)
Watching TV, movies, or series	3	8	13	0.35 (-0.22;0.74)
Using computer or tablet	3	7	13	0.26 (-0.32;0.69)
Listening to music on radio or CD	4	9	12	0.30 (-0.30;0.73)
Using a telephone	4	8	13	0.36 (-0.22;0.75)
Playing a musical instrument	5	11	12	0.79 (0.42;0.94)
Reading	6	10	13	0.26 (-0.31;0.70)
Travelling	5	9	11	-0.14 (-0.66;0.48)

* This question was asked separately for a weekday, Saturday, and Sunday; values are reported for average per week.

Short QUestionnaire to ASses Health-enhancing physical activity for people with ID (SQUASH-ID)

For the SQUASH-ID, suitability can be reported only for the intensity items because the days per week items had tick boxes as answers option, making it impossible to distinguish missing values from 'none of these apply'. For the intensity items, missing values were low; only 1 out of 40 respondents did not answer the items. As the answer options were closed, there were no non-quantifiable values. The test-retest reliability results are shown in Table 2. For the days per week items, 7 out of the 11 SQUASH-ID items showed a substantial to almost perfect correlation. In Table 2, Kappa (95% CI) is also reported. Kappa values (95% CI) for the test-retest of *intensity* were predominantly moderate.

Table 2: SQUASH-ID, Test-retest reliability.

Items	Test-retest reliability (n=15)		
	n	n of days per week ICC (95% CI)	Intensity Kappa (95% CI)
Commuting activities			
Walking	15	0.92 (0.77;0.97)	0.61 (0.21;1.00)
Biking	15	0.88 (0.67;0.96)	0.40 (0.04;0.72)
Activity at work and school			
Light activities	15	0.27 (-0.26;0.68)	0.18 (-0.09;0.48)
Intense activities	15	0.80 (0.51;0.93)	0.45 (0.08;0.77)
Household activities			
Light household activities	15	0.82 (0.54;0.93)	0.45 (0.10;0.78)
Intense household activi-ties	15	0.57 (0.10:0.83)	0.65 (0.30;1.00)
Household activities			
Walking (leisure time)	15	0.72 (0.48;0.93)	0.50 (0.13;0.81)
Bicycling (leisure time)	15	0.64 (0.21;0.86)	0.17 (-0.22;0.61)
Gardening	15	0.61 (0.16;0.85)	0.55 (0.13;0.88)
Odd jobs	15	0.14 (-0.38;0.60)	0.63 (0.32;1.00)
Sports	15	0.18 (-0.35;0.62)	

Self-Reported Health scale for people with ID (SRH-ID) and Coloured Health Scale for people with ID (CHS-ID)

The two single-item scales on self-reported health from Phase 1 were the SRH-ID requiring a 1–10 score and the CHS-ID requiring a colour score. Thirty-five persons answered the CHS-ID and 36 persons answered the SRH-ID. The median score was *yellow* for the CHS-ID and *8* for the SRH-ID. Although answers provided to the CHS-ID covered all answer options, respondents gave no scores below 5 on the SRH-ID. For both single-item scales, the test-retest reliability was about 0.40. While answers to the CHS-ID scale covered all answer options, on the 1-10 scale respondents did not give a score below 5. The correlation between the CHS-ID and SRH-ID scales was strong ($\tau = 0.73$, $P < 0.001$) (Table 3).

Table 3: SRH-ID and CHS-ID, Test suitability and Test-retest reliability.

Scales	Test suitability (n=40)	Test-retest reliability (n=15)	
	n missing answers	n	ICC (95% CI)
SRH-ID	4	15	0.39 (0.14;0.74)
CHS-ID	5	13	0.41 (0.13;0.71)

Phase 3: reflecting on adjusted scales and results in group discussion

Reflections and recommendations for the adjusted scales

In the reflection phase the co-researchers discussed the results of phase 2 and identified possible improvements of the adjusted scales.

In the SBQ-ID many missing and non-quantifiable answers had been reported. Looking at these results the co-researchers believed the question format, in which *hours spent on an activity on a weekday* were queried, to be very difficult. This questions format was deemed to be too difficult because it requires remembering activities over a week's time, awareness of time, and numeracy skills. Suggested possible improvements include: 1) use the same answer type as used in the SQUASH-ID; 2) structure items in the categories 'commuting activities', 'activity at work, day-care and school', 'household activities' and 'leisure time activities'; and 3) give examples of the items.

Comparing the results of the SBQ-ID with the SQUASH-ID, the co-researchers valued the SQUASH-ID scale as much easier due to clearer answer options and requiring less detailed time-based judgements (estimating and calculating hours was not needed). Nonetheless, the co-researchers identified some possible difficulties in SQUASH-ID, including understanding what intense activities mean, understanding the difference between leisure time and work, and fitting in activities which are not specifically asked for in the items. Recommendations to improve the SQUASH-ID included: 1) clarify intense activities by listing physically intense activities; 2) change the questions on walking and biking in leisure time slightly, into *'Do you walk in leisure time, that is not to get to school, work or day care?'; and 3) providing example activities.*

Comparing the results of the CHS-ID and SRH-ID, the co-researchers considered the CHS-ID as easier than the SRH-ID. A suggestion to make the SRH-ID easier was to include a row of numbers or to combine the colour scale with the numbers. Differences between colours on the CHS-ID were unclear for one co-researcher which could be mitigated by the use of more contrasting green and red colours and by placing a line between the colours, or adding numbers. For the SRH-ID, the co-researchers reflected that respondents might not have given answers lower than 5 because a 6 is usually valued as sufficient and below 6 as insufficient and bad.

Reflection on test-retest differences

The co-researchers provided possible explanations for the test-retest results. The co-researchers argued that people might have become aware of their own behaviour and therefore gave another answer the second time they answered the questions, which describes a research effect. Co-researchers also suggested changes in health state, leisure activities, or weather conditions, and, forgetting may have caused differences between test and retest answers.

Discussion

This study aimed to explore possibilities for self-reported health scales by adjusting, testing, and reflecting on self-reported health scales in an inclusive manner. In the adjustment phase, the co-researchers with ID gave recommendations for the online questionnaire in general and specifically for the scales. Please note that the items of the SQUASH and SBQ were used as starting point. Pilot testing the adjusted scales on suitability among 40 persons with ID suggested that the SQUASH-ID was more suitable than the other scales, as non-response was higher in the SBQ-ID, the SRH-ID, and the CHS-ID. Pilot testing the adjusted scales on test-retest reliability among 15 persons with ID showed a test-retest reliability of the items of the three scales, varying between *poor* and *almost perfect*. In the reflection phase, building on the results of phase 2, further recommendations were done. Answer options that require less detailed memories and calculations, like *days per week* and *intensity* as used in the SQUASH-ID, seem to be more suitable to the cognitive abilities of people with mild ID than answer options in the SBQ-ID.

Inclusively adjusting and reflecting on health scales

By using the described approach, we aimed to gain a better insight into what is needed to design measurement instruments that better fit the capacities of people with ID and how this may be achieved in an inclusive manner. The co-researchers provided a respondents' perspective by carefully and patiently discussing the scales, which, according to the literature, is a very important issue in adapting measurements for self-reports of people with ID [10,26]. In the adjustment phase, co-researchers helped to apply general rules stated in the literature on informed consent, questions, easy language and settings and lay out of the questionnaire. [10,12,14,22]. During the reflection phase the adjusted scales and test outcomes provided clues for the in-depth discussion on further recommendations. Concluding, thanks to the inclusive process, the researchers and co-researchers got insights that they might not had gained otherwise.

Suitability and reliability of the scales

The results from this pilot study indicate that the better a scale is adjusted to the target population, the better the scale performs on suitability. In our study, the SQUASH-ID scale, in which less precise time-based judgements are sought, was more suitable than the SBQ-ID scale. Although caution should be taken when discussing the test-retest results because of the small sample size, it seems the SQUASH-ID scale performs better than the SBQ-ID scale. Although our results suggest that simplification of time-based judgements increases suitability and yields more reliable data, there is a cost also; it affects measurement equivalence to the original scales and reduces the precision of the concepts' measurement.

In general, it is difficult to develop reliable items and scales to measure time-based judgements of behaviour [42,43]. The test re-test reliability of the SQUASH-ID and SBQ-ID were somewhat lower than in the studies where the original scales were tested (with N=49 and 50, respectively) [35,36]. This lower reliability could be partly explained by the fact that behaviour patterns among people with ID are prone to change as a consequence of changed availability of support persons. The item test-retest reliability of the SQUASH-ID and SBQ-ID varied strongly, just like in the original scales. The two versions of the single-item questionnaire for self-reported health (the SRH-ID, and the CHS-ID) correlated strongly with each other, although both showed poor test-retest reliability. Further research on these scales is necessary, including the exploration of the last recommendations of the co-researchers.

Strengths and limitations

To the best of our knowledge, this study piloted an inclusive process in which people with ID contributed to the adjustment, testing, and reflecting on the suitability and reliability of self-reported health scales for people with ID. This study suffered from difficulties in recruitment, a commonly mentioned problem in studies among people with ID [25]. Despite the fact that a large sample was invited to participate, only a small group participated in our study. Support persons were gatekeepers to participating in this study, a commonly mentioned problem in studies among people with ID [24]. The retest phase took place over summer a period (holidays) during which, support to fill in the questionnaire can be hampered. The heterogeneity of people with ID with respect to levels of cognitive and linguistic abilities need be taken into account [22]. Our sampling strategy aimed at people with mild ID who are interested in physically activity, which is a selective sample.

This study described a pilot of scale adjustment by means of an inclusive procedure. Further research is needed to test reliability and investigate (face, content, construct, concurrent and predictive) validity of the SBQ-ID, the SQUASH-ID, the CHS-ID, and the SRH-ID in a large and diverse sample of people with ID. Testing responsivity of the scales in a longitudinal study is required to investigate whether these scales could be used in physical activity intervention studies. Although testing the scales in an online questionnaire may be convenient and time saving, testing the scales in a face-to-face mode should also be considered as this might improve response rate and decrease item non-response. In general, to increase the quality and availability of measurement instruments for this population, more projects are needed in which scales are adjusted together with people with ID and tested on reliability and validity.

Conclusion

This study contributes to informed decision making on using self-reports and adjustments to self-reported health scales for people with ID. This pilot study's results indicate that commonly used self-reported measurements can be made suitable to people with ID in an inclusive process and may yield reliable scales. Nonetheless, scale adjustment may reduce measurement equivalence with original scales.

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CHAPTER

Shared decision making in inclusive research: Reflections from an inclusive research team

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Manuscript under review

Abstract

Health research is increasingly conducted with the active involvement of the people who are the focus of the research. People with intellectual disabilities also participate actively in research; this is called inclusive research. Collaboration in inclusive research teams requires shared decision making (SDM). Although inclusive studies frequently refer to decision making as something the research team does together, the decision-making process is still a black box. This study aims to provide more insight into SDM in inclusive research by reflecting on a three-year collaboration in an inclusive research team. The research questions are: 1) What kinds of decisions were made by the inclusive research team? 2) How were decisions made by the inclusive research team? 3) What impact did the decisions have on the research project?

To answer the research questions, the inclusive research team members reflected on SDM in their project by looking at the documentation of the inclusive research process and by conducting semi-structured interviews with the team members. In all research steps, the inclusive research team decided together on the content and procedures of the studies and on role division. Reflecting on SDM resulted in an overview of the types of decisions made, the information needed, and the processes involved in making shared decisions. Furthermore, the team provided an account of how SDM impacted positively on the quality of the studies and empowered people with intellectual disabilities. This study provides insights into types of decisions, SDM processes, and their impact on research. The insights give an overview of opportunities and key components of SDM that can foster conceptual clarity of SDM in inclusive research. In practice, inclusive research teams can use these insights to advance successful ways of sharing power in decision making, having an impact on the quality of research, and empowering people with intellectual disabilities.

Introduction

In the last decades, health research has increasingly been conducted with active involvement of people who are the focus of the research (Elberse, 2012; Harrison et al., 2019). This also occurs in research among people with intellectual disabilities (Bigby, Frawley, & Ramcharan, 2014; Puyalto, Pallisera, Fullana, & Vilà, 2016; Walmsley, Strnadová, & Johnson, 2018). Research in which co-researchers with intellectual disabilities are part of the research team and whose perspectives are included is called inclusive research (Walmsley & Johnson, 2003; Walmsley et al., 2018). Inclusive research studies frequently refer to the activities in their research as something that the research team decides together. To our knowledge, literature is scarce on shared decision making (SDM) in inclusive research. Therefore, the current study aims to provide more insight into (facilitators of) SDM by reflecting on decision making in a long-term inclusive research project.

Previous studies have focused primarily on the facilitators and challenges of collaboration and decision making in inclusive research (Brookes et al., 2012; Buettgen et al., 2012; Chapman & McNulty, 2004; Michell, 2012). Facilitators include competences of researchers and co-researchers, such as communication skills and a strong trusting relationship between (co-)researchers (Embregts, Taminiau, Heerkens, Schippers, & Van Hove, 2018; O'Brien, McConkey, & García-Iriarte, 2014). Challenges also relate to relationships, in combination with role divisions and power dynamics between the members of the inclusive research team (Embregts et al., 2018; García Iriarte, O'Brien, & Chadwick, 2014; Nind, 2017; O'Brien et al., 2014). These challenges vary in line with the varying degrees of involvement that co-researchers can have in research projects, ranging from providing advice to having control over the study (Bigby et al., 2014). Frankena and colleagues found that partnership and shared decision making power were perceived as crucial in a collaborative form of the inclusive research team (Frankena et al., 2016; Frankena, Naaldenberg, et al., 2019). However, SDM in inclusive research is perceived as challenging because researchers without intellectual disabilities need to support researchers with intellectual disabilities by providing information in language that is easy to understand and guiding the decision making process without taking control over of the decision (Ellis, 2018; Puyalto et al., 2016). These studies highlight that the form of co-researchers' involvement is intertwined with power distribution in decision making and that it is important to find a balance in the inclusive research team to make shared decisions.

Although previous studies have provided examples of research activities by examining the facilitators and challenges of inclusive research, few studies have identified the types of decisions made during inclusive research activities. For example, Flood and colleagues reflected on the decisions that they made as co-researchers, such as planning, data collection methods, information sheets for informed consent, and supportive materials for researchers during data collection (Flood, Bennett, Melsome, & Northway,

2013). However, the information and the processes used to make shared decisions during inclusive research activities and the actual impact of SDM on inclusive research remain a black box (Brookes et al., 2012; Buettgen et al., 2012; Michell, 2012).

Inclusive research could learn from the literature on SDM processes in clinical settings, in which patient-centred care is increasingly guided by patient values and patient participation. Theory and review studies on SDM in clinical settings have produced conceptual frameworks in which key components of SDM are identified (Bomhof-Roordink, Gärtner, Stiggelbout, & Pieterse, 2019; McCaffery, Smith, & Wolf, 2010; Waldron et al., 2020) that show overlaps with concepts discussed in inclusive research (Ellis, 2018; McCaffery et al., 2010; Nind, 2017). In general, SDM is based on: (1) understanding the situation and decisions to be made, (2) knowledge transfer and exchange in which awareness of risks, limitations, benefits, alternatives, and uncertainties are discussed, (3) identifying individuals' values and preferences and imagining future (health) states, (4) deliberation and participation in decision making at a desirable level, and (5) implementing a shared decision and making it consistent with individuals' values and preferences, or postponing the decision (Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010). Throughout the SDM process, additional components such as determining roles or next steps, fostering partnership, offering time, tailoring information, and taking patient expertise into account are deemed important (Bomhof-Roordink et al., 2019). Similar to the findings about SDM having a positive impact on patient empowerment, decisions, (patient) outcomes, and effective use of health care (Joosten, De Jong, de Weert-van Oene, Sensky, & van der Staak, 2011; Légaré et al., 2014; Schattner, Bronstein, & Jellin, 2006), SDM in inclusive research is expected to contribute to the empowerment of people with intellectual disabilities, research outcomes, quality of life, and the reduction of health (care) inequalities (Frankena, van Schrojenstein Lantman–de Valk, et al., 2019).

The current study examined decisions, SDM, and their impact on research by reflecting on the activities undertaken by an inclusive research team during a three-year collaboration in a long-term research project. The inclusive research team, consisting of researchers with and without intellectual disabilities, reflected on their collaboration and the SDM processes involved. The aim was to provide insight into SDM in inclusive research by answering the following questions: 1) What kinds of decisions were made by the inclusive research team? 2) How were decisions made by the inclusive research team? 3) What impact did the decisions have on the research project?

Methods

Setting

In this study, we reflected on the decisions, the (facilitators of the) decision making process, and their impact on research in the inclusive project Healthy Settings for People with Intellectual Disabilities. The funding organization encouraged the involvement of co-

researchers with intellectual disabilities in the execution of the project, which encompassed four studies on health promotion for people with intellectual disabilities (see Table 1). The members of the inclusive research team were two co-researchers with intellectual disabilities (Anneke and Henk) and an academic researcher (Kristel, PhD student), all employed by the Radboud university and medical centre. They followed a training course for inclusive research teams (Sergeant et al., 2020). The decision making reflected upon in this study was part of a three-year collaboration by the inclusive research team who worked together on a weekly basis (March 2017 to July 2020). Advisors on the project were the thesis committee of two senior researchers and two professors and the project's advisory group, including two persons with intellectual disabilities, two caregivers, three health professionals, and one manager. Others involved were a programme manager from the funding organisation, and the leaders of the Healthy Settings for People with Intellectual Disabilities project, whose approval was needed if the inclusive research team wished to make changes to the project's proposal (i.e., a broad description of research topics, aims, and methods, see Table 1). A diagram of the actors involved is presented in Figure 1.

Materials and procedures

The materials used to identify decisions and reflect on SDM were: 1) documentation developed during the project and 2) semi-structured interviews. The documentation included: the project proposal, scientific articles on studies within the project, agendas for the weekly meetings, the project plan, a timeline on a poster visualizing the team's achievements, and a research clock including pictures and words about the research steps in each study (see Figure 2). The agendas, plan, timeline, and research clock were developed by the team to maintain an overview of the project and foster memory and comprehension. The semi-structured interviews focused on how the research phases were conducted, what enabled decision making in inclusive research or made it difficult, and the impact of decisions on the project. During the interviews with the co-researchers, the timeline and research clock were used to help them remember the activities that they had undertaken. The team chose Jenneken, a member of the thesis committee and project leader, to conduct the semi-structured interviews as they thought that her overview of the project and her ability to talk in easily understood language would be beneficial for the interviews. The interviews were audio recorded and conducted in November 2019.

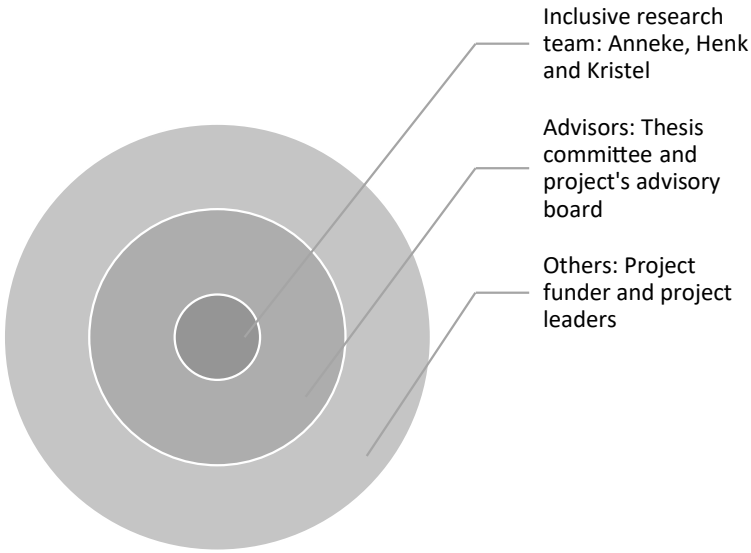

Figure 1: Actors involved in decision making about the inclusive research studies reflected upon in this article.

Table 1: Overview of aims, data collection methods and participants in four studies on healthy settings for people with intellectual disabilities.

Study	Aims	Data collection methods	Participants
1	Develop a conceptual framework of healthy set-tings for people with intellectual disabilities (authors' reference)	Mixed methods: Concept mapping	Researchers specialized in healthcare for people with intellectual disabilities and/or healthy settings
2	Identify assets supporting healthy nutrition and physical activity in care settings for people with intellectual disabilities (authors' reference)	Mixed methods: Nominal group technique	People with mild/moderate intellectual disabilities and proxy respondents for people with severe/profound intellectual disabilities
3	Develop a comprehensive, clear, and usable tool for environmental asset mapping that people with intellectual disabilities and other users of support settings for intellectual disabilities can use (authors' reference)	Mixed methods: Interviews, questionnaire, observations, and group discussion	Experts, people with mild/ moderate intellectual disabilities, proxy respond-ents for people with severe/profound intellectual disabilities, and daily care professionals
4	Provide insight into the extent to which the environmental asset mapping tool is able to provide a comprehensive view of availability, user-satisfaction, and dreams regarding assets for physical activity and nutrition and the ability to provide actionable knowledge to improve the health-promoting capacities of support settings for people with intellectual disabilities (authors' reference)	Questionnaire	People with mild/moderate intellectual disabilities, proxy respondents for people with severe/profound intellectual disabilities, and daily care professionals

Analysis

First, we identified the inclusive research team's decisions by analysing the documentation and the interviews. Kristel analysed the study documentation to determine the list of decisions made in each research step according to the research clock. Tessa (an academic researcher and former colleague of the inclusive research team) and Jenneken analysed the transcripts of the interviews by coding the text on decisions made. Next, they labelled them to determine the list of decisions made in each research step as shown on the research clock (Figure 2). Tessa, Jenneken, and Kristel discussed the similarities and the differences on these lists until they agreed on a final list of decisions made in the research steps in the four studies in this project. Second, a discussion was held amongst the inclusive research team using the list of decisions to further reflect on the information and the processes used to make the decisions and the impact of these decisions on the project. The discussion was audio recorded and led by Tessa. Finally, Kristel developed a summary of this discussion, structured in line with the research steps, which was again checked by Anneke, Henk, and Tessa. This was used in the results description in the next section together with the list of decisions.

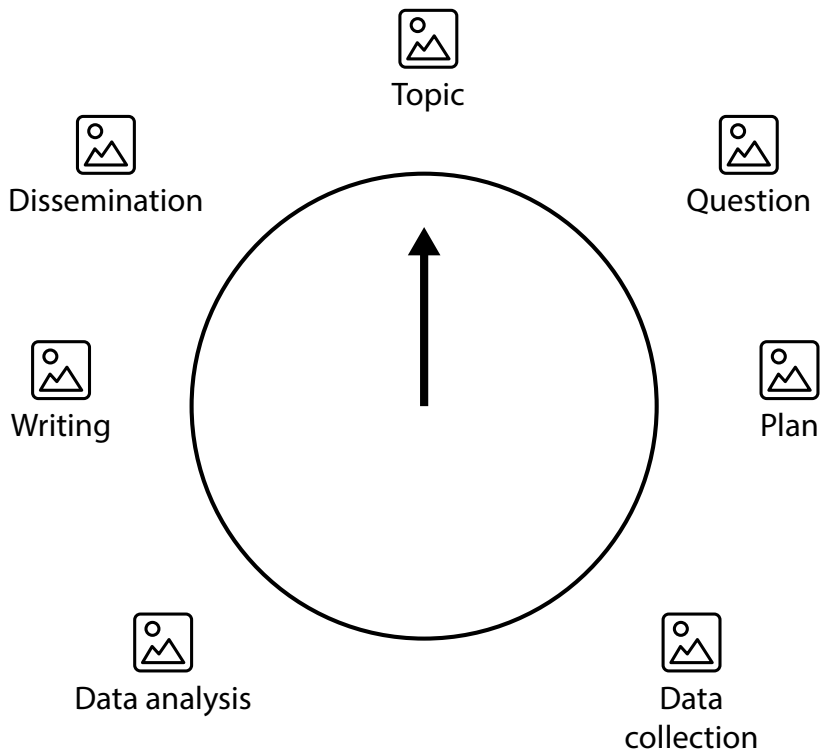

Figure 2: Research clock including pictures and words about the research steps in each study reflected upon in this article.

Results

An overview of the identified decision types and their impact on the research project are summarized and structured according to the research clock steps across the four studies shown in Table 2. The activities and information used in SDM are described in the next sections, also ordered by the research clock steps and including descriptions of exemplary situations.

Decision making on research topic, aim, and questions

For the research topic, aim, and questions, the team made decisions on how to familiarize themselves with the topic of healthy settings and how to operationalize the research questions in the project proposal. Activities that the team undertook for these decisions related to discussing the topic and the project proposal. For example, to familiarize themselves with the topic, the team walked across the university campus to take pictures of what they experienced as enabling or constraining for a healthy setting. Also, in discussing the operationalization of the research question for Study 1, Anneke and Henk indicated that the topic was too difficult to talk about with people with intellectual disabilities. After several meetings and discussions with the team and advisors to identify methods to talk with people with intellectual disabilities about healthy living settings, the team and the thesis committee decided that a preliminary study was necessary; this was approved by the funding organization. Information that proved specifically helpful in this phase included the project proposal, experiential knowledge on conducting research among people with intellectual disabilities, and an overview of relevant scientific literature and skills to summarize relevant parts in easily understood language.

The impact of SDM on the research topic, aim, and questions included, for example, the addition of Study 1 to the project. In Study 1, the sub-themes of the healthy settings topic were identified and translated into easily understood language to enable people with intellectual disabilities to talk about the different components in a setting that could enable healthy living; this was a prerequisite to carrying out Study 2 of the project. Further examples of the impact of SDM are provided in Table 2.

Decision making on study plan

For the study plans, decisions were made regarding the research method, inclusion criteria, informed consent procedure and forms, data collection methods, and supportive materials for participants and researchers during data collection. For each of the studies, seven steps were taken. First, Kristel gathered and summarized the relevant literature. Second, the team discussed the relevant literature and the study description in the project proposal. Third, the team decided which data collection method to use while building the draft plan, whether and what adaptations and supportive materials were needed for meaningful participation by participants, recruitment, and the informed consent

procedure. Fourth, Kristel drafted the information letters for potential participants and informed consent forms based on the decisions made and the recommendations for what should be included. Fifth, Anneke and Henk improved the easily understood language in the easy-read versions of the information letters and informed consent forms. Sixth, draft plans were discussed with the thesis committee and the project's advisory group (for Studies 2–4) and adjusted according to their feedback. Finally, the plans, information letters, and informed consent forms for participants were submitted to the Medical Research Ethics Committee of the Radboud University and Medical Centre to request approval.

To make decisions in these phases, information was needed on available scientific knowledge on the research topic and methods and experiential knowledge on easily understood language and the involvement of participants with intellectual disabilities in research. To apply this knowledge together, the team deemed the following as helpful: asking one another questions, explaining, discussing the scientific and the experiential knowledge together in easily understood language, and using visual supports.

The impact of these decisions on the project was, for example, that the methods were drafted and evaluated in small iterative steps enabling step-by-step improvements to enable meaningful participation of people with intellectual disabilities as study participants (e.g., in Studies 2 and 3).

Decision making on data collection and analysis

For data collection and analysis, content-related decisions were made and roles were divided. Content-related decisions included, for example, how to conduct data analysis inclusively. For Study 2, the focus groups' voice recordings were used instead of transcriptions, and data were analysed by making a visual web of ideas on paper instead of using software. For the role division, team discussions were held to prioritize the tasks and the roles on which the co-researchers would spend their available time.

Information on which the co-researchers based these decisions included their perceptions on costs and benefits of involvement for themselves and the research project. Therefore, by looking at the topics, types of participants, data collection methods, and types of data and analyses, the team discussed the roles and the talents that the team members could deploy. Identified benefits of co-researchers' involvement included putting people at ease, supporting the use of easily understood language, practical support, hearing participants' opinions, and looking at the data from the perspective of a person with an intellectual disability. The costs turned out to relate to time needed (executing data collection, participants' travel time, data analysis), disturbance of regular working times (flexibility needed) and its impact on work/life balance, and adjustments needed to conduct data analysis inclusively; for example, analysing voice recordings instead of transcripts.

The impact of these decisions was that experiential knowledge was deployed in most of the data collection and analysis where people with intellectual disabilities were involved as participants. For example, in the development of the DIscovering Health-promoting Assets in Settings for people with Intellectual Disabilities (DIHASID) tool, both experiential and scientific knowledge was used to determine the changes that needed to be made to improve clarity, based on the cognitive interviews with people with intellectual disabilities.

Decision making on writing and dissemination

For writing and dissemination, the team made decisions regarding the summaries for study participants, involvement in scientific publications, what information to incorporate in scientific publications, easy-read summaries of publications, and other ways of disseminating study results. Activities in these research steps were similar for all four studies. Study participants received a summary of the results, and an easy-to-read summary was written. Therefore, Kristel drafted these documents and Anneke and Henk improved the text with easily understood language. For the scientific publications, the team and the thesis committee discussed and decided who met the criteria for authorship. Like other co-authors, Anneke and Henk decided whether or not they agreed with the manuscript and provided feedback. To enable them to do this, Kristel explained the manuscript in easy wording in Dutch so that Anneke and Henk could provide verbal feedback. Also, the team, with advice from the advisory board, decided on other ways of disseminating study findings. For example, for Study 2, they decided to develop a video blog.

To make decisions about who should be involved in writing and dissemination, specific attention was directed at each person's interests and talents. All the researchers were interested in informing study participants and people with intellectual disabilities in general about the results, but Kristel also wanted to inform other researchers about the results by publishing scientific articles. Competences needed for this task include English scientific writing skills and skills on easy writing for people with intellectual disabilities.

The impact of these decisions included the team developing easy-read summaries and video blogs on the study results. Also, researchers with intellectual disabilities were acknowledged as authors of scientific publications that provide insight into the inclusive research process.

Table 2: Overview of decision topics and decision makers per research step.

Research step	Decisions identified by research team	Examples of impact of the decisions on the research project
Topic and aim	How to become familiar with the topic	The team members familiarized themselves with the topic by using photovoice and group discussions.
Research question	Operationalize the research question and describe it in easily understood language	The development of the DIHASID tool was operationalized in three steps: what improvements can be made to make the tool 1) clear, 2) com-prehensive, and 3) usable in practice? (Study 3).
	Decide whether preliminary study is needed to be able to design a method to answer the research question (Study 1 was added)	With approval from the funding organization, Study 1 was added to the project. This enabled conceptualization and clarification of the healthy settings topic in sub-themes in easily understood language.
Study plan	Define aspects of research plan: choice of research method, adapta-tions to research method, inclusion criteria for participants, informed consent procedure	For Study 3, the team used the questionnaire appraisal system to develop the interview protocol for the cognitive interviews to improve the clarity of the tool.
	Develop research information letters and informed consent forms	In all studies, easy-read information letters and informed consent forms were available for potential participants with intellectual disabilities to enable informed decision making on whether or not to participate.
	What to incorporate in draft of the data collection methods	The draft of the DIHASID tool was built on both the experiential and the scientific knowledge of the research team (Study 3).
	How to improve the drafts of the data collection methods	In Study 2, an adjusted nominal group technique (NGT) was tested among the advisory board. The team incorporated their feedback and split the NGT into two sessions to enable meaningful participation of people with intellectual disabili-ties as study participants. In session 1, ideas were generated using pictures of themes. In session 2, participants voted on the importance of ideas in a step-by-step voting procedure.
	What supportive materials to provide for study participants	In Study 2, participants received handouts for the idea generation session and the voting ses-sion to facilitate the process.
Data collection	Who is involved in data collection, how and when?	Anneke and Henk were involved in data collection in group meetings with people with intellectual disabilities (Studies 2 and 4).
	Roles during data collection	Study participants with intellectual disabilities were supported by Anneke and Henk who made them feel at ease and assisted in talking in easily understood language.
Data analysis	Who is involved in data analysis, how and when?	Anneke and Henk were involved in data analysis to identify and sort ideas (Study 2), determine the changes needed to make the DIHASID tool clear and usable (Study 3), and determine what to incorporate in the infographic of the study results (Study 4).
	Roles during data analysis	Experiential knowledge was used to interpret the data gathered among participants with intellectual disabilities, as Anneke and Henk applied their role as expert-by-experience and co-researcher.

Table 2: continued.

Research step	Decisions identified by research team	Examples of impact of the decisions on the research project
	How to conduct data analysis inclu-sively	Adjusted data analysis was used, such as analysing voice recordings and making a visual web of ideas in Study 2.
	Content-related decisions during data analysis	Experiential knowledge was used to determine what changes to make to the DIHASID tool based on input from participants (Study 3).
Writing and dissemination	Content and layout of the summary for study participants	All study participants with intellectual disabilities were reminded about the input they gave in the study by providing them with an easy-read summary.
	Whether or not Anneke and Henk are co-authors of a scientific publication and in what form	Anneke and Henk are co-authors of the publications relating to Studies 2 and 3.
	What information to incorporate in scientific publications	The scientific publications include information on the inclusive research process.
	Content and layout of the easy-read summary	For each publication, an easy-read summary was developed.
	Other, creative ways of disseminating study results	For Studies 1 and 2, a vlog was made to share the study results.

Discussion

This is the first study to examine the types of decisions, information used, and processes for SDM, and the impact of SDM on inclusive research, by reflecting on a long-term research project. The study provides potential groundwork for future research on SDM in inclusive research by showing that SDM processes in the inclusive project aligned with key components of SDM in clinical settings.

Our study showed examples of shared decisions made throughout the entire research cycle of the project. To create understanding of the situation and decision(s) to be made (Stacey et al., 2010), the inclusive research team identified the different decision types that they made together. The decisions ranged from relatively straightforward and previously identified research activities (e.g., planning, development of easy-read information letters, and choice of output materials) (Flood et al., 2013), to crucial modifications to the research project such as operationalizing the research topic, choosing and adjusting research methods, and adding an entire extra study to the research project. The variety of decisions presented in this study provides an overview of the opportunities for SDM that other inclusive research teams could use to realize fully their potential impact on their research project.

The information used for SDM and the processes to foster SDM in inclusive research align with key components of SDM in clinical settings. Knowledge transfer and exchange, and discussing risks, limitations, benefits, alternatives, and uncertainties (Bomhof-Roordink

et al., 2019; McCaffery et al., 2010; Stacey et al., 2010; Waldron et al., 2020), consisted of inclusive research on sharing and discussing scientific and experiential knowledge as a research team; for example, the stepwise development of a research plan whereby the team members complemented one another by each bringing something unique and created what Walmsley et al. (2018) call a shared space to work fruitfully together as an inclusive research team.

Identifying individuals' values and preferences for SDM (Stacey et al., 2010) was also recognized in our reflections on the SDM process. In inclusive research, this was focused on preferences based on interests, values, competences, and skills that are helpful for role divisions. For example, the team members indicated with whom and how they wanted to share the results based on what they valued as important and interesting.

Deliberation and participation in decision making (Stacey et al., 2010) consisted of inclusive research discussions during research activities amongst the research team; for example, developing a data collection method and discussions on task division. For the latter, the team looked at their skills and competences and where these were of most added value to spend the limited time effectively, in the literature reflected as a discussion on team members' roles (Frankena et al., 2018). Whereas in some inclusive research studies the aim is to collaborate in every aspect, our approach was similar to other cases where the inclusive research team worked in partnership, with task division based on individual strengths and skills needed for tasks at hand (Frankena, Naaldenberg, et al., 2019; Nind, 2017). For data collection and analysis in particular, co-researchers' costs of involvement (e.g., extra time and disturbance of regular working times) were also discussed in task division to prevent overburdening. This potential risk of overburdening co-researchers aligns with reflections of other researchers in inclusive research (Nierse & Abma, 2011; Turk et al., 2012).

In addition to the key components of SDM, facilitators of SDM mentioned in this study include time for decision making or determining roles and next steps, as also mentioned in the SDM literature (Bomhof-Roordink et al., 2019). Furthermore, individual and team-related preconditions mentioned in this study relate to literature on facilitators of collaboration in inclusive research teams; for example, motivation and communication skills, knowing one another well, a trusting relationship, and awareness of power dynamics (Embregts et al., 2018; Nind & Vinha, 2014; O'Brien et al., 2014).

Overall, the impact of the decisions made in the inclusive research project resulted in a transparent stepwise research approach in which the inclusive research team deployed individual and team skills. This improved the quality of the studies and empowered people with intellectual disabilities, thereby aligning with potential inclusive research outcomes previously identified (Frankena et al., 2018). Decisions relating to changes to the original research plan and adjusted data collection methods tailored the research project and accompanying studies, thereby facilitating the meaningfulness of the project outcomes in practice and enabling meaningful participation by participants with intellectual

disabilities. The involvement of co-researchers in data collection and analysis led to a comfortable environment for participants during data collection and strengthened the quality of data analysis by the inclusion of experiential knowledge. The positive impact of co-researchers' involvement in data collection to create a comfortable environment and of data analysis to include experiential knowledge aligns with the literature (O'Brien et al., 2014; Tilley et al., 2021). Decisions on dissemination facilitated valorization of the research and led to the availability of easy-read information, information on inclusive research processes, and co-authorship of researchers with intellectual disabilities in scientific publications.

The study's findings should be interpreted in the light of a few limitations. Although this paper reflected on SDM in four studies, these studies were conducted by one team who conducted one large project. Being critical or negative about the SDM processes might have been difficult for the team members who had a working relationship and knew one another well. To foster open and honest reflections, the team chose to be interviewed individually by someone outside the team with whom the team members had a trusting relationship. To enable the co-researchers to remember decisions and SDM processes, our reflective study involved two steps. First, we created an overview of decisions based on interviews and document analysis, which helped co-researchers in the second step to remember and discuss how SDM took place, what facilitated the process, and what impact it had. Even though this thorough process supported the co-researchers in their reflections, it was still difficult for them to remember all the details of SDM.

To the best of our knowledge, SDM processes of inclusive research teams have not yet been reflected upon by inclusive research teams themselves. Whereas Ellis (2018) explored decision-making processes from the standpoint of an academic researcher, this study provides perspectives of researchers both with and without intellectual disabilities. This inclusive reflection on decision making is a major strength of this study. Previous studies have provided insight into competences needed and role division for collaboration in inclusive research, and this study adds to this knowledge base by providing insight on decision making and SDM processes by using key components of SDM from clinical settings. These insights can contribute to more awareness of decisions and processes that foster fruitful ways of sharing power in inclusive research teams, which is at the centre of inclusive research practice (Walmsley & Johnson, 2003), Furthermore, as this study provides conceptual clarity of SDM, it may contribute to the quality of future inclusive research (Walmsley et al., 2018).

Conclusion

Reflecting on SDM as an inclusive research team provided insight into the types of decisions that inclusive research teams can make per research step regarding content and task division. The variety of decisions presented in this study presents an overview of

the opportunities for SDM that inclusive research teams can exploit to achieve their full potential impact on their research project. Also, the overview of key components of SDM processes, which align with SDM in clinical settings, contributes to more conceptual clarity of SDM in inclusive research. In practice, this can create awareness and foster fruitful ways of sharing power in decision making and collaboration in inclusive research teams.

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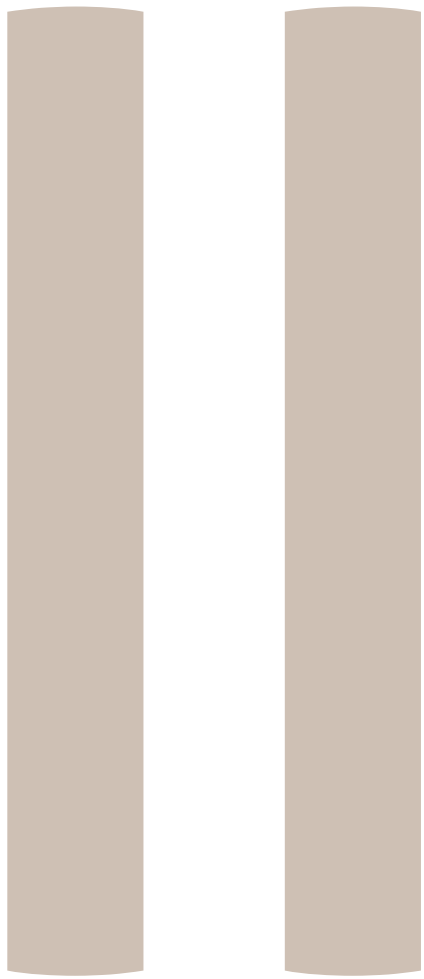

Conceptualising healthy settings for people with intellectual disabilities

CHAPTER

5

Towards healthy settings for people with intellectual disabilities

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Health Promotion International, doi:10.1093/heapro/daz054

Abstract

People with intellectual disabilities (ID) depend on their environment for support to live healthily. The characteristics of healthy settings for people with ID are unknown. This study aims to conceptualize healthy settings for people with ID by conducting an international and multidisciplinary concept mapping study. As theoretical framework the settings approach, an ecological model with a whole system focus towards health promotion, was used. The integrative mixed-methods approach of this study involved concept mapping with researchers specialized in healthcare for people with ID and researchers specialized in healthy settings. The 41 participants generated statements that were later sorted and rated. Findings encompass 13 clusters relating to the social environment, the physical environment and societal preconditions. Specific factors of healthy settings for people with ID include: (i) universal design of the physical environment, (ii) the role of care professionals in the social environment to empower people with ID, (iii) possibilities for care providers to contribute to a health-promoting setting and (iv) preconditions that allow people to engage in society. These factors can be used in strategies to apply the approach in practice and give directions to put in place policies on developing enabling environments and decreasing health inequities.

Introduction

Developing healthy settings has the potential to develop a supportive context within the places in which people engage and to support individuals to live a healthy life. The settings approach adopts an ecological model, meaning that there are dynamic interrelations between personal and environmental factors that promote or damage health. Settings are also viewed as complex systems, and the settings approach takes a whole system focus aimed at embedding health within routines and the culture of the setting (Dooris, 2013). In line with this dynamic view, health can be promoted if inside agents are given the capacity to address behavioral and environmental factors within the setting (Whitelaw et al., 2001). The settings approach has been applied in many contexts, of which the Healthy Cities, Healthy Universities and Healthy School projects are well-known examples resulting in transformed policies, organizational structures and community action to facilitate healthy living and participation (Mŭkoma and Flisher, 2004; Dooris et al., 2012; Schwab et al., 2015). People with ID are characterized by limitations in adaptive behavior, communication and cognitive processes (APA, 2013). Applying the settings approach in care settings where people with ID live, work, and engage is expected to be beneficial to the health and well-being of people with ID for three major reasons.

Firstly, people with ID experience health inequalities, and face problems with accessing healthcare, prevention and health promotion (van Schrojenstein Lantman-de Valk and Walsh, 2009; Beange and Durvasula, 2001; Cooper et al., 2004; Heslop et al., 2014). Reducing health inequalities by developing a healthy settings approach for people with ID is in line with the United Nations (UN) sustainable development goals on reducing inequities and promoting health and well-being, the UN convention on the rights of people with disabilities, and the World Health Organization (WHO) goals on increasing health equity and developing enabling environments for people with disabilities (United Nations, 20151,2; WHO, 2008 ; WHO, 2011). The settings approach has been mainly applied in on contexts where vulnerable populations often do not engage and elaborating on this approach for people with ID addresses this imbalance (Whitelaw et al., 2001).

Secondly, the settings approach should be applied in setting where people with ID engage. Specialized care providers have a considerable influence on the everyday life and living environment of people with ID. These specialized care providers can provide housing, help with daily living tasks, organized daytime or work activities, and medical care for people with ID (Ras et al., 2013). However, the organizational culture of these care providers and the education of support staff is mainly centered on treating health problems rather than on health promotion (O'Leary et al., 2018).

Thirdly, existing health promotion faces difficulties and research identified the need for developing a supportive context for healthy living. Traditional lifestyle interventions for the general population often do not reach people with ID, because many of them do not have the required independence, money and literacy skills to participate (Messent

et al., 2000; Robertson et al., 2000). Health promotion efforts in care settings for people with ID and through care provider services are focused on individual behavior change, group behavior change and interpersonal support. These efforts have often failed to produce sustained health benefits over time (Heller et al., 2011; Scott and Havercamp, 2016; Naaldenberg et al., 2013). People with ID themselves have expressed the need for a supportive setting, including support from the social environment and facilities in the physical environment that enable healthy choices (Kuijken et al., 2016). Setting-related factors, including support from others, embedment of health promotion policies in organizations for people with ID and facilities for physical activity and healthy eating are mentioned in the literature as facilitators of healthy living (Temple and Walkley, 2007; Caton et al., 2012; Bergström et al., 2014; Kuijken et al., 2016; Sundblom et al., 2015) which implies a need for developing supportive contexts for health living of people with ID. To develop healthy settings for people with ID, account must be taken of the characteristics of the population, their support needs, their living environment and the core business of the setting (Dooris, 2016).

Our study aims to conceptualize healthy settings for people with ID. To better tailor health promotion for people with ID a multidisciplinary approach was chosen making use of the knowledge base on healthy settings and needs of people with ID (Dooris, 2016; Poland et al., 2011, Naaldenberg et al., 2013). To study factors that are perceived to be important for developing a healthy setting for people with ID, this study takes an international perspective in which researchers with experience in academic research and practice (development and delivery of care) participate in a concept mapping study.

Materials

Study design

In this study an integrative mixed method approach was used in which both quantitative and qualitative data were collected and combined in the analysis (Cresswell, 2013). The concept mapping method was used because it is specifically developed to explore complex concepts and generate conceptual frameworks (Kane and Trochim, 2007; Trochim and Kane, 2005). The method consists of two data collection phases: (i) brainstorming guided by focus prompts and (ii) sorting and rating of statements resulting from phase 1. Including the experts both in generating topics as well as in structuring the topics into clusters was expected to lead to a conceptualization of healthy settings which is reflective of perspectives of diverse groups (Kane and Trochim, 2007).

Procedures

Expert sampling was used to select researchers who were involved either in healthcare for people with ID or in healthy settings. Names of potential participants were acquired from: (i) the conference proceedings of the health conference of the International Association for

the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) in June 2017; (ii) members of the European Training Consortium in Public Health and Health Promotion; (iii) the network of members of the research team; and (iv) key authors with expertise in the field of healthcare for people with ID or field of healthy settings. A list of 66 potential participants was agreed among the research team. For the brainstorming phase, live and online brainstorming were combined. Live brainstorming facilitates group interaction and focuses on the task, and online brainstorming allows people from different countries to participate (Kane and Trochim, 2007). Potential participants who attended the IASSIDD 2017 health conference were personally invited to participate in live brainstorming during the conference. Other potential participants received an email invitation to the online brainstorming. Prior to the live and the online brainstorming, the study information was repeated and informed consent was obtained. The live brainstorming session was voice-recorded.

The participants in the brainstorming phase were invited to participate in the next phase of sorting and rating. Additional participants were recruited to include more healthy settings researchers. The data were collected between 21 June 2017 and 31 October 2017, supported by Concept System Global MAX software.

Participants

The response rate for the brainstorming phase was 62% (n=41) and to the sorting and rating phase 65% (n=32). In the brainstorming phase, 7 participants participated in live brainstorming and 34 in online brainstorming. Their field of expertise was either healthy settings (n=11 in the brainstorming and n=6 in the sorting phase) or healthcare for people with ID (n=30 in the brainstorming and n=26 in the sorting phase). The participants had on average 16 years of research experience and 15 years of experience as a practitioner (development and delivery of care). Participants were resident in the UK (n=12), the USA (n=6), the Netherlands (n=6), Canada (n=3), Australia (n=2), Ireland (n=2), Norway (n=2), Spain (n=2), Chili (n=1), Finland (n=1), Germany (n=1), Iceland (n=1), Italy (n=1) and Saudi-Arabia (n=1).

Data collection and analysis

The phases, actions and results of data collection and analysis are described in Table 1. The brainstorming phase was guided by focus prompts that participants were asked to finish in as many different ways as possible. The focus prompts used were: 'I am a person with an intellectual disability and my setting looks like ....' and 'I am a person with an intellectual disability and my setting is promoting health by....' During the live brainstorming, the participants wrote their statements finishing the focus prompt sentences on post-its and expressed ideas within the group. For the online brainstorming, statements were entered in the online system. To stimulate participants' thinking process, previous participants' statements were visible. The brainstorm phase resulted in 445 statements. As required

by the procedure (Kane and Trochim, 2007) the statements were synthesized until a set of maximum 100 statements was reached These statements were used in the sorting and rating phase (Table 1).

In the online sorting and rating phase, the participants sorted each of the 100 statements into a category based on how similar in meaning or theme they were and named the categories according to their content. Next, the participants rated each statement, on a 5-point Likert scale, on its importance for healthy settings for people with ID. Participants were asked to complete questions on country of residence, expert group, years of academic experience, years of experience as a practitioner, and whether they wished to be mentioned in the acknowledgements of this article.

Data analysis was conducted using Concept Systems Global MAX software. The software created a similarity matrix indicating the number of people who placed a statement in the same pile by using the group's sorting data. This was analyzed using non-metric multidimensional scaling, and a point map was created, representing the distances and relations between statements. Hierarchical cluster analysis was used to divide the map into clusters. To determine each cluster size and name, the procedure recommended by Kane and Trochim was used, see Table 1 (Kane and Trochim, 2007). A stress value was calculated for the cluster map; this gives an indication of the goodness of fit of the map to the original similarity matrix, where a lower value represents a better overall fit. Bridging values, indicating how much a statement is anchored to those around it or bridges with statements further away, were calculated for all statements and clusters in the cluster map (Kane and Trochim, 2007). The importance ratings of the statements were analyzed by calculating the mean rate for each statement and for all clusters. To investigate sensitivity for sampling variation the jackknife resampling method was used. The original distribution of statements within clusters was compared with the 31 distributions resulting from systematically leaving out one participant from the sample (delete one jackknife). The amount of statements that were placed in another cluster was calculated.

Results

This section presents the results of the brainstorming and the sorting of statements, including the concept map with a description of each cluster, the sensitivity of the concept map and the importance ratings of statements and clusters.

Brainstorming and sorting of statements

The 100 statements that resulted from the brainstorming phase are presented in Supplementary Appendix S1. The participants sorted the statements on average in 9 clusters, with a minimum of 5 and a maximum of 16 clusters. In Supplementary Appendix S2, the point map is displayed, a visual representation of the relationship of the 100 statements to one another based on the sorting data of all participants.

Table 1: Phases, actions and results of data collection and analysis.

Phase	Action	Result
Preparation phase 1	Develop and pilot focus prompts to obtain information on 'health promoting characteristics of the setting' with re-search team (KVA, JN, TH, LV, KV, GL)	2 focus prompts
Phase 1: brainstorm	Create statements related to the focus prompts • 1 live brainstorming with 7 researchers • Online brainstorming with 34 researchers	455 statements
Preparation phase 2	Data synthesis of statements using the following procedure: • Split up statements containing >1 statement per sentence • Remove identical statements • Assign keywords to the statements and sort to bring overlapping statements together • Combine overlapping statements • Participant check on reduced set by 2 participants	Statements reduced to a set of 100 statements
Phase 2: sorting and rating	• 32 participants sort statements in categories and rate statements on a 5-point Likert scale	100 statements individually sorted and rated
Data analysis	(A) Multidimensional scaling: create a point map based on the sorting data to visualize the relationship and proximity of statements to one another	A) Point map
	(B) Hierarchical cluster analysis: create a cluster map: • Decide upper and lower limits of clusters (KV, JN) • Assess individually what cluster size retains most useful detail between clusters by looking at the bridging values and how the clusters merge together when moving from the upper limit to the lower limit of the cluster sizes (KVA, JN, TH, LV, KV, GL) • Choose final cluster size and names (examining cluster statements and top-10 cluster names generated by participants) (KVA, JN, TH, LV, KV, GL) • Calculate stress value and bridging values for the concept map • Estimate sensitivity of the concept map using jackknife	B) Final cluster map
	(C) Analyze importance ratings: Calculate mean rate for each statement, clusters, and cluster per participant group	C) Rating of statements and clusters

Concept map

The final concept map includes 13 clusters. Figure 1 depicts how the statements relate in a spatial representation to these clusters. Items that are closer to one another are more closely related to one another. The cluster with the highest coherence contains 5 statements and the cluster with the lowest coherence contains 11 statements. The stress value of the final concept map was 0.32, which is similar to other concept mapping projects where stress values range between 0.21 and 0.37 (Kane and Trochim, 2007).

The 13 clusters have the following names: *Healthy home environment, Enabling environment, Homely environment, Tailored environment, Encouraging support, Supportive network, Financial aspects, Confidence-building support, An open conversation, Values about healthy lifestyle, Healthcare and prevention, Accessibility and Opportunities to engage*. Based on the statements within the clusters, for each cluster a definition was formulated by the research team (see Table 2). The majority of clusters has mean bridging values ranging

between 0.35 and 0.65, representing an overall moderate level of cluster anchoring (Supplementary Appendix S1). Clusters *Healthy home environment* (0.07), *Enabling environment* (0.14) and *Homely environment* (0.21) have very low mean bridging values, indicating that the statements within these clusters are conceptually closely related to one another. The cluster *Opportunities to engage* (0.91) has a relatively high mean bridging value, which is a product of statements that were frequently grouped with items other than those in their immediate vicinity. Table 2 presents the clusters sorted by mean bridging value.

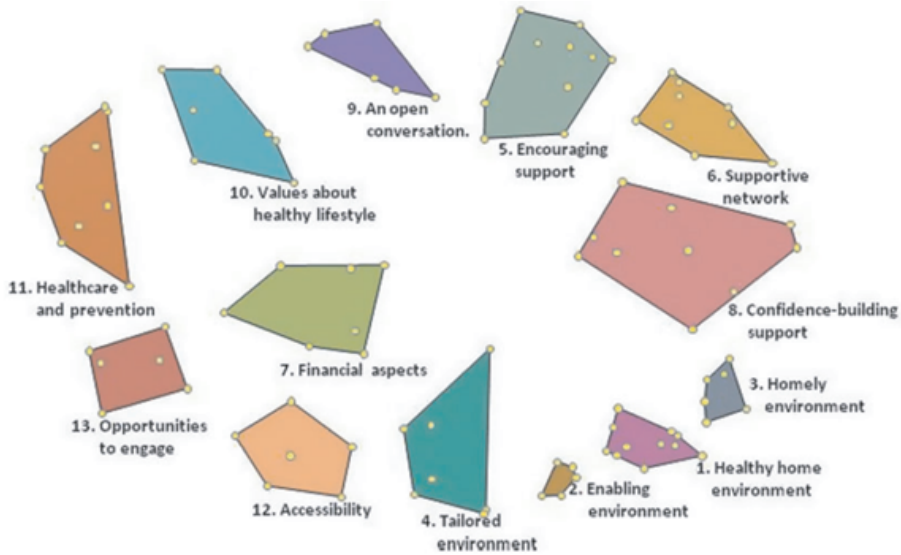

Figure 1: Final concept map: a spatial representation of how the 100 statements (dots) relate to the 13 clusters.

Interpretation of concept map

The 13 identified clusters describe how the physical environment, the social environment and preconditions for healthy living in society can support health. Resources in the physical environment are described in the clusters *Healthy home environment* and *Enabling environment*. The clusters *Tailored environment* and *Accessibility* describe barriers and resources specifically for people with ID, which demonstrated the need for a fit between resources and needs of people with ID. The interconnectivity between the physical and social environment is visible in the cluster *Homely environment,* where statements related to places and people are included. The clusters relating to the social environment describe the social network (*Supportive network*) and prerequisites for it to be promoting health (*Values about healthy lifestyle, An open conversation*, *Confidence-building support and Encouraging support)*. Notably is the role of the social network of people with ID to empower them. Preconditions for healthy living in society are described

in three clusters (*Financial aspects, Healthcare and prevention and Opportunities to engage)* including access to healthy food and health professionals as well as (not) having the same opportunities as everyone else in society. Besides, several opportunities for care providers to contribute to healthy settings were mentioned in the 13 clusters.

Importance of statements and clusters

Table 2 presents the importance of the statements at cluster level; the importance of each statement is indicated in Supplementary Appendix S1. The importance of the statements ranged from 2.72 to 4.78. The importance ratings of the clusters were denser and ranged from 3.33 (*Tailored environment*) to 4.17 (*Enabling environment*).

Table 2: Clusters, descriptions, mean bridging values (B) and importance ratings (I).

Cluster (number of state-ments)	Description	B[a]	I[b]
1. Healthy home environment (11 statements)	A comfortable and attractive house with facilities for healthy living such as a kitchen, garden, room with daylight and nice views	0.07	3.79
2. Enabling environment (5 statements)	There are accessible places nearby that are inviting for physical activity and meeting people	0.14	4.17
3. Homely environment (6 statements)	A place you can call home, where you feel safe, and can experience happiness	0.21	3.82
4. Tailored environment (7 statements)	The alignment and connectivity between an individual and his/her environment	0.35	3.33
5. Encouraging support (11 statements)	Support (tangible, emotional and companionship) from others that encourage a person to live a healthy life	0.36	4.05
6. Supportive network (9 statements)	Having people around you that can provide sufficient support	0.41	4.12
7. Financial aspects (7 statements)	Sufficient money for healthy food, healthy activities, adaptations and resources	0.45	3.86
8. Confidence-building support (10 statements)	A person gets personal space to enable independence and also receives the right amount of support and cues in daily life	0.49	4.11
9. An open conversation (6 statements)	A discussion about health topics in which everyone's ideas are taken seriously	0.50	4.14
10. Values about healthy lifestyle (7 statements)	How other people think about healthy living for people with ID	0.56	4.08
11. Healthcare and prevention (9 statements)	Having access to health professionals providing person-centered medical care, health-related guidelines and attention to prevention	0.65	4.00
12. Accessibility (6 statements)	Visible and invisible things that make it possible to go to healthy activities, such as safety and absence of obstacles	0.65	3.78
13. Opportunities to engage (6 statements)	(Un)equal rights, control, power to influence, access, and (financial) dependence	0.91	3.66

[a] B=mean bridging value for clusters between 0 and 1.
[b] I=importance (rated on a 5-point Likert scale).

Sensitivity of concept map

To investigate the sensitivity of the concept map to sampling variation, the jackknife resampling method was applied. Comparison of the jackknife distributions (of statements within clusters) and the original distribution revealed that, on average, 17 of the 100 statements were placed in another cluster than in the original distribution. At cluster level, some of the jackknife simulations yielded less than 13 clusters. The following clusters did not show in all jackknife simulations; Healthy home environment, Enabling environment, Tailored environment and Accessibility. Using full data and a cluster size of 11, these four clusters would be combined in *Physical environment* (*Healthy home environment* and *Enabling environment*) and *Accessibility* (*Tailored environment* and *Accessibility*).

Discussion

This study aimed to conceptualize healthy settings for people with ID. The combined experience of researchers involved in healthcare for people with ID and healthy settings researchers was capitalized to conceptualize healthy settings for people with ID. The study resulted in 13 clusters, which each make their own specific contribution to a health-promoting setting and encompass the physical environment, the social environment and societal preconditions. Several aspects – including a whole system approach (social, economic, policy and environmental), and values as equity and empowerment – of the settings approach (Dooris, 2009) are part of the concept map. In addition, the concept map highlights specific aspects of the settings in which people with ID live, work and engage.

Firstly, the five clusters related to the physical environment describe the physical resources of the setting, the interconnectivity between personal characteristics and place, and the home environment where the physical and the social environment merge. Physical resources that can support healthy living include resources indoors (*Healthy home environment)* and resources in the nearby area (*Enabling environment)*. The contribution of these factors to individual lifestyles is supported by the literature. For example, accessibility of facilities for physical activity, aesthetics, perceived nature, or the local food environment are related to physical activity and dietary intake (Keskinen et al., 2018; Botchwey et al., 2014). Furthermore, the extent to which the environment is tailored *(Tailored environment)* and accessible *(Accessibility)* relates to universal design, including principles for designing the built environment in accordance with the needs of a wide variety of potential user groups (Steinfeld and Maisel, 2012). Specific needs of people with ID in relation to the built environment emanate from the high prevalence of mobility limitations (26%) and visibility limitations (19%) in this population (Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten, 2012). If these needs are not taken into account, the built environment can increase the effect of having a disability on health (Eisenberg et al., 2016). Other specific factors for people with ID include living

with other persons with ID and having support staff around them, described in the cluster *Homely environment*. Feeling at home in one's house relates to factors in the social environment.

Secondly, the five clusters related to the social environment describe the social network of people with ID and prerequisites for a health-promoting social network. The *Supportive network* includes family, friends, people in the community and care professionals. Care professionals are often involved in the lives of people with ID living in residential care facilities. People with ID often view these professionals as members of their social network (Kamstra, 2017). A health-promoting supportive network provides a sense of belonging and intimacy and helps people to be more competent and self-efficacious (Berkman, 1995). These prerequisites were mentioned in the clusters: *Values about healthy lifestyle, An open conversation*, *Confidence-building support and Encouraging support*. Statements within these clusters relate to enabling people by focusing on their strengths, adapting to their needs, including them in decision making and providing them with personal space and independence. Empowering people to take active control of health determinants, one of the health promotion principles (WHO, 1986), is especially relevant to people with ID as their support and care has until a few decades ago been dominated by a protective atmosphere where rights to autonomy were often denied (Jenkinson, 1993).

Lastly, the clusters *Financial aspects, Healthcare and prevention and Opportunities to engage* relate to preconditions in society and are interconnected with both the physical and the social environment. The interaction and connections between components of a setting within components of other settings and the wider environment is reflected on in literature on the settings approach (Dooris, 2013; Bloch et al., 2014). For people with ID specifically, the relationship between the physical environment and *Opportunities to engage* is underlined in McConkey's study, which showed that the type of living accommodation of a person with ID has considerable influence on social inclusion (McConkey, 2007). Health-related policies *(Healthcare and prevention)* also are specifically important for people with ID, as such people have more health-related problems than the general population (van Schrojenstein Lantman-de Valk and Walsh, 2009). Furthermore, *Financial aspects* are specifically important for people with ID on an individual level, as people with ID often have limited financial resources, and this is detrimental to their opportunities for healthy living, and for the governmental level including governmental budgets on specialized care for people with ID and social safety (Emerson, 2007).

Besides and beyond the 13 clusters, many statements provide guidance on how care providers for people with ID could facilitate health promotion. These include allocating funding for resources for health promotion, health promotion policies, access to health professionals, regular health checks and having employees who are educated about health promotion and know how to connect healthy lifestyles to daily routines. These factors align with the literature on organizational facilitators of healthy living for people

with ID (Sundblom et al., 2015; Bergström et al., 2014; O'Leary et al., 2018; unpublished results). As the core business of settings for people with ID is the provision of care, a culture change is needed whereby care providers for people with ID adopt a health promotion ethos (O'Leary et al., 2018).

This study applied the settings approach as theoretical framework. Results of this study indicate different aspects of the whole systems approach including social, economic, policy and environmental factors. Furthermore, this study provides points for attention when applying the settings approach to settings in which people with ID engage. Firstly, this study highlights a health promoting social network of people with ID as a prerequisite for change. What makes the social context of people with ID distinct is the limited ability of people with ID to address changes themselves and support needs from their social network. In practice this might be challenging as people with ID often have a small social network which they find difficult to maintain over the course of their life (Kamstra, 2017). Secondly, due to the heterogeneity of the population there is no 'one size fits all' regarding the physical context since there is a broad variety of adjustments needed Lastly, connecting upwards, meaning ensuring action on overarching determinants of health, is described as a way forward in the settings approach (Dooris (2013). This strongly applies to people with ID since many people with ID face health inequities related to overarching determinants of health, of which income, social status and access to health services were mentioned in this study. This needs to be addressed on (inter)national level. In sum, this study provides challenges and directions for care providers, local and international policymakers to develop healthy settings for people with ID.

This study's findings should be interpreted in light of a few limitations. The first relates to potential selection bias as a result of expert sampling. Although the sample size was relatively small, it is similar to that of other studies conducted using concept mapping (Rosas and Kane, 2012). Most clusters had low (n=3) or moderate (n=9) mean bridging values; the cluster *Opportunities to engage* had a high mean bridging value, which is a product of statements that were frequently grouped with items other than those within the cluster. Furthermore, this study reflects only perspectives of expert researchers and therefore lacks the perspective of people with ID, their guardians and caregivers.

A strength of this study is the additional sensitivity to sampling variation analysis, which we have not seen used before in similar studies. This analysis indicated 4 of the 13 clusters to be sensitive to sampling variation. An 11-cluster solution, where the 4 sensitive clusters are combined, would result in a cluster map that is less sensitive to sampling variation. We chose, however, to stay with the original 13-cluster map because of the stage of this research and our aim to develop a conceptual framework where a distinction between aspects of the physical environment and accessibility for healthy settings seem relevant. Future studies can investigate the empirical relevance of all clusters.

The multidisciplinary and international approach in which perceptions of researchers both in healthcare for people with ID and in healthy settings from 14 different countries

are included is beneficial for the scope and applicability of the cluster map. These results can help to guide discussion with people with ID themselves about important factors for a healthy setting. In a future study, the views of people with ID will be gathered to complement the views of researchers, validate the results of this study and tailor the cluster map to more local applications.

Conclusion

This study used concept mapping to conceptualize healthy settings for people with ID. The social environment, the physical environment, and societal preconditions and their interconnectivity with one another and with individuals in the setting, play an important role in healthy settings. Clusters not only reflect concepts already familiar in health promotion for the general population, but also indicate where tailoring is required for settings where people with ID live, work and engage. Factors specifically for healthy settings for people with ID include: (i) universal design of the physical environment, (ii) the role of care professionals in the social environment to empower people with ID, (iii) possibilities for care providers to contribute to a health-promoting setting and (iv) preconditions that allow people to engage in society. By identifying these factors, this study contributes to the limited knowledge on applying principles of healthy settings for people with ID. The identified factors that contribute to healthy settings for people with ID can be used put local and international policies on developing enabling environments for people with disabilities and decreasing health inequities in place.

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CHAPTER

6

How can care settings for people with intellectual disabilities embed health promotion?

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Journal of Applied Research in Intellectual Disabilities, doi:10.1111/jar.12776

Abstract

People with intellectual disabilities (intellectual disabilities) depend on their environment to live healthily. Asset-based health promotion enhances a settings' health-promoting capacity starting with identifying protective or promotive factors that sustain health. This inclusive mixed-methods study used group sessions to generate and rank ideas on assets supporting healthy nutrition and physical activity in Dutch intellectual disability care settings. Participants included people with moderate intellectual disabilities and family and care professionals of people with severe/profound intellectual disabilities. Fifty-one participants identified 185 assets in group sessions. They include the following: (i) the social network and ways "people" can support, (ii) assets in/ around "places," and person–environment fit, and (iii) "preconditions": health care, prevention, budget, and policy. This inclusive research provides a user perspective on assets in the living environment supporting healthy living. This gives insight in contextual factors needed for development and sustainable embedment of health promotion in the systems of intellectual disability support settings.

Introduction

Increasingly, perspectives of people with intellectual disabilities are included in research concerning their health (Gibbs, Brown, & Muir, 2008; Kuijken, Naaldenberg, Nijhuis-van der Sanden, & Schrojenstein-Lantman de Valk, 2016; Young & Chesson, 2006). Regarding health promotion, recent studies provide insights into perspectives of people with intellectual disabilities on enabling and constraining factors for physical activity and healthy nutrition (Cartwright, Reid, Hammersley, & Walley, 2017; Caton et al., 2012; Doherty, Jones, Chauhan, & Gibson, 2018; Kuijken et al., 2016; Spassiani, Meisner, Abou Chacra, Heller, & Hammel, 2019; Temple & Walkley, 2007). These perspectives are helpful in targeting common lifestyle problems among this population such as unhealthy diets, sedentary behaviour, and physical inactivity (Adolfsson, Sydner, Fjellström, Lewin, & Andersson, 2008; Hilgenkamp, Reis, van Wijck, & Evenhuis, 2012; Melville et al., 2017). Although people with intellectual disabilities identified the need for a supportive social and physical living environment in these studies, the focus was mainly on individual behaviour and provides little insight into how the setting in which people with intellectual disabilities engage can contribute to healthy living. For people with intellectual disabilities, the setting, for example the social, physical and organizational environment, of intellectual disabilities support providers plays a key role in health promotion (Marks & Sisirak, 2014; O'Leary, Taggart, & Cousins, 2018).

Existing health promotion for people with intellectual disabilities tends to focus on programme-based interventions aimed at individual behaviour and not on health promotion in settings where day-to-day lifestyle choices are made (Kuijken et al., 2020; Naaldenberg, Kuijken, van Dooren, & de Valk, 2013). These programmes are often short term and therefore fail to become embedded in organizational policy after the programme ends (Kuijken et al., 2020). An exception is the study of Marks and colleagues who attempted to integrate their program 'Health Matters' into daily routines of people with intellectual disabilities and train support staff to support their physical health (Marks, Sisirak, Magallanes, Krok, & Donohue-Chase, 2019). Although this program attempts to integrate the activities in daily routines and provide social support for participants, it is not targeted on the setting itself. Only a few studies in health promotion for people with intellectual disabilities have adopted a focus on the setting of intellectual disabilities support providers. These point out factors that hinder the implementation of health promotion, including a limited health promotion culture, lack of clarity among staff on roles and responsibilities regarding health promotion, and lack of health-promotion capacity in intellectual disabilities support providers (Kuijken et al., 2018; O'Leary et al., 2018; Spassiani et al., 2019). As settings in which people with intellectual disabilities engage play a key role in promoting a healthy lifestyle (Marks & Sisirak, 2014; O'Leary et al., 2018), a broader understanding of how factors in the setting can contribute towards a healthy lifestyle is vital for applying integrated multi-level health promotion interventions

for people with intellectual disabilities and creating sustainable effects (Kuijken et al., 2018; Marks & Sisirak, 2014; Steenbergen, Van der Schans, Van Wijck, De Jong, & Waninge, 2017).

Setting approaches to health promotion is in line with principles from systems thinking where the focus is on understanding the influence of the context and involved stakeholders in how behaviour patterns are created and sustained (Hawe, 2015 ; Naaldenberg et al., 2009). Rather than focusing on 'fixing' one part of the system (being the whole of the issue or problem), the aim is to create a system that allows for healthy behaviour to 'emerge' (Fletcher et al., 2016; Hawe, 2015; Rosas, 2015; Rutter et al., 2017). This requires insight in how actors and context relate to each other within the system and highlights the importance of involving all stakeholders (including end users) as they have intimate knowledge of the system in everyday practice (Moore & Evans, 2017).

An health promotion approach in which system thinking is adopted is the healthy settings approach, an integrated approach aimed at creating continuous attention on health promotion in the living environment (Rosas, 2015). The approach is underpinned by socio-ecological theory and organizational change theory (McLeroy, Bibeau, Steckler, & Glanz, 1988; Mittelmark et al., 2017). It was developed in the 1980s and has been a priority of the World Health Organisation (WHO) ever since the 1986 Ottowa Charter for Health Promotion (WHO, 1986). It is applied in different settings, for example the Healthy Cities and Healthy Schools programmes (Barnekow Rasmussen & Rivett, 2000; De Leeuw, 2009). This whole systems approach aims to understand the relationship between individual behaviour and environmental conditions for health by considering multiple sources of influence. It is focused on embedding health in the routines and culture of a setting (Dooris, 2013). Identifying assets within a setting can enhance the setting's capacity to promote healthy living (McKnight & Kretzmann, 1993). Assets are protective or promoting factors that maintain and sustain health and wellbeing in a setting, such as skills of individuals, friendship networks, money and schools (Morgan & Ziglio, 2007).

To facilitate intellectual disabilities care settings to become health-promoting systems that stimulate healthy behaviour, it is helpful to gain user-perspectives on structural contributors to physical activity and healthy nutrition in intellectual disabilities care settings. This study aims to answer the following research question: "What assets for physical activity and healthy nutrition do people with moderate intellectual disabilities and proxy informants of people with severe/profound intellectual disabilities identify and prioritise?"

Method

Context

This study was conducted in the Netherlands and focused on people with moderate to profound intellectual disabilities who receive support from care providers specialising in

people with intellectual disabilities. The support for this population includes personal, daily, social, and home-health tasks, mainly provided by daily care professionals who are paid carers trained in behaviour aspects and/or assistant nursing (Heutmekers et al., 2016). In 2017, about 68,000 people with intellectual disabilities lived in facilities provided by intellectual disabilities care providers (ZorginstituutNederland, 2019), ranging from clustered group homes, to small-group living in apartments, and single-family homes in neighbourhoods (Van Staalduinen & ten Voorde, 2011).

Inclusive approach

This study actively involves people with intellectual disabilities as co-researchers in all stages, following Frankena's (2018) guidelines in the consensus statement for inclusive health research. This was used to deploy experiential and scientific knowledge and contribute to appropriate data collection, data quality, and relevant outcomes (Frankena et al., 2018; Johnson, Minogue, & Hopklins, 2014). The research team consisted of researchers with intellectual disabilities (co-researchers) and without intellectual disabilities, all employed by the university. In weekly meetings, the co-researchers (AC) and (HJ) developed the procedure, data collection method, and data analysis, and incorporated feedback from other members of the research team and the project's advisory group including people with intellectual disabilities , caregivers, health professionals, and a manager. Data collection and analysis were conducted by KVA, HJ, AC and MKL.

Before the start of this study, co-researchers expressed the need to better explicate the concept of health-promoting settings for people with intellectual disabilities and thereby facilitate meaningful data collection. Therefore, a concept mapping study (Vlot-van Anrooij et.al., 2019) with researchers specialized in healthcare for people with intellectual disabilities and researchers specialized in healthy settings was conducted, resulting in the Healthy Settings for People with Intellectual Disabilities (HeSPID) framework described in Figure 1.

Collaboration between the researchers with and without intellectual disabilities was supported by (i) the "research clock", a clock on which steps of the study were visualised to prompt memory, (ii) a script with points for attention during data collection, (iii) pre-selected parts of audio-recordings rather than transcripts for data analysis, (iv) the use of sticky notes during data analysis to visualise generated themes and structure data by placing them on a flipchart based on similarity, and (v) verbal explanation of this manuscript to obtain feedback. In addition to this scientific paper, an easy-read abstract and vlog were written to disseminate the results in an accessible manner.

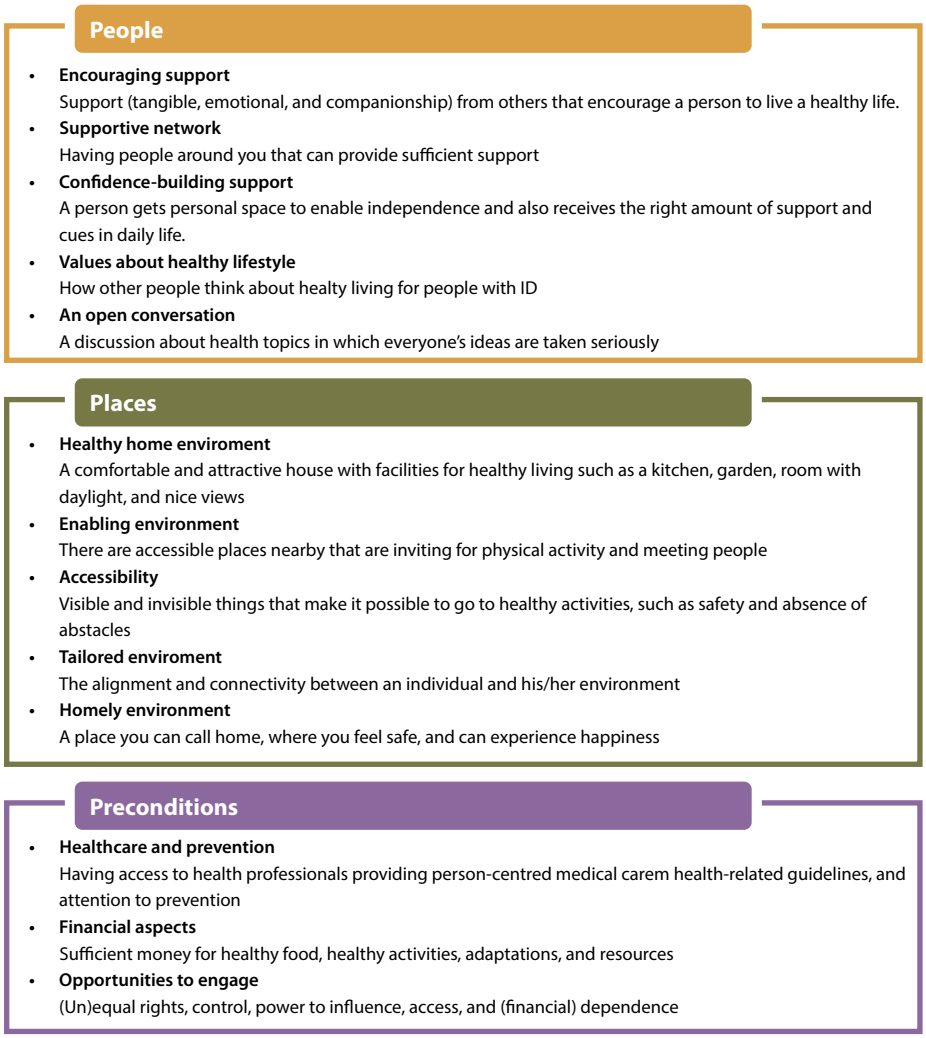

Figure 1: Clusters and overarching themes of the Healthy Settings for People with Intellectual Disabilities (HeSPID) framework (Vlot-van Anrooij et.al., 2019).

Procedures

Participants were recruited from 8 intellectual disabilities care providers. Purposive sampling was used to recruit 4 groups of people with moderate intellectual disabilities and 4 groups of proxy informants of people with a severe or profound intellectual disabilities. Adults with moderate intellectual disabilities were able to communicate verbally and lived in accommodation or participated in day activities provided by an intellectual disabilities care provider. Proxy informants were able to respond on behalf of a person with severe or profound intellectual disabilities whom they had known for at least 6 months and with

whom they had weekly contact. Diversity was sought in type of accommodation (living or day activities) and type of proxy (family or care professional). Potential participants received written study information. People with intellectual disabilities were provided with easy read information. After stating their interest, written informed consent was obtained. For participants with intellectual disabilities it was checked whether or not a legal representative should sign the consent form.

The meetings took place between April and August 2018 at a place that was convenient for the participants, mostly in or near their living accommodation. In the meetings with people with moderate intellectual disabilities , the research team consisted of a facilitator (KVA), a co-researcher who assisted in communication (AC or HJ), and an observer (MKL). In the meetings with proxy informants, the research team consisted of a facilitator (MKL) and an observer (KVA). If requested by participants with moderate intellectual disabilities , support staff were present.

The study was conducted according to the principles of the Declaration of Helsinki and the EU General Data Protection Regulation. The Medical Research Ethics Committee of Radboud University and Medical Centre approved this study (registration number: 2018-4160).

Data collection

The Nominal Group Technique (NGT) was used to identify and prioritise assets. The NGT is a mixed method to explore expert opinion on a given topic and establish priorities. It has already been used successfully in studies with people with intellectual disabilities (Friedman, Arnold, Owen, & Sandman, 2014; Roeden, Maaskant, & Curfs, 2011; Natasha A Spassiani et al., 2015; Tuffrey-Wijne, Bernal, Butler, Hollins, & Curfs, 2007). For this study, the NGT was modified to foster meaningful participation of people with intellectual disabilities by splitting the process into two meetings: generating ideas and ranking. After a pilot, small amendments were made to supporting materials.

Generating ideas

Ideas were generated in four rounds. Round one included an open discussion, guided by the question *"What in your living environment helps you to be physically active and eat healthily?"* Then, three thematic rounds were held on (i) "People", (ii) "Places", and (iii) "Preconditions", relating to the 13 clusters of the HeSPID framework as described in the methods section, see Figure 1 (Vlot-van Anrooij et.al., 2019). These thematic rounds were used to stimulate participants to think about all aspects related to their living environment. At the start of these rounds, pictures relating to the clusters, physical activity and nutrition were explained and visualised. In all rounds, participants were asked to mention all possible assets, for example both existing and desired assets and assets related to themes other than the ones introduced. All participants were stimulated to contribute by giving everyone a turn and using probing questions. The meetings lasted 60–90 min and were audio-recorded.

Ranking

In the second meetings, participants ranked their group's ideas in order of importance using a step-by-step procedure. Ideas were presented on slips and read out for participants with moderate intellectual disabilities. The participants classified the ideas individually as "important" or "unimportant" by putting the slips in one of two envelopes and compiled a top 5 most important ideas.

Data analysis

Data analysis was conducted through (i) thematic content analysis of audio-recordings of the idea-generating meetings with the co-researchers (AC and HJ) using Atlas.ti software 9.2.29 and sticky notes of ideas , and (ii) and statistical analysis of rankings of ideas.

After each idea-generating meeting, a list of ideas was developed for each group's ranking meeting, using the following procedure: 1) selecting relevant fragments (KVA), 2) coding relevant fragments and writing down ideas (KVA and HJ or AC in participant groups with people with ID), 3) checking analysis (MKL), and 4) finalising list of ideas (KVA, HJ, and AC). The ideas were thematically analysed independently (KVA, HJ and AC together and MKL alone). Ideas were grouped and where possible linked to the HeSPID framework (Vlot-van Anrooij et.al., 2019). Additional categories were allowed to prevent the framework from being restrictive in the analysis. Differences and the 'other' category were discussed until consensus was reached. This categorisation of ideas by clusters was used for a qualitative description of the gathered ideas, as presented in the results section.

The ranking data were analysed using descriptive statistics. Individual top 5 rankings were transformed into individual scores (e.g. 5 points for first place, 4 points for second place, and so on). The ideas were categorised in clusters to calculate relative importance on cluster level using the formula: (total score for the cluster/maximum points) x 100 (maximum points is calculated as the total number of participants x total points that 1 participant can give) (McMillan et al., 2014). The relative importance on cluster level is presented in the results section for all participants, people with intellectual disabilities and proxy respondents.

Results

Participants

Table 1 provides an overview of study participants (n=51).

Table 1: Participant characteristics.

	Groups with people with moderate ID	Groups with proxies for people with severe/profound ID
Number of participants (n)	21	30
Number of groups (n)	4	5
Age of person(s) with intellectual disabilities (range)	21 to 69 years	7 to 83 years
Disabilities of person with intellectual disabilities	• wheelchair bound	• visual impairments • hearing impairments • physical impairments • wheelchair bound • behaviour problems
Housing of person with intellectual disabilities	• group home on campus • group home in neighbourhood	• group home on campus • group home in neighbourhood • with parents
Accommodation for daytime activity for person with intellectual disabilities	• day activity centre, on campus • day activity centre, in neighbourhood • other (paid jobs)	• day activity in group home
Relationship to person with intellectual disabilities	n/a	Parent: 8 Daily care professional: 9 Care professional (both daily care and day activity care): 7 Day activity care professional: 5 Other (physiotherapist): 1

Generated ideas

The groups generated between 13 and 26 ideas each. The total of 185 ideas overlapped between the groups and fitted mostly within the 13 clusters presented in the framework. One additional cluster was added: *Health-promoting organizational policies*. The interrelationship between ideas was also discussed by participants.

Figure 2 shows the number of ideas relating to each cluster. About half of the ideas focused on the overarching theme "People" (n=90), with the cluster *Encouraging support* (n=58) including the most ideas. Below, the generated ideas are described for each cluster *(in italics)* and are structured by the overarching themes "People", "Places", and "Preconditions".

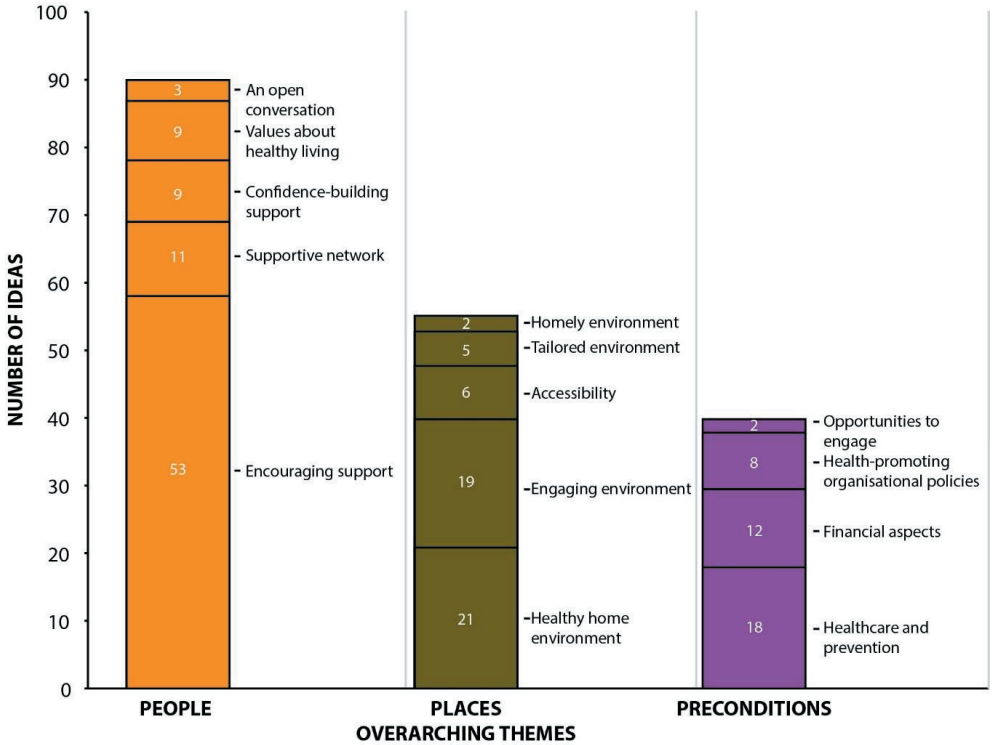

Figure 2: Number of generated ideas per cluster and overarching theme.

How "People" can support healthy living

Ideas related to "People" focus on how the social network can support healthy living, the conditions for a stable network, and dilemmas in providing support. The participants provided a variety of practical ideas relating to how *Encouraging support* and *An open conversation* can be provided:

- Emotional support: encouraging healthy nutrition
- Informational support: providing tips and reminding clients about agreements
- Tangible support: taking clients to sports facilities, buying healthy foods, and providing a balanced diet
- Providing positive social interactions: cooking healthy meals together, being active in daily life, doing sports together, and discussing healthy options
- Activating clients to be active in daily life: using creative ways to activate clients during the day
- Showing role model behaviour.

Furthermore, topics mentioned that relate to a *Supportive network* include knowing each other well, continuity of people in the network, enough staff, and time to support healthy

living. Knowledge, skills, alignment, and a shared view of the network regarding healthy living were also mentioned. These factors were often perceived as lacking in the networks of people with intellectual disabilities.

In ideas relating to *Values about healthy living* and *Confidence-building support,* dilemmas regarding supporting autonomy and healthy living were shared. Different ways of supporting autonomy and balancing this with support for healthy living are illustrated in the following ideas:

- Making a weekly menu together. For example, care professionals choose the type of meal and clients choose the type of pasta.
- Clients take turns choosing what they want to eat. Some can choose themselves, others get help from a care professional who introduces two options. If it is necessary to adjust (because an unhealthy option is chosen) then care professionals do this.
- Care professionals provide tips for healthy eating and drinking. Clients decide themselves.
- A balance is sought between quality of life including a client's preferences and healthy and safe nutrition. For instance, a family can choose to give their child with diabetes more insulin instead of taking away everything he likes and is unhealthy.

How "Places" can support healthy living

How "Places" can contribute to healthy living was reflected in assets relating to tools, facilities, person–environment fit, and accessibility. Examples of tools in a *Healthy home environment* include: tricycle, interactive tactile wall panel (with movable items to stimulate activity), multi-sensory stimulation room, hoist, kitchen, vegetable garden, and a list with ingredients that clients like/dislike. Other ideas relate to how space in or around a building can stimulate physical activity, for example enough indoor space for physical activities.

In the wider environment, the following facilities were identified as assets for an *Enabling environment*: a swimming pool, supermarket, sports centre, forest, playgrounds, and an equestrian centre. Ideas also relate to a beautiful and safe area for physical activity. Demonstrating this, one participant mentioned the idea: "Safe and defined terrain with lots of trees and little traffic where clients can walk freely and do not get lost". A good fit between facilities and tools in the physical environment and the needs of people was emphasised as essential. This relates to *Accessibility* and a *Tailored environment*, including suitable activities, flexible opening hours of facilities, and accessibility of buildings. For example, one participant with intellectual disabilities mentioned that a cycle path (separated from the road instead of a cycle lane) makes it safer and less scary to cycle to places. Accessibility of the outdoor environment was further reflected in ideas on facilities nearby (such as a supermarket, day-care, bus stop, and park) that can stimulate active forms of transportation, safe routes, and accessible forms of transportation. Only two ideas related to *Homely environment*, which focused on feeling safe, accepted, and appreciated.

"Preconditions" supporting healthy living

Participants also acknowledged "Preconditions" as assets and gave ideas relating to *Healthcare and prevention*, *Financial aspects*, and *Health-promoting organizational policies*. Ideas related to *Healthcare and prevention* include: access to medical support and support from allied health professionals by sharing knowledge with care professionals and helping people with intellectual disabilities to live healthily. *Financial aspects* of healthy living as assets focused on several levels: (i) individual budgets for people with intellectual disabilities for physical activity and healthy nutrition, (ii) budgets for group-homes/day activity centres for healthy nutrition, and (iii) budgets for care providers to ensure sufficient working hours for care professionals to support healthy living for people with intellectual disabilities and for buying tools for healthy living. Organizational budgets link to ideas on an organization's policy. Other ideas related to *Health-promoting organizational policies* include: (i) attention on care professionals' knowledge about healthy living, (ii) discussing healthy living in clients' personal development plans, and (iii) including healthy living in an organization's vision and mission. Only two ideas related to *Opportunities to engage* and focused on equal treatment and sufficient sports activities tailored to people with intellectual disabilities.

Table 2: Relative importance of clusters compared by participant type.

Cluster	Participants with moderate ID		Proxy informants of people with severe/ profound ID		All participants	
	%*	n**	%*	n**	%*	n**
Encouraging support	27%	26	30%	32	29%	58
Healthcare and prevention	16%	6	5%	12	9%	18
Enabling environment	14%	11	1%	8	6%	19
Healthy home environment	12%	7	5%	14	8%	21
Accessibility	9%	7	1%	1	4%	8
Confidence-building support	7%	5	5%	4	6%	9
Opportunities to engage	6%	2	0%	0	2%	2
Financial aspects	3%	4	12%	8	8%	12
Tailored environment	3%	2	3%	3	3%	5
Homely environment	3%	2	0%	0	1%	2
Supportive network	1%	2	21%	9	13%	11
Health-promoting organizational pol-icies	0%	0	9%	8	6%	8
Values about healthy living	0%	0	7%	9	4%	9
An open conversation	0%	3	0%	0	0%	3

*%= Relative importance based on top 5 scores (total score for the cluster/maximum points (participant number X total points that 1 participant can give) X 100)
**n= Number of ideas per cluster

Rankings of ideas

Participants ranked the importance of the ideas individually by compiling a top 5 of the ideas generated in their group. Table 2 shows the relative importance on 14 cluster levels for all participants. The clusters *Encouraging support* (29%) and *Supportive network* (13%) were ranked as most important, followed by ideas related to *Healthcare and prevention* (9%), *Financial aspects* (8%), and *Healthy home environment* (8%). The cluster *Enabling environment* is remarkable, as it includes many ideas but scores relatively low (6%). The other clusters with a low relative importance (6% or below) include few ideas.

Differences between participants with intellectual disabilities and proxy respondents

Comparison of participants with intellectual disabilities with proxy respondents reveals that there were many commonalities, but also differences in type and relative importance of ideas. Regarding the type of ideas, participants with intellectual disabilities mention practical and visible assets for support, whereas proxy respondents mention more abstract assets and preconditions for support. For example, when looking at *Healthcare and prevention*, participants with intellectual disabilities mentioned cooking lessons from a dietician and proxy respondents mentioned support from health professionals for care professionals to provide ideas on how to activate people with intellectual disabilities. Also, the ideas of participants with intellectual disabilities related to *Financial aspects* focus on an allowance for groceries, whereas proxy respondents mention attention on healthy living in organizational budgets and policy.

Comparison of the number of ideas per overarching theme reveals that proxy respondents mention more ideas related to "People" (65% vs. 35%) and participants with intellectual disabilities mention more ideas related to "Places" (41% vs. 10%). Both groups mention about the same number of ideas related to "Preconditions" (26% vs. 25%). The relative importance of ideas also differs. The participants with intellectual disabilities ranked *Healthcare and prevention* (16% vs. 5%) and *Enabling environment* (14% vs. 1%) higher and *Supportive network* (1% vs. 21%) and *Health-promoting organizational policies* (0% vs. 9%), and *Financial aspects* (3% vs. 12%) lower than the proxy respondents (see Table 2).

Discussion

This study aimed to identify and prioritise assets for physical activity and healthy nutrition in the living environment of people with intellectual disabilities from their own perspective. The previously developed HeSPID framework supported data collection and analysis (Vlot-van Anrooij et.al., 2019). The generated ideas fit well within this framework and highlight the assets that participants deem important for a health-supporting environment. Most ideas link to the overarching theme "People". In particular, *Encouraging support,* through activation, role models, and regular types of social support, is valued highly. This aligns

with the strong dependence of people with intellectual disabilities on others to facilitate healthy living (Kuijken et al., 2018). Care professionals, who are important stakeholders in supporting people with intellectual disabilities to live healthily (Kuijken et al., 2018), lack the prerequisites mentioned as necessary for a *Supportive network*, including knowledge, time, and attention on healthy living (Hamzaid, Flood, Prvan, & O'Connor, 2018; Melville et al., 2009; Sundblom, Bergström, & Elinder, 2015). Ideas generated relating to "Places" provide a clear user perspective on what kind of tools, devices, and facilities they consider to be assets that help create a healthy and enabling environment that is accessible and fits their needs (*Tailored environment*). Identified assets related to "Preconditions" elaborated how allied health professionals can contribute to *Healthcare and prevention* and refined *Financial aspects* into several levels. Furthermore, *Health-promoting organizational policies* was added as a new cluster in the HeSPID framework. Many of the assets mentioned in this cluster, such as organization's vision and mission, and time and money for assets related to healthy living, are perceived to affect health promotion practice (Robinson, Driedger, Elliott, & Eyles, 2006).

The HeSPID framework distinguishes three overarching themes consisting of 13 clusters. The results from this study indicate that, in practice, identified assets relate to each other within themes and clusters as well as between themes and clusters. For example, to support a person with intellectual disabilities to live healthily (theme "People", cluster *Encouraging support*), care professionals need knowledge and skills (theme "People", cluster *Supportive network*), for which an intellectual disabilities care provider can provide training opportunities (theme "Preconditions", cluster *Health-promoting organizational policies*). Participants stressed that this interrelatedness made it difficult for them to rank ideas and consequently difficult to favour one over another. This indicates that, to create a health-supporting setting for people with intellectual disabilities, an integrated approach is helpful. This is in line with the settings approach to health promotion (Dooris, 2013).

Strengths and limitations

The inclusive approach in which co-researchers were actively involved is a major strength of this study as this helped to make the right adjustments to the study design for meaningful participation of people with intellectual disabilities as study participants. Lessons learned from the inclusive process include making a protocol with a clear division and instruction of roles and responsibilities of the facilitator and co-researcher enabled team work and helpful support for participants during data collection. Also, analysing the voice recordings to determine ideas and using sticky notes to group ideas helped to work together as co-researchers and researchers during data analysis. This improved data analysis as experiential and scientific knowledge was used to interpret the data. However, when considering an inclusive approach, researchers should bear in mind that it takes time and exploration to find ways of working together that contribute to a valuable

partnership. The prerequisites and attributes needed for inclusive research, as described in a consensus statement on inclusive research, were helpful in shaping this approach (Frankena et al., 2018).

The adjusted NGT and preparatory study in which the HeSPID framework was developed enabled participants to share their perspective on the abstract term living environment and provided a thorough and diverse overview of assets. The participants stated that the pictures were very helpful. Mentioning the clusters helped them to assess whether a cluster is helpful and to think about ideas (assets) relating to a cluster. Using a pre-defined framework runs the risk of being too prescriptive and steering the participants. This was mitigated by starting the NGT with an open round before introducing the framework and allowing participants to talk about other themes. The fact that the results altered the original framework by adding a new cluster indicates that this strategy worked well. Although most participants found it easy to value ideas as important or unimportant, many participants found it difficult to compile a top 5 of ideas. This was perceived as difficult by participants with intellectual disabilities because they could choose only 5 out of many important ideas. Proxies also found the task difficult because of the interrelationship between ideas.

To gather perspectives of people with severe and profound intellectual disabilities , we could use only proxy reports. Although this could be seen as a study limitation, as proxy informants cannot truly reflect the voice of people with intellectual disabilities (Scott & Havercamp, 2018), the proxy respondents were able to point out underlying factors that are necessary to create the assets that people with intellectual disabilities mention as needed. The differences in ranking between proxies and participants with intellectual disabilities , however, indicate that using only proxy respondents would have yielded a perspective that was too narrow. This highlights the importance of adjusting research methods to enable people with intellectual disabilities to participate in research.

The context in which support for people with intellectual disabilities takes place is diversely organized across the globe. As this study was executed in the Netherlands, it focuses on the Dutch context in which intellectual disabilities care providers play an important role in the lives of people with moderate to profound intellectual disabilities. Nevertheless, the HeSPID model was developed in an international context and the results of this study fit well in this model. Applying the HeSPID model and method used in this study in other countries will provide insight in the similarities and differences of assets in other contexts.

Implications for practice

To work towards healthy intellectual disabilities support settings in practice this study points out implications on governmental, organizational, interpersonal and intrapersonal level. In the last decades more attention has come for environmental and systems influences on lifestyle, such as how the obesity epidemic is sustained by obesogenic environments

(Alvaro et al., 2010). To move beyond an individual focus on health promotion and create system change, governmental policy is critical (Alvaro et al., 2010). When governments want to contribute to healthy intellectual disabilities care settings, it is pivotal they also gain insight in environmental factors. This study provides key factors to investigate in care settings in order to identify assets and challenges that can be addressed.

To help intellectual disabilities care providers create a promotion ethos and increase knowledge and time for health promotion, which are currently lacking (O'Leary et al., 2018; Hamzaid et al., 2018; Melville et al., 2009; Sundblom et al., 2015), this study provides points of attention that organizations can use. These include: (i) specific attention on care professionals' professional development, (ii) protected time for health promotion by care professionals, (iii) tools and facilities that are accessible and fit the needs of people with intellectual disabilities , and (iv) linking health promotion to personal and organizational values. These factors align with Robinson and colleagues' points of advice for capacity building (Robinson et al., 2006). More specifically, organizations can use the overview of assets to gain insight in the availability and user-perspectives of these assets in the context of their organization which serves as input for a health promotion policy and a context specific strategic action plan (Marks & Sisirak, 2014).

On inter- and intrapersonal level, more attention for health promotion in education for people with intellectual disabilities , their families and care professionals can increase their awareness of the importance of healthy living for health and wellbeing and the different ways in which the environment influences lifestyle choices. They can use this to identify what changes they wish to see in the environment and address these at organizational level. A structured tool based on the study results might be helpful to gather these ideas.

Future research

Future research could identify ways in which people with intellectual disabilities can be involved and empowered in (re)shaping their own living environment. This inclusive study provides an example of how perspectives of people with intellectual disabilities on assets can be gathered, for which the HeSPID model can be a guide. However, tools are needed on how to involve them in the process of (re)shaping their living environment. Furthermore, the identified assets provide context factors which are helpful for development and sustainable embedment of interventions to facilitate healthy behaviour in the system of intellectual disabilities support settings (Moore & Evans, 2017). Future studies could use these context factors to better understand contextual influences on implementation outcomes and determine what works for whom and under which circumstance (Fletcher et al., 2016; Moore & Evans, 2017; Pfadenhauer et al., 2017).

Conclusion

This study provides a user perspective on assets for physical activity and healthy nutrition in intellectual disabilities care settings, and thereby also practical implications of the HesPID framework for health promotion practice. The interlinked assets identified can be used in an integrated approach to enhance an intellectual disabilities care setting's capacity to promote health and focus on: (i) building the capacity of a health-promoting social network for people with intellectual disabilities , (ii) tools and facilities that are accessible and fit the needs of people with intellectual disabilities , and (iii) capacity building on the organizational level to create a health promotion ethos and (re)orient assets towards health promotion. So, the results provide insight in contextual factors needed for development and sustainable embedment of health promotion in the systems of intellectual disabilities support settings.

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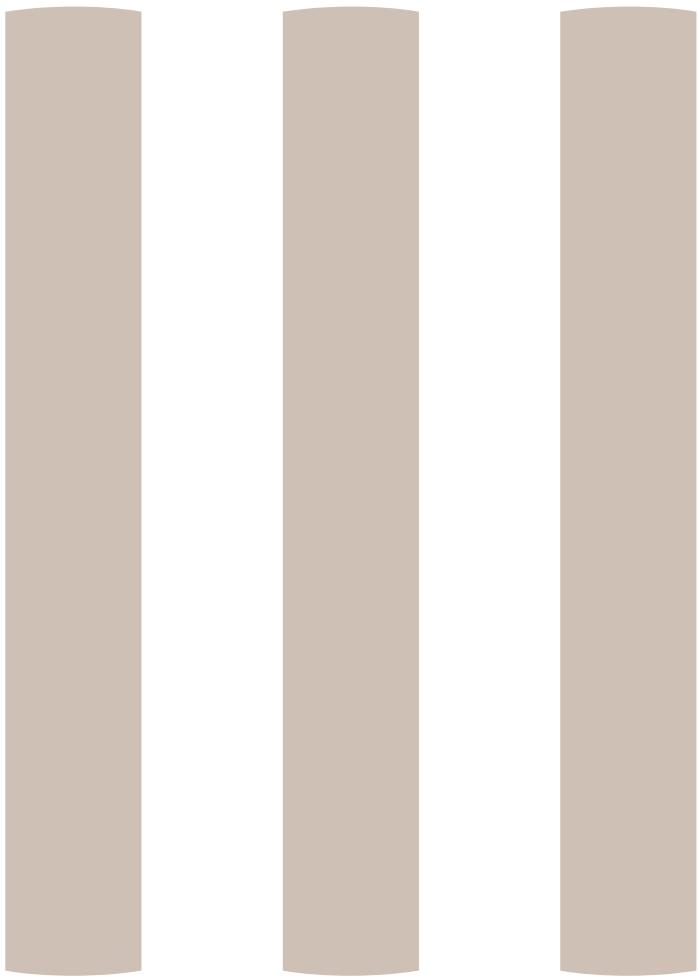

Improving health-promoting capacities in practice

CHAPTER

7

Improving environmental capacities for health promotion in support settings for people with intellectual disabilities: inclusive design of the DIHASID tool

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Journal of Applied Research in Intellectual Disabilities, doi:10.1111/jar.12776

Abstract

People with intellectual disabilities (ID) have unhealthier lifestyles than the general population. To sustainably improve their lifestyle and health status, a whole-system approach to creating healthy environments is crucial. To gain insight into how support for physical activity and healthy nutrition can be embedded in a setting, asset mapping can be helpful. Asset mapping involves creating a bottom–up overview of promoting and protective factors for health. However, there is no asset mapping tool available for ID support settings. This study aims to develop an asset mapping tool in collaboration with people with ID to gain insight into assets for healthy nutrition and physical activity in such settings. The tool is based on previous research and development continued in an iterative and inclusive process in order to create a clear, comprehensive, and usable tool. Expert interviews (n = 7), interviews with end-users (n = 7), and pilot testing (n = 16) were conducted to refine the tool. Pilot participants perceived the tool as helpful in pinpointing perceived assets and in prompting ideas on how to create inclusive environments with support for physical activity and healthy nutrition. This overview of assets can be helpful for mobilizing assets and building the health-promoting capacities of ID support settings.

Introduction

People with intellectual disabilities (ID) have unhealthier lifestyles than people without disabilities, with more physical inactivity and unhealthy dietary habits [1-4], and their lifestyles contribute to many of their health problems [1,5]. The promotion of physical activity and healthy nutrition may help to decrease the health inequities faced by people with ID. However, people with ID are more dependent on their environment to live healthily. In a previous study on health promotion, people with ID expressed the need for a supportive social and physical environment to be able to live healthily [6]. This is supported by the growing evidence of environmental factors associated with lifestyle, such as the association between the presence of convenience stores and fast- food restaurants and nutrition intake, and the association between the accessibility of facilities, street safety, aesthetic attributes, and physical activity [7-10]. ID support settings are specialized in providing long-term residential, community living arrangements, and day activities for people with ID, who face limitations in intellectual functioning and adaptive behavior [11]. In the Netherlands, about 68,000 people live in facilities from ID support settings, ranging from clustered group homes to small-group living in apartments or single-family homes in neighborhoods [12,13]. People with ID spend a lot of time in these settings where they receive support with personal, daily, social, and home health tasks, mainly provided by daily care professionals trained in behavior aspects and/or assisted nursing [14]. So, environmental support for health promotion could contribute to sustainable improvement in the health status of people with ID and achieve more equality for this population in which ID support settings can play a crucial role.

Despite the efforts of ID support organizations to improve the lifestyle of people with ID, the sustainable embedment of health promotion in daily support faces challenges [6,15,16]. On the one hand, many interventions developed by researchers in program settings are challenged by difficulties in implementing them in practice [15]. On the other hand, many of the interventions developed in practice focus mostly on the individual, consist of stand-alone activities, and lack embedment in policy [17,18]. Moreover, they lack sustainability as they are not embedded in the daily support system of ID support organizations [17,18]. To sustainably improve the lifestyles of people with ID in settings where they engage, a whole-system approach has been identified as a way forward [19].

Taking a whole-system approach is complex, as it requires health promotion to be embedded in the day-to-day practices of ID care organizations. This whole-system approach has been successfully implemented using the healthy settings approach [20,21]. This healthy settings approach is a whole- system approach where stakeholders are given the capacity to address behavioral and environmental factors and embed health within the routines and the culture of a setting [20,21]. It has been successfully implemented in hospitals and schools as healthy school and healthy hospital projects. These have resulted in transformed policies, organizational structures, and community action to

facilitate healthy living [22,23]. Due to these successes in other settings, this approach might also be beneficial for health promotion in ID support settings.

Co-creating healthy settings is key, as the people who actually use a setting know best which of the existing resources can be useful and how health promotion can be made part of the whole-system in a certain setting [24]. Asset mapping is a bottom–up process for creating an overview of those resources (promoting and protective factors) that maintain and sustain health and well-being in a defined setting. In this approach, people who use the setting are actively involved, as they have essential knowledge and experiences about living in a place and the resources available. Therefore, asset mapping can be used to provide input for the whole-system approach. In general, there is a lack of asset mapping techniques [25]. Although existing tools can help assess resources for health promotion in the environment [26–36], these tools fit poorly with an assets mapping approach due to the lack of a whole-system focus, the lack of a positive approach, or a scope that is too narrow. Furthermore, making a tool that can be used by people with ID themselves requires a clear structure and language with instructions to create meaningful engagement by people with ID.

This study aimed to develop a comprehensive, clear, and usable inclusive tool for environmental asset mapping for ID support settings that can also be used by people with ID themselves. The tool, developed in Dutch, provides insight into perceived environmental assets and points for improvements regarding support for healthy nutrition and physical activity for people with moderate to profound ID in settings where they engage. These insights can be used to create inclusive and health-promoting environments. This article describes the iterative and inclusive development process of creating the tool using expert interviews, cognitive interviews, and pilot testing. The inclusive research team used this input to create a functional tool that can be used by people with ID and care professionals.

Materials and Methods

Development Phases

This study used an iterative process in which end-users were involved to develop the asset mapping tool named DIscovering Health-promoting Assets in Settings for people with Intellectual Disabilities (DIHASID). End-users include people who engage in a living or day-activity location, e.g., people with mild to moderate ID, proxy respondents for people with severe/profound ID, and care professionals. The three development steps are visualized in Table 1 and described below.

The DIHASID tool is underpinned by an ecological model and the theory of salutogenesis. This implicates a focus on multiple environmental levels and on protective or promotive factors rather than on barriers and needs, and a focus on assets [37,38].

Table 1: Development of the DIHASID tool: phases, action, results, and participants. ID: intellectual disabilities.

Phase	Action	Result	Participants
Make the DIHASID tool comprehensive	Check the extent to which the DIHASID tool represents all facets of a given construct	Based on expert feedback, the DIHASID tool is adjusted to make it comprehensive	Experts on physical activity, nutrition, and health promotion for people with ID (n = 7)
Make the DIHASID tool clear	Check the readability, clarity of language, and consistency of style of the questions and format of the DIHASID tool	Points of attention deduced in the cognitive interviews are used to improve the clarity of the DIHASID tool	End-users: people with mild/moderate ID, proxy respondents for people with severe/profound ID, and care professionals (n = 7)
Make the DIHASID tool usable	Pilot test the DIHASID tool to test the usability of the scan in settings where people with ID live, work, and engage	Pilot testing improves the tool's usability, and the final DIHASID tool is developed	End-users from three pilot locations (n = 16)

The research team developed a draft asset mapping tool based on the Healthy Settings for People with Intellectual Disabilities (HeSPID) framework. This framework was built on two studies in which academics, people with ID, and proxies for people with ID developed a framework of themes and assets relevant for physical activity and nutrition in ID support settings [39,40]. The framework consists of 14 environmental-asset themes relating to people, places, and preconditions for healthy living.

This draft was discussed during expert interviews. Focus points were elicited on the comprehensibility of the themes and questions of the DIHASID tool, including all possible assets relevant for healthy living in ID support settings. Firstly, the aim of the DIHASID tool and an overview of the themes were introduced. Secondly, each theme was introduced, with a description based on the HeSPID framework [39,40]. Then, for each theme, the questions were read aloud, and the participants were asked to provide feedback on how representative the questions were. In addition, further suggestions were requested. Lastly, participants were asked to reflect on the tool and share ideas on other themes that should be included.

The cognitive interviewing (CI) technique was used to check the clarity of the questions for the users. CI is a method to evaluate the quality of transferring knowledge in questionnaires and has been used successfully among people with ID [41,42]. In CI, the interviewer reads the questions aloud and asks the interviewee to think aloud when answering the question. Probing questions are used to let the interviewees paraphrase questions, discuss thoughts, feelings, and ideas, and suggest alternative wording. The Question Appraisal System (QAS-99) was used to develop the interview protocol, including probing questions related to possible problems identified by the research team [41]. The interviews started with an explanation of the aim of the interview and the tool. Then, each question was read aloud by the interviewer, and the interviewee expressed what he/she thought and what he/she would answer. If applicable, probing questions related to

the question were asked. After one hour, the interview stopped, unless the interviewee explicitly wanted to continue. Interviews were audiotaped and conducted by K.V.v.A. in a place that was convenient for the interviewee.

To improve the usability of the DIHASID tool in practice, people with ID and care professionals at the three pilot locations (1) completed the DIHASID tool; (2) completed the After-Scenario Questionnaire (ASQ), a 3-item questionnaire about user satisfaction [43]; and (3) participated in a group discussion in which task usability, user satisfaction, functional usefulness, and ideas for improvements of the DIHASID tool were discussed. The group discussion topics were based on usability domains [44].

Procedures

For the expert interviews, experts were sought on physical activity, nutrition, and health promotion for people with ID. For the cognitive interviews, end-users were recruited: adults with mild/moderate ID who are able to communicate verbally, proxy respondents for persons with severe/profound ID, and a care professional. Diversity was sought in type of location (living or day- activity location). For the pilot, living or day-activity locations for people with moderate to profound ID were sought. In each pilot location, between two and four care professionals and between two and four adults with mild/moderate ID who were able to communicate verbally or between two and four proxy respondents for adults with severe/profound ID were recruited. Participants were recruited through purposive sampling. For the expert interviews, the research team's network was used to recruit participants by inviting them through email. For the cognitive interviews and pilot, the contact persons of eight ID support providers helped to recruit participants. They sent the information leaflet to team leaders and care professionals and asked them to identify potential participants.

The care professionals identified potential participants who were interested and able to participate and provide consent. Care professionals provided them with an information leaflet on the content and procedure of the study. If needed, the care professionals assisted in reading and understanding the information. Those who were interested to participate were asked to read or listen to the consent form. It was possible to contact the researcher by phone or email to ask questions. Those who agreed to participate were asked to sign the form themselves. After consent was obtained, the contact information was shared with the researcher, who contacted them or their care professional to schedule the meeting(s). For the expert interviews, informed consent was obtained when the appointment was being made.

The study was conducted according to the principles of the Declaration of Helsinki and the EU General Data Protection Regulation. The Medical Research Ethics Committee of Radboud University and Medical Center approved this study (registration number: 2018-4408).

Inclusive approach

This study actively involved people with ID as co-researchers to deploy experiential and scientific knowledge and contribute to appropriate data collection, data quality, and relevant outcomes [45,46]. The inclusive research team consisted of researchers with ID (co-researchers) and without ID, all employed by the university, and followed Frankena's [46] guidelines in the consensus statement for inclusive health research. K.V.v.A., A.v.d.C., and H.J. developed the procedure and the data collection method and incorporated feedback from other team members and the project's advisory group, which included people with ID, care professionals, health professionals, and a manager. Data collection and analysis was conducted by K.V.v.A. The co-researchers assisted when interpretation questions arose regarding the analysis of the cognitive interviews and group discussions of the pilot. Then, they listened to the audiotapes and discussed the meaning of what participants said. After each phase, K.V.v.A., A.v.d.C., H.J., and J.N. discussed how to adjust the tool in light of the problems and possible solutions identified during data collection. Given the important contribution of the co-researchers to this study, they are also recognized as co-authors on this paper. Collaboration between the researchers with and without ID was supported by (1) the research clock, a clock on which steps of the study were visualized to prompt memory; (2) audio recordings rather than transcripts for data analysis; (3) verbal explanation of this manuscript to obtain feedback; and (4) a training on working as a team of researchers with and without ID. In addition to this scientific paper, an easy-read abstract was written.

Analysis

Data analysis was performed using Atlas.ti software 8.2.29 and SPSS (version 25, SPSS Inc., Chicago, IL, USA. The suggestions from the expert interviews were collected and grouped based on type of problem and suggested improvements for the DIHASID tool. The audio recordings of the cognitive interviews were analyzed using Atlas.ti. The identified problems were selected and categorized according to the eight QAS-99 categories [41]. Then, the categories were thematically analyzed, and suggestions for improvements were logged.

The pilot data on the DIHASID tool and the ASQ were analyzed using descriptive statistics in SPSS. The audio recordings of the group discussions were thematically analyzed using Atlas.ti. Relevant fragments were structured in the categories of the TURF framework on usability, where TURF stands for Task, User, Representation and Function [44], and then thematically analyzed. The gathered information was discussed among the research team to finalize the DIHASID tool.

Results

Participants

Thirty persons participated in the development of the DIHASID tool. Seven female experts in lifestyle and health promotion participated in interviews on the comprehensibility of the DIHASID tool: three experts on physical activity for people with ID, two experts on nutrition for people with ID, and two experts on health promotion. The following end-users participated in cognitive interviews on the clarity of the DIHASID tool: people with ID, aged 18–55 (two male, three females, three filled it out for living location and two for day-activity location), a female proxy respondent (parent), and a female care professional. The tool was piloted on usability among 16 persons from three different living and/or day-activity locations for people with moderate to profound ID, i.e., six persons with ID (five males, 1 female), two female proxy respondents, seven female care professionals, and one male manager.

Comprehensive DIHASID Tool

The analysis of the expert interviews resulted in six points for improving the comprehensibility of the DIHASID tool: (i) add a theme, (ii) add answer options, (iii) clarify or divide broad or vague questions, (iv) find better matching response categories for which respondents have the knowledge to answer, (v) use reminders for what is viewed as healthy living and a healthy living environment, and (vi) personalize questions. The input was used to change the tool regarding (i) adding or changing questions and answer options, (ii) providing more instructions, and (iii) personalization of the questions. Table 2 provides a full list of the points for improvements and changes made to the DIHASID tool.

Analysis also resulted in points that did not match the aim of the DIHASID tool and therefore did not result in changes to the tool. Examples include suggestions on the knowledge or professional attitude of clients and care professionals, relaxation, and negative environmental factors. The stability of the social network of people with ID was not included in the DIHASID tool, as this was perceived as too difficult to ascertain via a questionnaire. Details on accessibility (e.g., does the swimming pool have a hoist) were not included, as this would make the list too detailed and too long.

Table 2: Points for improvement suggested in expert interviews and changes to the DIHASID tool.

Point for improvement	Changes to the DIHASID tool
Add theme: Include communication about healthy living within an organization in questions about health-promoting organizational policies.	**The question:** "How do you perceive the attention on healthy living in communications by this organization?" was added.
Add answer options for the questions: 1. Type of disabilities: type of wheelchair, I am not allowed on the road by myself, epilepsy 2. Type of support persons: friends, occupational therapist, speech therapist 3. Type of support: others buy food/devices: bicycle for the wheelchair, book with ideas about exercise activities, games in which you need to move, meal service, and meal-in-a-box 4. Type of autonomy-supported decision making: clients choose themselves, they do not receive help.	The suggested answer options were added to the questions.
Clarify or divide broad or vague questions: 1. The answer options for the question on types of advice from types of health professionals are not complete. Many health professionals can give several types of advice. 2. How participants experience the help of others for healthy living is very broad. It might be better to split 'others' into categories such as family and friends, health professionals, care professionals, volunteers, and clients. 3. The question, "What do you think of the opportunities for healthy living in the neighborhood?" was found to be vague. This could be interpreted as places for healthy living or activities for healthy living.	1. The question was split into two questions: "At this location, there is enough opportunity for care professionals to get tips about...?" <answer options include types of advice> and "Who is available to provide this advice?" <answer options include types of health professionals>. 2. The answer option for the question, "How well do others help with healthy living?" was split into three categories: (a) care professionals, clients, and volunteers, (b) family and friends, and (c) health professionals. 3. The question was split into: "Are there enough places for healthy eating, healthy drinking, physical activity, and sports in the neighborhood?" and "Are there enough activities for healthy living in which you/the client can participate?"
Matching response categories: 1. The answer type for the question on talking about healthy living was perceived as difficult and not appropriate. The answer type on how often talks about healthy living were held was perceived as less important than how talking is experienced. 2. The answer option for the questions, "How much time do care professionals have for activating clients?" and "How much time and attention and do care professionals have for providing food and drinks?" were perceived as too difficult. It was perceived as too difficult for participants to express this in days per week, as this largely varies between weeks.	1. The answer options were changed to a 5-point smiley answer. 2. The answer options were changed to never/sometimes/often/always.
Use reminders: The experts stated that clients would need reminders of what is viewed as healthy living and a healthy living environment.	The explanation of healthy living was repeated at several places in the questionnaire. The subthemes of People, Places, and Preconditions were repeated above the open questions to stimulate the participants to think about all the questions that they answered about the overarching theme and formulate wishes.
Personalized questions: The participants perceived referrals in questions as too general. Personalization of the questions was perceived as helpful for clients (e.g., "Who supports you with healthy living?" instead of "Who at this location supports healthy living?").	Separate questions were devised for clients, proxies, and care professionals.

Clarity of the DIHASID Tool

Analysis of the cognitive interviews identified 152 problems with clarity, resulting in 119 adjustments to the DIHASID tool. The problems and their adjustments are described below using the eight QAS-99 categories, see Table 3.

In the Clarity category (n = 64), problems related to the wording of the questions, technical terms, such as health professionals and epilepsy, and vague questions. Regarding Response categories (n = 38), problems related to technical terms and vague, overlapping, and missing answer options. For example, the differences between the five smileys were vague according to the participants. Problems with Instructions (n = 23) included lack of clarity on what to consider when answering the questions, information missing on how many answers could be chosen, and surplus information. A few problems related to Knowledge or Memory (n = 10), including difficulty in knowing the boundaries and facilities of—and distances from—facilities within the neighborhood and care professionals' knowledge on organizational policy and budgets. For Sensitivity or Bias (n = 7), problems related to questions on the nature of a person's disabilities and use of the word 'client'. Only one problem related to the Assumptions category: it was perceived as difficult to choose one smiley for how a person perceives help from all health professionals. Other problems (n = 9) related to the size and unclear meaning of pictures.

The identified problems and suggestions were used to improve the clarity of the DIHASID tool by shortening and specifying instructions, explaining how many answer options to choose and where to fill in the answer, including or changing pictograms, changing word order, replacing technical terms with easy words, explaining unclear words, removing/inserting answer options, and changing sensitive words.

Table 3: Problems identified in cognitive interviews and changes to improve the clarity of the DIHASID tool.

QAS-99 Category	Description of Problems	Changes to the DIHASID Tool
1. Reading Difficulty reading the question (what and how to read)	n.a.	n.a.
2. Instructions Problems with instructions or explanations (conflicting, inaccurate, or complicated)	• unclear for participants what to consider when answering the questions • unclear instruction on the number of answers that can be chosen • unclear what to write or where to write an answer • difficult explanations: pictograms with words under them would help them understand the question better • some information was perceived as surplus • including that a support person is allowed to help was perceived as helpful for getting answers to the open questions	• shorten the questionnaire instruction • specify the instruction • explain how many answers may be chosen • specify that help from a support person is allowed • explain where to fill in the answer • include pictures and words beneath them
3. Clarity Problems related to communicating the intent of the question (wording, technical terms, vague, reference points)	• participants had difficulty understanding the sentence for some questions • technical terms, such as health professionals, aids, patient lift, masseur, epilepsy, spasm, residential and daytime support center • vague questions, for example what a neighborhood is	• change word order in sentences • give explanation or examples for unclear words • replace technical terms with easy words
4. Assumptions Problems with assumptions made or underlying logic (inappropriate, assumes constant behavior, double-barreled)	• it was perceived as difficult to choose one smiley for how a person perceives help from all health professionals	n.a.
5. Knowledge/Memory Whether respondents are likely to know or remember information (knowledge, attitude, recall failure, computation problems)	• difficulty in knowing the boundaries and facilities of, and distances from, facilities within the neighborhood • for care professionals: to know about the policy and financial budget of their organization	• make the distance from facilities broader (within 15-min walking distance, within 15-min biking distance, you need a car/cab/bus to get there) • insert "I don't know" options for questions for care professionals about budget and policy
6. Sensitivity/Bias Sensitive nature, wording, or bias of questions (sensitive content or wording and social acceptability)	• the nature of a person's disabilities • use of the word client	• include the response option "I don't want to say" for the question about disabilities • change client into resident or participant at daytime activities
7. Response categories Adequacy of range of responses (difficulty of open-ended questions, mismatch, technical terms, vague, overlapping, missing, illogical order)	• unclear technical terms: fitness center, hydrotherapy bath • vague answer options: smiley response categories because differences between the five smileys were unclear for participants • overlapping answer options: kitchen and adjusted kitchen • missing answer options: vegetable garden for the question about aids for healthy nutrition	• replace technical terms with easier words • change words or add examples for vague answer options • remove answer options (use of three instead of five smileys) • remove overlapping answer options • add open answer options for incomplete response categories
8. Other problems	• size of pictures-unclear meaning of pictures	• size of all pictures was increased • unclear pictures were changed into pictures that were perceived to be clearer

Usable DIHASID Tool

The analysis of the DIHASID tool pilot provided information on (1) how the task was performed and experienced, (2) final points for improvements on usability, and (3) what the DIHASID tool can yield in practice. It took the 16 participants on average 34 min (38 for participants with ID, 35 for proxy respondents, and 30 for care professionals) to complete the task, and only a few answers were missing. Seven participants, of which six people with ID, chose to fill the DIHASID tool out on paper, and nine used the online questionnaire; both were perceived as clear and easy to navigate. Most participants perceived the explanation and clarity of the task (n = 13 out of 16), the ease of the task (n= 12 out of 16), and the length of the task (n = 13 out of 16) as good. All participants viewed themselves as the right person to answers the questions, except those on financial aspects and health-promoting organizational policies, which care professionals perceived as difficult because they were not familiar with these issues. Regarding financial and policy aspects, participants identified a team leader as the right person to be involved in filling out the DIHASID tool. Participants with ID perceived the help from a care professional as pleasant, needed, and not influencing their answers.

Final points for improving the DIHASID tool included: (1) page numbering, larger answer fields, and larger fonts for the paper version, (2) allowing participants to choose more than one answer option for multiple choice questions, (3) instructing proxies that they can tick 'not applicable' for questions that are irrelevant for the person they represent, e.g., a question about talking when the person they represent cannot speak, and (4) final changes to questions and explanations to improve clarity, for example changing the description of clients 'resident or participant at daytime activities' back to 'client'.

In the group discussions, participants reflected that the DIHASID tool can help to (1) raise awareness and put healthy living in the spotlight, (2) create an overview on what is available to support healthy living, and (3) use the overview to create changes in the organization. Participants identified a summary of the outcomes as needed for generating actionable knowledge. For example, teams of care professionals can discuss this summary and devise action steps together. Participants identified the following stakeholders with whom to share this summary: clients, clients' families, care professionals, team leaders, personal support coordinators, policymakers, and quality assurance officers of the organization.

Final version of the DIHASID tool

The final DIHASID tool (see Supplementary Material) consists of 37 questions divided into four parts: (1) participant and setting characteristics, (2) how people support healthy living including their social network, types of support, and values regarding healthy living, (3) how places support healthy living including tools, facilities, accessibility, and person–environment fit, and (4) the preconditions for healthy living that are available, including financial aspects and health-promoting organizational policies. Regarding the type of questions, part one includes multiple choice questions. Parts two, three, and four include

the following type of questions: (1) tick boxes on presence of assets, (2) multiple choice questions (3-point smiley scale, but 5-point Likert scale for questions that are aimed only at care professionals and proxies) on how respondents experience a theme, and (3) an open question on wishes and dreams regarding the theme. The tool can be completed by people in a living or day-activity location, e.g., people with mild to moderate ID, proxy respondents for people with severe/profound ID, care professionals, and team leaders.

Discussion

This study aimed to develop an inclusive and functional tool for mapping assets for physical activity and healthy nutrition in ID support settings. An iterative process of applying feedback from expert interviews, cognitive interviews, and pilot testing was used to develop a comprehensive, clear, usable tool. The tool, named DIscovering Health-promoting Assets in Settings for people with Intellectual Disabilities (DIHASID), can be completed in approximately 30 min by people with mild to moderate ID who are assisted by a support person, proxy respondents for people with severe/profound ID, care professionals, and team leaders.

The DIHASID tool is an inclusive tool for people with ID and care professionals that can be used to facilitate bottom–up engagement to improve the health-promoting capacities of ID support settings. This approach is empowering and aligns with the 'Nothing about us, without us' movement that advocates for the involvement of people with ID in matters that affect them [47]. Furthermore, this bottom–up approach can create awareness among policymakers of what supports people with ID and their care professionals in facilitating healthy lifestyles. The DIHASID tool helps to implement inclusive and healthy environments and thereby facilitates policymakers in the trend toward a greater focus on environmental impacts on health. For example, the Dutch Environment Act and Green Deal provide good opportunities to include attention on health promotion in spatial planning and sustainable innovations, including a healthy living environment in the care sector [48,49]. Participants perceived the DIHASID tool as helpful for providing an overview of user-experienced assets and wishes regarding a healthy living environment for physical activity and healthy nutrition of people with ID, thereby aligning with the goals of asset mapping [24]. From an asset-based community development perspective, the next steps for building healthy ID support settings include (1) finding connectors and engaging them in (re)building relationships between people to link assets and create a health-promoting infrastructure, (2) creating a joint vision and action plan, and (3) embedding this plan and vision in the settings' organizational structure [50,51]. These steps are important but also challenging to implement in ID support settings because currently there is a lack of clarity among stakeholders on roles and responsibilities regarding health promotion. Care professionals who are involved in everyday support are often not trained on this topic. Allied health professionals often focus mostly on curative care rather than prevention and may not know how to facilitate care professionals [19,52]. Furthermore, it might be

challenging to involve people with ID in developing a joint vision and action plan. Future studies could design and pilot how this bottom–up process can be tailored to their needs.

A major strength of this study is the co-design of the DIHASID tool by the inclusive research team together with experts in practice, experts in research, and experts by experience. This ensured that tailored methods were used to enable people with ID to meaningfully engage as participants and led to a better match between research and practice. In addition, the insights of the researchers with ID helped in interpreting user perspectives and in deciding on appropriate changes to improve the usability of the tool.

The number of interviews to improve the comprehensibility, clarity, and usability of the tool was limited. However, an iterative process was used, and after the pilot, hardly any changes were required. Although the DIHASID tool gives prompts about a wide range of assets in the physical, social, and organizational environment, the results depend on the participants' familiarity with local assets. Therefore, it is preferable that multiple persons in a setting fill out the DIHASID tool to gain an overview that is as complete as possible. Lastly, some caution should be exercised about implementing this tool in other countries. The type of questioning and general themes are expected to be relevant in other countries, as the tool was built on the basis of an existing international concept mapping study [39]. However, the clarity of the questions was tested in Dutch, and the tool's comprehensibility and usability were tested in the support organization in the Netherlands. Therefore, we advise anyone who wants to apply the DIHASID tool in another country to conduct a pilot to see whether adaptations are needed for that context.

Future studies could use the DIHASID tool to (1) provide insight into how people with ID are currently supported by ID support organizations to live healthily, (2) enhance intervention effectiveness in specific settings by identifying assets that can support the intervention in that particular setting and/or interweave the intervention in the setting [53], and (3) gain insight into contextual factors that might influence the outcomes and successes of health promotion interventions applied in that particular setting [54].

Conclusions

The DIHASID tool is a comprehensive, clear, and usable tool to map health-promoting assets in ID support settings. Using the tool provides insight into perceived environmental assets and into points for improvements regarding support for healthy nutrition and physical activity of people with moderate to profound ID in settings where they engage. The bottom–up development of this tool for co-learning ensures that the DIHASID tool asks about assets that may be relevant for users of ID support settings. The tool empowers people with ID and care professionals to pinpoint assets that they find helpful and to identify future directions for creating healthy environments for physical activity and healthy nutrition. The tool can be used together with stakeholders who are responsible for health promotion and organizational policy, and the overview of assets can be used to mobilize and build on assets to inclusively improve the health-promoting capacity of ID support settings.

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CHAPTER

Gaining actionable knowledge to improve local health promoting capacities of long term care support settings for people with intellectual disabilities

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Patient education and counselling, doi: 10.1016/j.pec.2021.05.033

Abstract

People with intellectual disabilities (ID) are largely dependent on their environment to live healthily and, in this, ID-support organizations play a vital role. An environmental asset mapping tool for ID-support settings has been developed. This study aims to provide insight into whether or not the tool can provide a comprehensive view on assets in the system and actionable knowledge to improve health-promoting capacities in ID-support settings. Fifty-seven users from four setting completed the tool on availability, user satisfaction, and dreams regarding social, physical, organizational, and financial assets. The findings provide a comprehensive view of available assets. Together with user satisfaction and dreams for improvements, they provide actionable knowledge for improving the health-promoting capacities of the settings, including: (1) how use of available assets can be improved, (2) the type of assets that should be enriched, and (3) the assets that can be added to the system. The asset mapping tool provides a comprehensive view on assets in the system and actionable knowledge to improve health-promoting capacities in ID-support settings. ID-support organizations can use the tool to generate actionable bottom-up knowledge for priority setting and implementing interventions to improve their health-promoting capacities.

Introduction

Support organizations for people with intellectual disabilities (ID) play a vital role in facilitating health and health promotion for people with ID [1-3]. They arrange (often) long-term everyday support in daytime and living accommodations for people with ID, who experience significant limitations in intellectual functioning and adaptive behavior [4]. People with ID face more lifestyle-related health problems and have unhealthier diets and lower physical activity levels than the general population [5-7]. Health-promotion through ID-support organizations can help reduce health disparities [8-11]. Moreover, people with ID themselves have expressed the need for a supportive social and physical environment to be able to live healthily [12,13]. However, ID-support organizations face difficulties in embedding health promotion in their organization and activities [3,14,15].

Health promotion for people with ID has focused mainly on program-based interventions targeting individual behavior and may benefit from expanding its focus to the context of settings in which people engage in daily life [2,16,17]. As behavior patterns are created and sustained through the setting in which people engage, it is challenging to integrate in daily life what has been learned in programs. Recognition of the importance of context in health promotion for people with ID helps to change behavior and maintain newly adopted habits [2]. Studies focusing on the context where people with ID engage show that available health-promoting activities are mostly stand-alone activities that lack embedment in ID-support organizations' policies [16,17]. Furthermore, studies on organizational factors in ID-support settings state that a health promotion culture is often lacking and that staff members have training needs and lack clarity on roles and responsibilities regarding health promotion [3,14,15,18]. Gaining a more holistic view of how multifaceted factors in ID-support settings support a healthy lifestyle can help ID-support organizations to make a strategic action plan and improve the health-promoting capacities of their organization [2].

User involvement is key to gaining insight into a setting's multifaceted factors that influence the lifestyle of people with ID. Users have intimate knowledge of everyday practices, for example the assets that are perceived to support healthy living. Assets are protective or promoting factors that maintain and sustain health and wellbeing in a setting [20]. Also, users' ideas for improvement foster bottom-up organizational change that fits with users' needs and wishes [19-21]. To enable users of ID-support settings to identify assets supporting physical activity and healthy nutrition and share their ideas for change, an asset mapping tool was developed in a previous study, named DIscovering Health-promoting Assets in Settings for people with Intellectual Disabilities (DIHASID) [22]. It focuses on social, physical, financial, and organizational assets for physical activity and healthy nutrition within ID-support settings and contains questions about asset availability, user satisfaction with those assets, and dreams for further improvements. Users of the setting, e.g. people with ID and care professionals, can complete the DIHASID

tool. The tool aims to gain a bottom-up comprehensive overview of the health-promoting capacities of a residential or daycare setting and to create actionable knowledge. Further research is needed to test the capacity of the tool.

In this study, the DIHASID tool is applied to ascertain whether or not the tool can in practice provide a comprehensive view on assets in ID-support settings and actionable knowledge to improve their health-promoting capacities. The following research questions are answered:

- Is the DIHASID tool able to provide a comprehensive view of social, physical, organizational, and financial assets for physical activity and healthy nutrition available in ID-support settings?
- Is the DIHASID tool able to provide actionable knowledge to improve health-promoting capacities in ID-support settings?

Methods

Setting

This study was performed in residential and daytime support settings of Dutch ID-support organizations for people with moderate to profound ID. In the Netherlands, about 70,000 people with ID live in residential accommodations and another 20,000 persons use daytime accommodations [23]. Support ranges from ambulatory support for several hours a week, to day activity support, and to long-term residential support and care in accommodations provided by ID-support organizations [24]. These accommodations range from clustered group homes, to small-group living in apartments, and to single-family homes in neighborhoods [23]. In these residential accommodations, care professionals, trained in social work and/or assistant nursing, provide 24-hour support by assisting in personal, daily, social, and health care. In the day-activity accommodations, the care professionals provide recreational or unpaid labor activities for people with ID.

Participants and procedures

Four residential and/or daytime accommodations for adults with moderate to profound ID from four different ID-support providers were recruited. Contact persons from six regional ID-support organizations assisted in recruitment by disseminating information flyers among team leaders in these settings. If they were interested, the researcher contacted them to discuss participation. Users of the setting, people with ID, proxy respondents for people with ID, care professionals, and team leaders who met the inclusion criteria received an information letter. Inclusion criteria for people with ID were: age ≥ 18 years with moderate to profound ID. For people with ID for whom verbal communication was difficult, proxy respondents were sought. Inclusion criteria for proxy respondents were the same as for the care professionals and team leaders: engaging for at least 2 months regularly at the setting where the study took place. Written informed consent

was obtained. For people with ID who had a legal representative, that representative also signed the consent form.

Participants completed the DIHASID tool on paper or online. To ascertain the credibility of the results, a participant check was conducted in a group meeting at each setting within two weeks of completion of the DIHASID tool. All participants were invited for this group meeting which was led by the first author. The participant check was conducted by discussing the accuracy and recognizability of the summary and the infographic of the results of the DIHASID tool. Also, differences in responses regarding availability of assets were discussed.

The study was conducted according to the principles of the Declaration of Helsinki and the EU General Data Protection Regulation. The Medical Research Ethics Committee of Radboud University and Medical Center approved this study (registration number: 2018-4408). Data were collected between January and April 2019.

Development DIHASID tool

The DIHASID tool is an inclusive bottom-up tool for environmental asset mapping in ID-support settings. It helps users of a setting to identify and reflect on available assets and to identify wishes regarding environmental support for physical activity and healthy nutrition [22]. The tool is underpinned by the settings approach, a whole systems approach aimed at embedding health within a setting's routines and culture [25]. The topics in the DIHASID tool are based on the Healthy Settings for People with Intellectual Disabilities (HeSPID) framework, a conceptual framework on assets for physical activity and healthy nutrition in ID-support settings developed by academics, people with ID, and proxies of people with ID [26, 27]. The DIHASID tool's development process is described in a previous study in which the tool is included as an appendix [22].

The DIHASID tool consists of 37 questions about: (1) participant and general setting characteristics, (2) social assets for healthy living including the social network, types of support, and values regarding healthy living, (3) physical assets for healthy living including tools, facilities, accessibility, and person–environment fit, and (4) financial and organizational assets for healthy living. The tool enquires about availability of, and user satisfaction with, available assets and wishes/dreams. Question types include tick-box questions, multiple choice questions (3-point smiley scale and 5-point Likert scale for questions for care professionals and proxies), and open questions. The tool can be completed in approximately 30 minutes by people with mild to moderate ID assisted by a support person, proxy respondents for people with severe/profound ID, care professionals, and team leaders. The questions are tailored to the type of accommodation (residential or daytime accommodation) and type of respondent (person with ID, proxy respondent, professional caregiver, team leader).

Data analysis

The tick-box and user satisfaction answers were analyzed using descriptive analysis in IBM SPSS (version 25). The answers to the dreams questions were grouped based on its content and then described per type of asset (social, physical, financial and organizational).

To gain an overview of the available social, physical, organizational, and financial assets at each setting, the tick-box answers were assessed. If ≥1 participant in a setting ticked the box indicating that an asset was present, the asset was included in the list of assets at the setting.

To gain an overview of the actionable knowledge gained through the DIHASID tool, the answers on user satisfaction and dreams and recordings of the participant checks were thematically analyzed. For user satisfaction, median scores of the multiple-choice questions for each theme were calculated per setting. Furthermore, a graphical overview was developed for each setting by calculating a score for the themes: total available social assets, user satisfaction with social assets, total available physical assets, user satisfaction with physical assets, perceived financial assets, and user satisfaction with organizational assets. For total available assets, the available assets per theme were counted. For each theme, the maximal score was calculated by adding up the maximal score for each question relating to that theme. The score on that theme for each setting was calculated as a percentage: score on theme for setting X / maximum score * 100.

Results

The participants' answers to the DIHASID tool resulted in overviews per setting on availability, user satisfaction, and dreams for improvements regarding assets for physical activity and healthy nutrition. This information is described below. Combined, this information provides actionable knowledge for health promotion practice, which is described in the final paragraph of the results section.

General characteristics of settings and participants

This study was performed in four ID-support settings of four different ID-support providers. In total, 74 persons completed the DIHASID tool to provide insight into the health-promoting capacities in these four settings, see Table 1. At all locations more than half of the employees and clients involved participated or were represented.

Table 1: Setting and participant characteristics.

Setting characteristics	Setting 1	Setting 2	Setting 3	Setting 4
Type of setting;				
• residential accommodation	Yes	Yes	No	Yes
• daytime care accommodation	Yes	No	Yes	No
Place of setting;				
• setting in neighborhood	Yes	No	No	No
• setting on care organization complex	No	Yes	Yes	Yes
Employees (n)	21	7	8	9
Clients (n)	11	5	12	12
Clients' characteristics:				
• Age (min–max)	20–70	40–60	15*–45	12*–33
• Spasms	Yes	Yes	No	Yes
• Epilepsy	Yes	Yes	Yes	Yes
• Autism	Yes	Yes	Yes	Yes
• Tube feeding	Yes	No	No	No
• Impaired vision or blind	Yes	Yes	Yes	Yes
• Hard of hearing	Yes	Yes	No	Yes
• Wheelchair use	Yes	Yes	No	Yes
• Not allowed on the road by themselves	Yes	Yes	Yes	Yes
Participants:				
• Total (n)	25	12	12	15
• People with ID (n)	5	0	2	2
• Proxy respondents (n)	3	5	4	4
• Daily caregivers and team leaders (n)	17	7	6	9

*Clients under the age of 18 were not invited to participate in this study.

Availability of assets

The DIHASID tool provides setting-level information on availability of social and physical assets, including potential stakeholders for support, types of support, aids for physical activity and healthy nutrition at the setting, nearby facilities, and ease of travel to nearby facilities. A complete overview is provided in Appendix A.

All social assets enquired about were available at ≥ 1 setting. Friends, clients, volunteers, and a massage therapist were available to support healthy living at only one or two of the four settings. All settings provided a large variety of types of support from care professionals and health professionals to people with ID (at least 12 out of 19 types of support), ranging from doing things together, to helping with choosing, and help from health professionals with exercise activities. Doing certain activities together, explaining things, giving tips, or displaying role-model behavior were not provided at all settings. Care professionals also received a variety of types of support from health professionals, but inspiring materials for healthy food or client-specific advice regarding nutrition were not available at all settings. In the support to people with ID, several levels of autonomy are given in decision making about healthy living. In one setting, clients could not choose themselves (with or without tips), but, in three settings, care professionals and clients choose together, with possible restrictions via the options to choose from.

Most of the physical assets enquired about are available at ≥1 setting. All settings have enough space for physical activity and accessible buildings for people with physical limitations. The following aids and equipment for physical activity were not available at ≥1 setting: stationary bicycle, activity-stimulating games, and a book with ideas about exercise activities. In the area surrounding the settings, many facilities for healthy living were available. Shops, supermarkets, hydro-therapy baths, and sports fields were not within walking or biking distance (15 min.) of one or two settings.

User satisfaction with assets

On user satisfaction, the results from the DIHASID tool generate an overview of social, physical, financial, and organizational assets in the four settings. A complete overview can be found in Appendix B.

The social assets mostly perceived as capable of improvement were: support in making personal choices and discussions about healthy living. Help for clients from health professionals was mostly perceived as good for clients and satisfactory for care professionals. In all settings, users perceived that there was often time to focus on food and eating time and sometimes time to motivate clients to be physically active and to talk about healthy living. Preconditions for a team to support healthy living that were perceived as neutral include: sufficient knowledge and skills, clear agreements with clients' family, and a shared vision on healthy living. Perceptions were more positive about the team's knowledge about providing clients with personalized support and clear mutual agreements.

User satisfaction with physical assets was mostly positive. The aids for healthy living at the settings and settings nearby for healthy food and drinks, physical activity, and sports were perceived as good. Activities for healthy living and the embedment of healthy living in day and evening programs were perceived as capable of improvement. Participants perceived ease of travel as safe and easy. The fit between clients' needs and the environment was perceived as enough for nearby places and capable of improvement for things available in the settings.

Participants' user satisfaction with financial and organizational assets was moderate or satisfactory. Whereas individual budgets and organizational budgets for healthy living were perceived as moderate, settings' budgets were perceived as satisfactory. The organizational assets mostly perceived as moderate were: collaboration with clients in creating health-promoting settings, collaboration with municipalities and sports providers, organizational guidelines on knowledge needed by employees and clients about healthy living, and coaching/education for care professionals from other employees. The organizational assets mostly perceived as satisfactory were: coaching/education for care professionals from external parties, attention on healthy living and differences between target groups in the organization's policy and communication, and attention on healthy living in development plans for people with ID.

Dreams for improvements

The DIHASID also generated dreams for improvements regarding social (n=72), physical (n=37), and financial and organizational assets (n=23).

Dreams on social assets focused mainly on types of support and preconditions for support. The types of support wished for included: more support through keeping an overview of clients' nutritional intake, cooking, providing healthy foods and variety in meals, regulating intake of unhealthy foods. Also, participants wished for more opportunities for clients to be physically active; this relates to both physical assets and care professionals' competence to integrate physical activity in daily routines. In general, participants wished for support and activities that are better tailored to clients' abilities and more client involvement in decision making. Care professionals' wishes on preconditions for social support included: knowledge on healthy living, motivation skills, ability to tailor support and embed healthy living in daily routines, role-model behavior, a positive attitude towards healthy living, and support from health professionals. Other dreams about preconditions focused on care professionals having more time to support healthy living, a shared vision, mutual agreements, and acting uniformly as care professionals and family.

Dreams about physical assets included the wish for more aids: treadmill, WII game computer, game materials, adjusted swings, sensory stimulation materials in garden, adjusted bikes, multisensory room, vegetable garden, and a healthy food book. Also, participants wished that the available aids would receive more attention and be used more often. Dreams about facilities in the nearby area for healthy living included: a fitness room, a soccer field, activity-stimulating materials in the swimming pool, a garden in the village with physical-activity-stimulating elements, a restaurant with healthy menus, and a supermarket with many healthy products. Access to facilities and a range of activities in which clients can participate at those settings were also wished for.

Dreams regarding financial and organizational assets focused on what participants would like to spend money on: aids and games that support physical activities, exercise activities, healthy food, and personnel to support healthy living. Also, participants wished for more attention on healthy living in the organization and its policy. Not only did participants want their organization to make its vision on healthy living clear, but also they wanted enough attention to be given to the preconditions to support healthy living. Lastly, they wished for more awareness regarding healthy living among personnel. For example, training could be used to raise awareness of the occasions that present opportunities to focus attention on healthy living and the aids that can be used.

Actionable knowledge to improve health-promoting capacities in ID-support settings

The combined information on asset availability, user satisfaction, and dreams provides ideas on which areas and what kinds of changes can improve the health-promoting capacities in the ID-support settings. Areas for improvement are visualized in Figure 1, which provides a graphical overview per setting on availability of, and user satisfaction

with, the different types of assets. For each location, this provides insight into differences between availability and user satisfaction regarding social and physical assets. Also, it identifies the domain (social, physical, financial, and/or organizational) in which improvements can be made. Regarding the content of potential change, it provides insight into how the health-promoting capacities can be built: firstly, how available assets can be tailored to users' needs – for example, how support can be better tailored to the autonomy that clients are able to have; secondly, how available assets can be used in a different and better way – for example, how health professionals can use part of their time to empower care professionals to support clients in doing movement exercises, so that clients receive more support. Lastly, it identifies the assets that can be added to the system to make dreams regarding that theme come true. During the participant check, users of the settings confirmed that the results of the DIHASID tool provided actionable knowledge. In each setting, a group meeting was held in which participants confirmed that the summary of the results provided an accurate description of the setting and actionable knowledge to improve health-promoting capacities. They reflected on this by saying that the results provide an overview of where changes are needed and provide ideas on what to change. Also, they stated that the ideas of other users inspired them to think about more ideas for improvements.

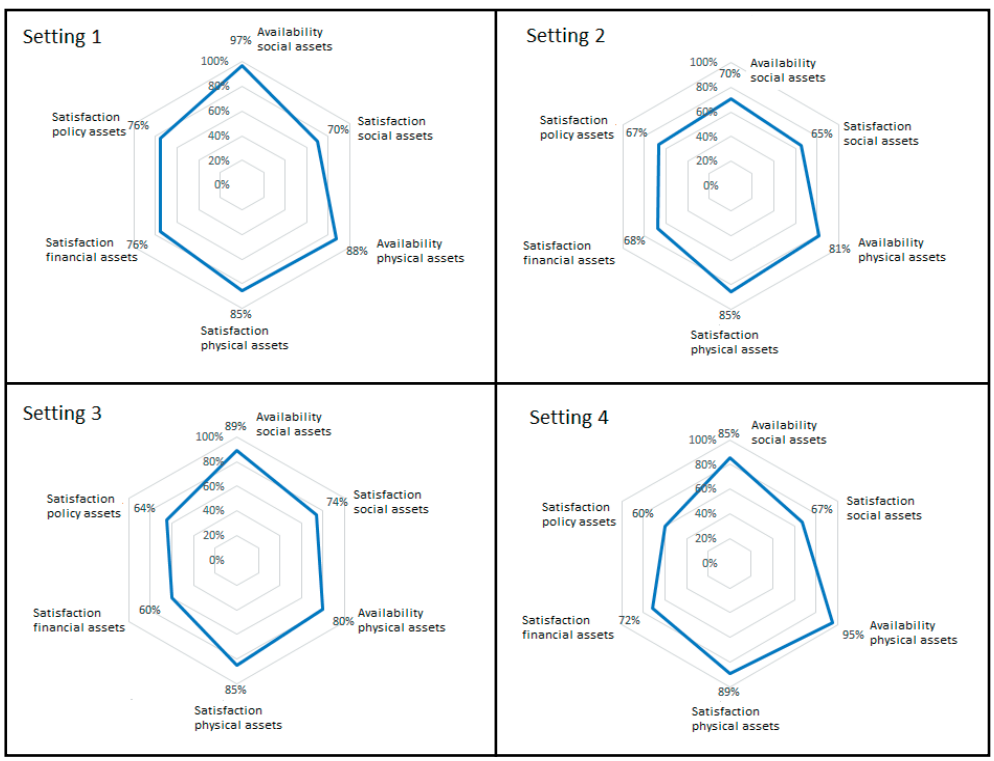

Figure 1: Graphical overview of available and perceived assets at the four settings.

Discussion and conclusion

Discussion

This study aimed to provide insight into whether or not the DIHASID tool can provide a comprehensive view on assets in ID-support settings and generate actionable knowledge to improve health-promoting capacities. By completing the DIHASID tool in four settings, the 57 participants provided an overview of availability, user perceptions, and dreams regarding social, physical, organizational, and financial assets that they perceived as comprehensive for the setting in which they engage. Although studies exist on user perspectives on factors that enable or hinder healthy living [3,12,15,28-30], this is the first study to take a settings approach to the multifaceted factors in the context of ID-support organizations. The DIHASID provides three types of actionable knowledge that can be used in a settings approach for health promotion. Firstly, an overview of how available assets are perceived and ideas for changing the use of existing assets or linking them better with other assets. Secondly, an overview of the type of asset enrichment needed in the system. In this study, this encompassed budget, time, attention, and support persons' capacities regarding healthy living; this aligns with literature on barriers to health promotion for people with ID [14,30-33]. Thirdly, insight has been gained into the components that should be added to increase the health-promoting capacity of the system. These insights are key for ID-support organizations to take the current context into account in building a bottom-up settings approach to strategically embed adaptations in the system and improve health-promoting capacities in settings.

A major strength of this study is that most users engaging in the four settings completed the DIHASID tool; this strengthens the reliability of the overview of user perspectives. This, together with the different question types and probing for different types of assets, creates a holistic overview of the four settings. Furthermore, the credibility of the outcomes of the DIHASID tool was confirmed by a participant check. Such a complete overview of the current situation is useful for asset-based development in practice [34].

Interpretation of the results is subject to some limitations however. As many of the people with ID engaging in the four settings had a severe/profound ID, they were not able to participate. However, for these persons, proxy respondents replied on their behalf and people with ID who did participate could share their perspective, as the DIHASID tool was adjusted to their needs [22]. Also, a much-discussed issue in asset-based approaches is the lack of overview on power relations between stakeholders in a setting [35,36], which is important in determining a strategy for implementing a settings approach [37]. Although the users of a setting are often not the stakeholders who have power over distribution of resources, enabling them to share their perspective can lead to empowerment [38]. Also, stakeholders who possess this power can use the results of the DIHASID as bottom-up input on the current situation/wishes to determine the best strategy to implement a

settings approach. Lastly, this study focused on the Dutch context of care and provides an overview for four ID-support settings. Although the results cannot be generalized to other care settings or countries, the results provide insight into the type of information that the DIHASID tool provides. This can help stakeholders in practice and researchers in other settings to determine how useful it is to apply this tool.

In future research, the DIHASID tool could be used as a first step in participatory action research aimed at increasing health-promoting capacities in ID-support settings. The tool provides information for understanding the context and for setting the priorities needed to define actions to take in such an approach [39]. Evaluation of the process and outcome of those actions can provide lessons for practice and research [35,39]. Furthermore, future research could explore how a settings approach in ID-support settings can facilitate other positive lifestyle factors such as sleep.

Conclusion

In conclusion, the DIHASID tool is able to provide a comprehensive picture of user perspectives on assets and actionable knowledge to improve health-promoting capacities in ID-support settings. Completing the tool provides a holistic overview of available social, physical, organizational, and financial assets, how they are perceived by users, and in what way users think that the health-promoting capacities in a setting can be improved. This provides actionable knowledge on: (1) how available assets can be used in a better way, (2) the type of assets that should be enriched, and (3) the assets that should be added to the setting.

Practice implications

The DIHASID tool can be used in practice to facilitate users and policymakers to take a bottom-up approach for improving health-promoting capacities in ID-support settings. For users, completing the DIHASID tool and receiving an overview of available assets can help them recognize and utilize available assets and express their wishes for change. In projects where users were involved in decision making and collaborative action to make changes to their setting, this empowered the users and had a positive impact on their self-efficacy and self-esteem [40]. Thus, involving people with ID in decision making and collaborative action might empower them and contribute to the exercising of their right to have a say about matters that affect them [41]. Policymakers can use the DIHASID results to apply a bottom-up approach for setting priorities, building a strategic action plan, and intervening through a settings approach to increase health-promoting capacities in ID-support settings [2,20,42,43].

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CHAPTER

9

General discussion

General discussion

Overview of main findings

In this thesis, we developed a conceptual framework of healthy settings for people with intellectual disabilities (ID). This framework was used to develop a tool that local stakeholders can use to create actionable knowledge for (further) embedment of health promotion in ID support settings. Furthermore, this thesis provides insight into how stakeholders can be involved in health promotion research.

Part I of the thesis focuses on the question: 'Who are the stakeholders in health promotion practice for people with ID and how can they be involved in research and practice involving the settings approach?' Chapter 2 provides insight into perceived roles and responsibilities of the various stakeholders involved in health promotion for people with ID. Stakeholders closest to the person with ID (such as care professionals, family, and so on) are said to be responsible for supporting healthy living, but those further away (such as physiotherapists and dieticians) are the ones who possess more knowledge, skills, and power. A shared vision and a united system, with clear roles and responsibilities for stakeholders, were mentioned as ways to improve collaboration in stakeholder networks and create a greater health promotion ethos in support for people with ID. Next, throughout this thesis, insight was provided on how stakeholder involvement in health promotion research can be applied. Two types of stakeholder involvement were adopted: obtaining advice from an advisory group and collaboration in an inclusive research team including researchers with and without ID. The inclusive research team undertook in all research-phases activities together and made decisions together on content and procedures of the studies and role division. Reflecting on shared decision making provided insight in the type of decisions and information and processes used to make shared decisions (Chapter 4). Also, the inclusive research team specified how shared decision making positively impacted the quality of the studies and empowered people with ID.

Part II of the thesis focuses on the question: 'What concepts and environmental assets are important for conceptualizing healthy settings for people with ID?' An international concept mapping study provided a first set of 13 themes relating to healthy settings for people with ID (Chapter 5). Then, these themes were discussed with people with ID in a series of discussions based on the Nominal Group Technique (Chapter 6). The resulting conceptual framework is called the 'Healthy Settings for People with Intellectual Disabilities' (HeSPID) framework and contains 14 clusters including assets relating to how the social, physical, policy, and financial environment can support physical activity and healthy nutrition.

Part III of the thesis focuses on the question: 'Can the asset mapping tool provide a comprehensive view of available assets in ID support settings and does it provide actionable knowledge for stakeholders to improve the health-promoting capacities of a

setting?' A draft tool based on the HeSPID framework was developed (Chapters 5 and 6). Experts and end-users contributed to (cognitive) interviews and pilot testing of the tool and provided feedback to make it a comprehensive, clear, and usable tool (Chapter 7). The final tool, named 'DIscovering Health-promoting Assets in Settings for people with Intellectual Disabilities' (DIHASID), contains 37 questions regarding the availability of, user satisfaction with, and dreams about, social, physical, policy, and financial assets for physical activity and healthy nutrition of people with ID in ID support settings. Using the tool results in a comprehensive overview of user perspectives on social, physical, policy, and financial assets (Chapter 8). Furthermore, the tool provides actionable knowledge for ID support organizations to improve the health-promoting capacities of these settings. This includes: 1) how available assets can be used in a better way, 2) the type of assets that should be enriched, and 3) the assets that should be added to the setting.

Discussion of main findings

Three principles of the settings approach were applied in this thesis: stakeholder involvement, a whole-system perspective, and embracing a setting as a complex adaptive system in which stakeholders can develop actions that can be added to the system to promote healthy living. This thesis provides guidance on how to apply each of these principles to health promotion for people with ID:

1. Processes to involve, and collaborate with, stakeholders in research,
2. Connectedness of people, places, and preconditions in a whole-system perspective for building health-promoting capacities of ID support settings,
3. Acquiring actionable knowledge for stakeholders to embed health promotion in the ID support settings system.

Processes to involve, and collaborate with, stakeholders in research

Stakeholder involvement was an important aspect of this thesis. Thereby, insights were gained on stakeholder involvement processes in long-term research projects, which are limitedly reported on in the literature. More specifically, insights were gained on how to involve stakeholders on an advisory board and how to involve people with ID in an inclusive research team.

The advisory board consisted of clients with ID, care professionals, a dietician, a movement instructor, and a mid-level manager, working in different ID support organizations. They participated in group discussions 2–4 times per year and provided feedback through phone calls or in writing. They helped with: identifying stakeholders, drafting data collection methods (interview guide, focus group guide, DIHASID tool, instruction manual for creating an action plan), drafting informed consent forms, recruitment, and decisions on dissemination of the study results in practice.

The inclusive research team, in which two persons with ID and the primary researcher collaborated, worked together every week on a collaborative basis. In all research steps the inclusive research team undertook activities together and made shared decisions on the content and procedures of the studies and role division. For the research topic, aim and questions, the team familiarized themselves with the topic of healthy settings and operationalized the research questions in the project proposal. In designing data collection methods, the team developed processes to elicit feedback from people with ID and care professionals on data collection methods (self-reported health scales and the DIHASID tool) to make them comprehensive, clear, and usable. They also used findings from previous studies to design methods that enable people with ID to share their perspective on assets for healthy living, the (preliminary) HeSPID framework to develop the Nominal Group Technique-method, and the DIHASID tool. To design the studies inclusively, the team incorporated scientific and experiential knowledge in team discussions and kept an overview of the design by using a research clock and writing down/drawing their plans on posters. Thereby the team complemented one another by each bringing something unique and creating what Walmsley calls a 'shared space' to work fruitfully together [1].

For data collection and analysis, role division in the inclusive research team was based on perceived costs and benefits of involvement of the researchers with ID. Data collection was coordinated by the primary researcher, and the co-researchers assisted when people with ID were participants by making them feel at ease and assisting in communication. The contribution of researchers with ID to creating a comfortable environment for data collection among participants with ID has also been noted by O'Brien and colleagues [2]. During data collection, a script helped them to apply the roles and responsibilities upon which they had decided. Data analysis was conducted by the team for three studies. In the development studies on the self-reported health scales (Chapter 3) and the DIHASID tool (Chapter 7), the primary researcher took the lead and the co-researchers helped to clarify participants' statements. They decide together as a team on what adjustments to make to the scales/tool based on the data. For the analysis of the Nominal Group Technique study (Chapter 6), the team conducted a thematic content analysis together. To facilitate the inclusive data analysis process, adjusted analysis methods were used, such as analysis of the voice recordings and sorting ideas on paper by making a visual web. The added value of perspectives of researchers with ID in data analysis has also been mentioned by other researchers [3].

For writing and dissemination, the primary researcher compiled drafts and the co-researchers provided feedback on easy language (easy-read information) and content (easy-read information and scientific articles). To enable an inclusive writing process, the primary researcher translated and read aloud the text of the draft scientific articles and the co-researchers provided verbal feedback.

Reflections on decision making of the inclusive research team gave an overview of opportunities and key components for shared decision making in inclusive research

(Chapter 4). In all research steps the inclusive research team made decisions together on the content and procedures of the studies and role division. Information and processes that the inclusive research team used for shared decision making align with key components of shared decision making in the clinical setting [4-6]. These include: 1) identifying decisions to be made, 2) knowledge transfer of scientific and experiential knowledge, 3) identifying own values and preferences based on interests, competences and skills, 4) deliberation and participation in decision making, with a specific focus for role division in inclusive data collection and analysis, and 5) implementing the decision. These insights can foster conceptual clarity of shared decision making in inclusive research. In practice, inclusive research teams can use these insights to advance successful ways of sharing power in decision making.

The impact of stakeholder involvement includes improved quality of the studies and empowerment of people with ID. Stakeholders helped to tailor the research project to enable meaningful participation of stakeholders, and in particular people with ID, in research. Also, they helped to develop studies and tools that are relevant for health promotion practice. This resulted in a tool for practice that enables stakeholders to be involved in health promotion. The DIHASID tool enables (representatives of) people with ID and care professionals to gain a comprehensive view of available assets for healthy living and identify action areas for embedment of health promotion in the ID support settings system. Furthermore, an instruction manual for stakeholders is provided to use the DIHASID results to co-create a joint vision and an action plan to improve a setting's health-promoting capacities.

Connectedness of people, places, and preconditions for building health-promoting capacities of ID support settings

Embracing a whole-system perspective resulted in the HeSPID framework of multi-facetted and connected factors that support healthy nutrition and physical activity in ID support settings. Whereas previous studies provided insight on barriers to, and facilitators of, healthy living for people with ID from mainly an individual perspective [7-20], this framework provides insight on the multiple levels of influence within a setting and is helpful for adopting a settings approach [21-24]. Similar to ecological models for health, the HeSPID model involves the social environment, the direct physical environment (tools and facilities at daytime/living accommodation), the wider physical environment (facilities and accessibility of neighborhood), and the policy environment [25]. Moreover, the HeSPID framework indicates focus areas that are specifically important for settings for people with ID, including: creating a health-promoting social network, adjusting the physical environment to users' specific needs, and ensuring actions on overarching determinants of health relating to the inequalities experienced by people with ID. Lastly, it provides insight into how assets are strongly connected to: 1) characteristics of users of a setting, 2) other assets within the setting, and 3) the wider environment. This interaction

across different clusters is also a principle in ecological models of health behavior [26]. The following paragraphs provide more details on the connectedness of assets.

Firstly, the HesPID framework highlights in several clusters the connection and the need for a fit between users and assets in the setting. In the clusters 'tailored environment' and 'accessibility', the importance of a universal design of facilities and a person–environment fit became apparent. Physical assets are helpful for healthy living only if they are accessible and tailored to the abilities and wishes of people with ID. The type of social support that is helpful for healthy living depends on the client's abilities. The DIHASID tool was developed to gather user perspectives on how existing assets for healthy living are perceived and users' dreams for improvement. This user knowledge can be used to tailor a health promotion approach in a setting to the wishes of its users and thereby enhance the setting's capacity to promote healthy living [27]. Thereby, the DIHASID tool contributes to the increasing call to view health promotion from a systems perspective in which the reciprocal relationship between people and the setting in which they engage is considered [28].

Secondly, this thesis highlights the fact that assets within a setting need to be connected to one another to optimize their health-promoting potential. As McKnight – the founder of asset-based community development – stressed, local assets should be connected like 'building blocks' to unleash their health-producing power [27]. For example, the stakeholder study showed that care professionals and health professionals both have important capacities for supporting people with ID to live healthily, but they lack clarity on their own roles and responsibilities and on how to collaborate in health promotion. Care professionals are in a good position to support people with ID to live healthily daily, in contrast to health professionals who are not engaged in daily support. However, health professionals have more knowledge and skills to promote healthy living of persons with ID. Collaboration between these stakeholders could strengthen the health-promoting capacity of the social environment.

Thirdly, assets in a setting connect with wider environment factors outside the setting. For example, at the living accommodation for people with ID, the policy and budgets of the ID support organizations have an influential role regarding available social and physical assets. There are also macro-level influences such as national health policies and budgets for specialized care for people with ID. This connection between components of a setting and components of the wider environment corresponds with literature on the settings approach [29-31]. Although the DIHASID tool is focused on the daytime or residential setting level, it also obtains information on the physical environment surrounding the setting and organizational budgets and policy. ID support organizations and municipalities can use this information to build their health-promoting capacities, from which that setting can benefit.

Acquiring actionable knowledge to embed health promotion in the ID support settings system

Organizations that support people with ID face difficulties in embedding health promotion in their organizational culture and routines, making sustainable embedment of health promotion interventions challenging [20,32-34]. The HeSPID framework provides a wide range of potential assets that could be addressed to embed health promotion in ID support settings. The DIHASID tool provides local stakeholders with a health promotion lens to identify the local changes that are needed to improve the health-promoting capacities of an ID support setting.

Applying the DIHASID tool elicits three types of actionable knowledge to (better) embed health promotion in the ID support settings system. These include: 1) how use of available assets can be improved, 2) the type of assets that can be enriched, and 3) the assets that can be added to the system. The change that can be initiated by using the DIHASID tool is similar to that achieved by asset-based community development [35]. The strengths of this approach lie in fostering change that fits the users' needs and wishes and in adopting an add-in instead of an add-on approach by making use of available resources. Such an add-in approach is more likely to be implemented and sustained successfully [28,35-38]. The importance of this is highlighted in systems thinking, which states that adding components into a system has the power to bring about change only if these components are embedded within the system [39]. Thus, by ascertaining local stakeholders' needs and wishes in order to build a strategic action plan, the DIHASID tool helps to develop add-ins to (better) embed health promotion in the setting.

To ascertain these local needs and wishes, a bottom-up settings approach was adopted with strong involvement of stakeholders in residential and/or daytime accommodations. This aligns with the organic way of thinking in settings approaches that individuals' actions throughout organizations facilitate and strengthen day-to-day processes and collective action, thereby changing the culture within a setting [40]. Although the DIHASID tool allows the acquisition of local knowledge on the changes needed in ID support settings, in order to implement the settings approach in ID support organizations a balance should be sought between top-down managerial and/or political commitment and bottom-up engagement and empowerment [41]. So, local action plans developed by the bottom-up engagement of local stakeholders in an ID support setting should go hand-in-hand with top-down managerial commitment in ID support organizations [15,32,41-44].

Methodological considerations

Methods triangulation and data source triangulation were applied across the studies to improve the validity of the studies. A broad range of qualitative, quantitative, and mixed methods were used: semi-structured stakeholder interviews, a concept mapping study, a Nominal Group Technique study, expert interviews, cognitive interviews with end-users, and the piloting and implementation of the asset mapping tool among end-users. A

wide range of stakeholders were involved as study participants. In the study in Chapter 2, stakeholders shared views on roles and responsibilities regarding health promotion. End-users participated in the development of suitable health scales (Chapter 3), as respondents' perspectives are important for developing data collection methods that are suitable for people with ID [45,46]. The HeSPID framework (Chapters 5 and 6) integrates international experts' perspectives and user perspectives of (representatives of) people with ID, making it internationally relevant and usable for practice. Experts and end-users were involved in developing the DIHASID tool (Chapter 7) to make it a comprehensive, clear, and usable tool for practice.

Involving people with ID as research participants posed some challenges. Getting clearance to conduct studies among people with ID who live or engage in ID support settings was time consuming. Besides the ethical approval of the university's medical ethics committee, some ID support organizations required clearance from their own ethics committees. This resulted in difficulties if these ID support organizations' ethics committees required amendments when the study had already been approved by the university's medical ethics committee. In recruitment, a contact person helped to get in touch with locations where clients met the inclusion criteria. The care professionals at the locations spread the information among clients. If clients were interested, then contact with the researchers was established. This indirect approach was deemed as ethically most appropriate to protect people with ID, but also gave employees, as their gatekeepers, the power to block access to people with ID. This might deny the right of people with ID to hear about, and be included in, the study. This dilemma has also been pointed out by Lennox and colleagues in relation to recruitment of people with ID [47]. Furthermore, this was another very time-consuming task, especially in organizations with many tiers of management, and required a lot of effort on the part of employees. To enable informed consent to be obtained from persons with ID, templates of an easy-to-read information letter and informed consent form were developed and used in each study, see Appendix 4. Although all participants were informed about the study, not all were capable of consenting on their own behalf. For those participants, care professionals contacted their parents or guardians to obtain informed consent. This was another time-consuming task for the care professionals and could not be executed by the researcher because of privacy issues. Furthermore, only persons with mild to moderate ID, who were able to communicate verbally, could participate in the studies included in this thesis. With help from the co-researchers, data collection methods were adjusted to enable them to participate. To also include the voice of people with profound or severe ID, proxy respondents were sought. As proxy informants cannot truly reflect the voice of people with ID, this should be seen as a study limitation [48].

This thesis adopted principles of the settings approach in health promotion for people with ID. Firstly, stakeholder involvement strengthened the research and its relevance for practice. Secondly, adopting a whole-system perspective gave insight into

the multi-facetted and connected factors that facilitate healthy nutrition and physical activity in ID support settings. The DIHASID tool enables users of a setting to obtain a comprehensive view of the setting. However, it should be noted that the DIHASID tool is not a measurement instrument and is therefore not able to provide a score on how health-promoting a setting is. Thirdly, applying the DIHASID tool helps stakeholders to identify what is needed to further embed health promotion in the complex adaptive system of an ID support setting. The outcomes of the tool can be used as a first step toward adopting the settings approach in ID support settings. However, the DIHASID tool focuses on bottom-up change at the daytime or residential accommodations level. To normalize health promotion in ID support organizations' organizational culture, this approach should be complemented with top-down actions [15,32,41-44].

Recommendations for practice, research, and policy

The studies presented in this thesis provide recommendations for practice, policy, and future research.

Practical implications

This thesis provides an overview of multi-facetted and connected factors that enable healthy nutrition and physical activity in ID support settings. As adopting a whole-system approach and creating continuous attention on health promotion can be overwhelming, seven main action areas are suggested:

1. Include all the ID support organization's employees in creating a shared vision toward health promotion.
2. Develop a health promotion policy in which the vision and mission of the organization is described, together with how health promotion is addressed throughout the organization.
3. Include the clients' needs and wishes regarding health promotion in developing personal development plans and developing healthy settings.
4. Build a network of engaged employees who address health promotion in their work and in which everyone has a clear description of their roles and responsibilities regarding health promotion.
5. Create training opportunities for care professionals to acquire knowledge and skills to promote healthy living in daily life.
6. Provide (financial resources for) tools, activities, and facilities that stimulate physical activity and healthy nutrition that are accessible and meet clients' needs.
7. Include (financial resources for) time set aside for care providers to spend specifically on health-promoting activities.

Besides these recommendations, this thesis provides a practical tool for initiating a bottom-up process for building the health-promoting capacities of an ID support setting. Completion of the DIHASID tool by users of an ID support setting provides a comprehensive overview of available assets that can be used for health promotion. It also provides actionable knowledge for improvements, including: 1) how the use of available assets can be improved, 2) the type of assets that should be enriched, and 3) the assets that can be added to the system. The DIHASID results can be used by local stakeholders to develop a joint vision and create and implement an action plan to improve a setting's health-promoting capacities. An instruction manual for co-creating this vision and action plan has been developed. All the tools developed for this process can be found on the project website *www.dekrachtengebundeld.nl*; a location account can be drawn up to let participants complete the DIHASID, a location summary can be extracted, and an instruction manual for developing an action plan can be downloaded. This systematic assessment of available resources and the planning process has been identified in settings approaches as a key lesson for implementing the settings approach in school settings [49]. It is advised to appoint a coordinator to lead this development and implementation process at a location and embed the changes at organizational level. To strengthen, implement, and continue the action plan, the Measurement Instrument for Determinants of Innovations for people with ID (MIDI-ID) could be used as a checklist before implementing the action plan [50,51]. Also, the Plan–Do–Check Act cycle, adapted for ID support organizations, could be helpful in this process [52].

Policy

To attract more attention for health promotion for people with ID, we need to acknowledge that lifestyle behavior is not just the result of individual decision making, but also influenced by a wide variety of environmental factors in everyday life. Actions can be undertaken to create healthy settings for people with ID not only in ID support organizations, but also in municipalities and at national level.

ID support organizations could take the recommendations for practice (section 8.4.1) into account to embed health promotion in their organization and its policy. Also, they could support the use of the DIHASID tool to develop and implement local action plans to embed health promotion in residential and/or daytime settings. Action areas that transcend the residential and/or daytime settings level, or that are important for several settings, could be addressed at organizational level by managers and policymakers.

Health insurance companies and/or the national government could provide ID support organizations with incentives to apply a settings approach to (better) embed health promotion. Worldwide, such incentives have been provided in similar settings, for example in Healthy Hospitals and Healthy Schools projects [53]. Adopting the settings approach led to transformed policies, organization structures, and community action to facilitate healthy living and participation [54-56]. In the Netherlands, the Healthy School

approach is government financed and widely adopted. Schools that want to become a Healthy School follow a 6-step process of mapping the current situation, determining themes and goals, developing, implementing, and evaluating the integral plan, and designing the next steps. During this process, a financial incentive, training, and advice are available from the public health service (GGD). Also, schools' efforts are assessed, and schools that meet the criteria are certified as a Healthy School, thereby increasing their attractiveness to parents. Such an approach might help ID support organizations to develop and implement an integral plan to improve their organizations' health-promoting capacities. The DIHASID tool could be used to map the current situation with stakeholders, determine themes and goals, and build a plan. An expert network on health promotion for people with ID could advise the organization on its plan's content and implementation process. Furthermore, in further implementation of the National Prevention Agreement (signed by >70 parties to improve the health of Dutch citizens by actions to reduce smoking, overweight, and problematic alcohol use), attention should be directed toward the needs of specific groups, such as people with ID, to live healthily.

At municipal level, through Local Prevention Agreements (focused on local commitment and collaboration to improve citizens' health), the collaboration between municipalities and ID support organizations could be strengthened to improve health-promoting capacities in neighborhoods. This could result in a more accessible and health-promoting physical environment for people with ID, improved access to sports activities, and stronger collaboration among care professionals, sports coaches (*buurtsportcoaches*), and social support teams *(sociaal wijkteam)* to support people with ID to live healthily. Action areas that ID support settings formulate, based on the outcomes of the DIHASID tool, could be integrated in community approaches to create a healthier living environment that contributes to the Local Prevention Agreement. Furthermore, municipalities have the obligation to pay attention to creating a health-promoting environment, as stated in the Environment and Planning Act (*omgevingswet*) introduced in 2021. This offers the opportunity to make facilities accessible for people with ID, to collaborate with ID support organizations to make general facilities in the municipality more accessible for people with ID, and to allow people in the neighborhood to make use of ID support organizations' facilities.

The current education of care professionals lacks attention for health and health promotion. It is advised to incorporate this in the vocational education (MBO) for care professionals and to provide on-the-job training. This training should be focused on support for healthy living in everyday life for people with ID, as well as on how to create a health-promoting environment in which healthy choices are easy choices. Furthermore, collaboration with health professionals could be supported by involving physiotherapists, movement instructors, lifestyle coaches, and dieticians in this training.

Directions for future research

This thesis focused on supporting physical activity and healthy nutrition in Dutch ID support settings. Future studies could broaden and strengthen the Healthy Settings for People with Intellectual Disabilities (HeSPID) framework. As macrosystem factors, such as culture, organization, and the financing of care, influence the results, it would be interesting to conduct the asset mapping study in other countries to strengthen the HeSPID framework. Furthermore, the HeSPID framework could be broadened by studying how other lifestyle components such as mental health, substance use, and sleep could be supported through various components of a setting.

Future studies could use the DIHASID tool as a first step toward action research on improving the health-promoting capacities of ID support settings. Applying the DIHASID tool provides user knowledge on available assets, user perceptions, and dreams for improvement. This information could be used to co-design a suitable local intervention to improve the health-promoting capacities of an ID support setting. Also, the DIHASID tool could be used as a tool to provide insight into the implementation context. Before the implementation of a predetermined health promotion intervention, the DIHASID could provide an overview of the current context in which the intervention will be implemented. This knowledge could be used to make adjustments to the intervention to make it fit better or even to weave the intervention into what exists in the setting [57]. For example, the results from the DIHASID tool have been used to adapt a training program for care professionals to their specific learning needs [58]. Furthermore, as contextual factors influence implementation outcomes and successes [59], the DIHASID results might give insight into why an intervention has different results in different settings. This aligns with the growing field of implementation research, which includes understanding how an intervention couples with the setting to increase the likelihood of effective implementation and sustainable embedment [57]. To follow the implementation process and study the effects, the contextual action-oriented research approach (CARA) could be adopted. This approach generates knowledge on context, the change process, and factors that affect it, how research contributes to the change process, and whether the health behavior of people engaging in the setting improves as a result of changes. Furthermore, monitoring and feedback are used to both support and evaluate the change process [60].

The insights gained in this thesis into stakeholder involvement processes could help other researchers in health promotion for people with ID to involve stakeholders in their research. In particular, the insights on decision making processes in inclusive research teams could help other inclusive research teams to collaborate meaningfully. To provide more insight on inclusive research processes and effects, future studies should report clearly on inclusive research processes in their publications. The consensus statement on inclusive research provides guidelines to this end [61]. Besides these insights and guidelines for inclusive research [61], coaching on the job or training could further support meaningful collaboration in inclusive research teams. Future research could contribute to this development.

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CHAPTER

10

Summary
Nederlandse samenvatting

(Samenvatting in eenvoudige taal staat in een apart boek
Zie: www.sterkeropeigenbenen.nl)

Summary

Chapter 1

Chapter 1 involves a general introduction on the topic of this thesis: health promotion for people with intellectual disabilities (ID). An overview is provided on the (health) characteristics of people with ID and the context they engage in, which influences lifestyle. This chapter introduces the concept of health promotion and different layers of environmental influences on health behavior. Furthermore, an overview is provided on health promotion approaches for people with ID. For improvements in health promotion for people with ID a multi-level approach is identified as needed whereby health promotion is normalized in organizational culture. The settings approach to health promotion is such an approach that targets multiple environmental determinants in a setting.

Three principles of the settings approach that are adopted in this thesis include:

- Involvement of stakeholders in co-designing and implementing health promotion actions to facilitate system-wide change in practice.
- Embracing a whole-system perspective by having attention for different levels of influence on health and addressing health promotion actions as part of a system.
- View a setting as a complex adaptive system. As systems keep changing, the current situation of a setting should be considered to develop actions which can be added in the system in which the nucleus of the setting is targeted to create organizational change that promotes healthy living.

This thesis focuses specifically on physical activity and healthy nutrition in ID support settings for people with moderate to profound ID in the Netherlands. The overall aim of this thesis is to gain insight in contextual factors that support physical activity and healthy nutrition of people with ID and develop an asset mapping tool for practice to improve the health-promoting capacities of ID support settings.

The three main research questions include:

1. Who are the stakeholders in health promotion practice for people with ID and how can they be involved in research and practice involving the settings approach? (Part I: Chapter 2,3&4)
2. What concepts and environmental assets are important for conceptualizing healthy settings for people with ID? *(Part II: Chapter 5&6)*
3. Can the asset mapping tool provide a comprehensive view of available assets in ID support settings and does it provide actionable knowledge for stakeholders to improve the health promoting capacities of a setting? *(Part III: Chapter 7&8)*

Part I: Stakeholder analysis and stakeholder involvement in research

Chapter 2

Chapter 2 presents a two-phase stakeholder study on expectations, roles, responsibilities, and perceived facilitating and hindering factors for health promotion for people with ID. In phase one, four workshops were conducted to identify stakeholders that support people with ID with healthy living. In phase two, 29 semi-structured interviews were conducted with stakeholders such as daily caregivers, family of people with ID, physiotherapists, dieticians and managers. Stakeholders experienced a lack of clarity about their (own) role and responsibility to support people with ID to live healthily. Daily caregivers were perceived as the most important and influential stakeholder, although they are not trained in promoting a healthy lifestyle of people with ID. Health professionals who have skills and knowledge to promote healthy living are not involved in everyday care and work mainly from a health-problems perspective. The results indicate the need for a culture change in which healthy living becomes the norm and is supported in everyday life. This requires a shared vision and a system in which all stakeholders know their roles and responsibilities an facilitate a health-promoting supportive network.

Chapter 3

Chapter 3 provides a pilot study of an inclusive process in which people with ID collaborated in adjusting, testing and reflecting on self-reported health questionnaires for people with ID. Firstly, the inclusive research team (researchers with and without ID) adjusted the sedentary behavior questionnaire (SBQ), SQUASH (physical activity) questionnaire, and self-reported health (SRH) questionnaire to people with mild ID. Secondly, persons with mild ID tested the questionnaires for suitability (n=40) and test-retest reliability (n=15). Lastly, the results were discussed with researchers with ID to identify further possible improvements for the questionnaires. Main adjustments to the questionnaires include the use of easy words, short sentences and easy answer formats. Testing the adjusted questionnaires suggested that the SQUASH-ID was more suitable than the SBQ-ID. Test-retest reliability varied between poor and almost perfect. Based on these results and the advice from the researchers with ID, other answer options for the SBQ-ID were advised. Answer options that require less detailed memories and calculations, such as in the SQUASH-ID, seem to be more suitable to the cognitive abilities of people with mild ID. Although the adjusted self-reported measurements may be reliable and suitable for the target group, the adjustments needed may impair measurement precision. This study's results contribute to informed decision making on the adaptation and use of self-reported health questionnaires for people with ID.

Chapter 4

Chapter 4 presents a reflection on shared decision making in the inclusive research team that was involved throughout this thesis.

To reflect on shared decision making the inclusive research team used documentation of the inclusive research process and semi-structured interviews with the team members. Reflecting on SDM resulted in an overview of the types of decisions made, the information and processes involved in making shared decisions, and the perceived impact of SDM on the inclusive research project. The team identified in all research steps decisions that were made together on the content and procedures of the studies and on role division. Also, key components for SDM process in inclusive research were identified, such as knowledge transfer and role division. Furthermore, the team provided an account of how SDM had a positive impact on the quality of the studies and empowered people with intellectual disabilities. The study insights give an overview of opportunities and key components of SDM that can foster conceptual clarity of SDM in inclusive research. In practice, inclusive research teams can use these insights to advance successful ways of sharing power in decision making, having an impact on the quality of research, and empowering people with intellectual disabilities.

Part II: Conceptualizing healthy settings for people with ID

Chapter 5

Chapter 5 provides an integrative mixed-methods study in which a conceptual framework of healthy settings for people with intellectual disabilities was developed. An international and multidisciplinary group of 41 researchers specialized in either healthcare for people with ID or healthy settings participated in a concept mapping study. Phase one involved a brainstorm in which statements were created about what a (healthy) settings for people with ID looks like. Phase two involved sorting the statements into clusters and rating them on level on importance. Non-metric multidimensional scaling and hierarchical cluster analysis was used to determine a cluster map. The resulting conceptual framework "Healthy Settings for People with Intellectual Disabilities" (HeSPID) framework consists of 13 clusters relating to the social environment, the physical environment and societal preconditions. Resources in the physical environment are described in the clusters *Healthy home environment* and *Enabling environmen*t. The clusters *Tailored environment* and *Accessibility* describe barriers and resources specifically for people with ID, which demonstrated the need for a fit between resources and needs of people with ID. The interconnectivity between the physical and social environment is visible in the cluster *Homely environment*, where statements related to places and people are included. The clusters relating to the social environment describe the social network (*Supportive network*) and prerequisites for it to be promoting health (*Values about healthy lifestyle, An open conversation, Confidence-building support* and *Encouraging support*). Notably is the role of the social network of

people with ID to empower them. Preconditions for healthy living in society are described in three clusters (*Financial aspects, Healthcare and prevention* and *Opportunities to engage*) including access to healthy food and health professionals as well as (not) having the same opportunities as everyone else in society. The clusters indicate where tailoring is requires for settings where people with ID live, work and engage.

Chapter 6

Chapter 6 involves a nominal group technique study on assets supporting healthy nutrition and physical activity in ID care settings. Fifty-one participants, divided in/spread over 4 groups of people with mild/moderate ID and 5 groups of proxy respondents for people with severe/profound ID. They participated in two group meetings were ideas were generated and ranked. The 185 identified assets fit well within the previously developed HeSPID framework and provide a user perspective on assets for physical activity and healthy nutrition in ID care settings. Regarding the social network, participants provided ideas how to provide encouraging support and open conversations about healthy living. This chapter also provides preconditions for a supportive network and ways of support in which both autonomy and support for healthy living. Assets related to places provide a user-perspective on what kind of tools, devices and facilities are perceived as helpful for creating a healthy environment that is accessible and fits to their needs. Assets relating to preconditions elaborate how health professionals can contribute to healthcare and prevention and highlight several financial levels of support for healthy living. A newly identified clusters 'Health-promoting organizational policy' contains assets on organizational level such as the vision and mission of an organization and time and money for assets related to healthy living. The results provide insight in contextual factors needed for development of healthy settings. As this study showed the interrelatedness of assets and clusters this asks for an integrated approach to sustainably embed health promotion in systems ID support settings.

Part III: Improving health-promoting capacities in practice

Chapter 7

Chapter 7 involved the development of the 'Discovering Health-promoting Assets in Settings for people with Intellectual Disabilities' (DIHASID) tool. This tool aims to provide insight into perceived environmental assets and points for improvements regarding support for healthy nutrition and physical activity for people with moderate to profound ID in settings where they engage. A draft version of the tool was based on the results of chapter 5 and 6. Then an iterative process was used, where expert interviews (n=7), cognitive interviews with end-users (n=7) and a pilot among end-users of three locations (n=16) led to amendments on the tool. Comprehensiveness of the tool was improved by adding or changing questions and answer options, providing more instructions and

personalizing the questions to user groups. Clarity of the tool was improved by specifying instructions, changing pictograms, replacing technical terms or unclear with easy words, changing word order, removing/inserting answer options and changing sensitive words. Pilot testing the DIHASID tool in practice provided information on perceived usability and provided some final points for improvement. Most pilot participants perceived the explanation, clarity, ease and length of the tasks as good. Participants reflected on the DIHASID tool as helpful for raising awareness and putting healthy living in the spotlight. They also perceived that the tool was able to create an overview of available assets which can be used to create changes in the organization. Participants identified a summary of the outcomes as needed for generation actionable knowledge. The final DIHASID tool consists of 37 questions about participant and setting characteristics and availability, user-satisfaction and dreams about social, physical, policy and financial assets. The tool can be completed by people in a living or day-activity location in approximately 30 minutes. Concluding, the DIHASID tool is a comprehensive, clear and usable tool which enables people with ID and care professionals to map health-promoting assets at a living of day-activity location. This bottom-up knowledge can be used for improving the health-promoting capacities of an ID support setting.

Chapter 8

Chapter 8 involves the implementation of the DIHASID tool in four ID support settings. Fifty-seven users from four settings participated; people with mild/moderate ID, representatives of people with severe/profound ID, care professionals and team leaders. They completed the DIHASID on the availability, user-satisfaction and dreams regarding social, physical, policy and financial assets. Based on this information a summary was developed for each location which was checked by participants. Testing the DIHASID tool confirmed it was suitable to provide a comprehensive overview of user perspectives on social, physical, policy and financial assets for healthy living in ID support setting. During the participant check, the participants confirmed that the results of the DIHASID tool provide actionable knowledge for ID support organizations to improve the health-promoting capacities of settings. This includes; 1) how available assets can be tailored to users' needs, 2) how available assets can be used in a different and better way, and 3) the assets that should be added to the setting. These insights are key for ID-support organizations to take the current context into account in building a bottom-up settings approach to strategically embed adaptations in the system and improve health-promoting capacities in settings.

Chapter 9

Chapter 9 includes the general discussion of this thesis, presenting an overview of the main findings and an discussion on how to apply principles of the settings approach to health promotion for people with ID:

Processes to involve, and collaborate with, stakeholders in research,

1. Connectedness of people, places, and preconditions in a whole-system perspective for building health-promoting capacities of ID support settings,
2. Acquiring actionable knowledge for stakeholders to embed health promotion in the ID support settings system.

Firstly, stakeholder involvement processes in this thesis included collaboration as an inclusive research team and involvement of an advisory board. This gave insight in potential processes and impact of stakeholder involvement in research on health promotion for people with ID. By participating in group discussions and providing feedback the advisory helped to make the design of the studies, study outcomes, and tools suitable for practice. Collaboration of the inclusive research team involved working together on a weekly basis. Decisions were made together in every phase of the studies on content and procedures of the studies and role division. Information and processes that the inclusive research team used for shared decision making align with key components of shared decision making in the clinical setting: 1) identifying decisions to be made, 2) knowledge transfer of scientific and experiential knowledge, 3) identifying own values and preferences based on interests, competences and skills, 4) deliberation and participation in decision making, with a specific focus for role division in inclusive data collection and analysis, and 5) implementing the decision. The impact of stakeholder involvement includes improved quality of the studies and empowerment of people with ID. Stakeholders helped to tailor the research project to enable meaningful participation of stakeholders, and in particular people with ID, in research. Also, they helped to develop studies and tools that are relevant for health promotion practice. The DIHASID tool enables stakeholders, including people with ID, to be involved in health promotion.

Secondly, the HeSPID framework can be used to embrace a whole-system perspective in health promotion for people with ID. It provides insight in the multifaceted and connected factors in ID support settings that support healthy nutrition and physical activity. The HesPID framework highlights the connection and need for a fit between users and assets in the setting. The DIHASID tool was developed to gather user-perspectives on how existing assets for healthy living are perceived and what their dreams for improvement are. This user knowledge can be used to tailor a health promotion approach in a setting to the wishes of its users. Thereby it contributes to the increasing call to view health promotion from a systems perspective in which the reciprocal relationship of people and the setting in which they engage is considered. Also, this thesis highlights that assets within a setting need to be connected to each other to optimize their health-promoting potential. Moreover, assets in a setting should connect with wider environment factors outside the setting. Although the DIHASID tool is focused on the level of a daytime or residential setting it also gains information on the surrounding physical environment of

the setting and organizational budgets and policy. This information can be used by ID support organizations and municipalities.

Thirdly, to acquire actionable knowledge for stakeholders to embed health promotion in ID support settings the asset mapping tool DIHASID was developed. It provides local stakeholders with a 'health promotion lens' to identify what local changes are needed to improve the health-promoting capacities of an ID support setting. The tool enables users of a setting to bring forward a comprehensive view of available social, physical, policy and financial assets. Combined with the information on user-satisfaction and dreams for improvement it provides actionable knowledge for ID support organizations to improve the health-promoting capacities of these settings. This knowledge can be used directly in a local action plan to add health-promoting components or make better use of available assets in the system of an ID support setting. The strengths of this approach lie in fostering bottom-up change that fit to the users' needs and wishes and adopting an add-in instead of an add-on approach by making use of available resources which is more likely to be implemented and sustained successful.

Next to applying the settings approach principles to health promotion for people with ID, the discussion also includes methodological considerations of the studies and implications for practice, policy and future research. Methodological considerations include: methods and data source triangulation, challenges in involving people with ID as research participants, and strengths and limitations of adopting the settings approach. A summary of the implications for practice, policy and future research is provided in the box below.

Implications for practice, policy and research

Practice

- Adopt a whole-system approach towards health promotion in ID support settings, because factors that enable healthy living of people with ID are multi-facetted and connected.
- Use the seven main action areas for ID support organizations to adopting a whole-system approach (see general discussion).
- Apply the DIHASID tool to initiating a bottom-up process for building the health-promoting capacities of an ID support setting. The web application of the DIHASID tool and an instruction manual for co-creating a local action plan can be found on the project website www.dekrachtengebundeld.nl (in Dutch).

Policy

- General: acknowledge the role of environmental factors in everyday life that influence lifestyle behaviour and create more attention for healthy settings for people with ID
- ID support organization level: support the action areas for practice (see general discussion) with policy and budget. Support the use of the DIHASID tool and implementation of local action plans to create healthy ID support settings.
- Municipality level: strengthen collaboration between municipalities and ID support organizations to improve health promoting capacities in neighbourhoods.
- National level: provide incentives to create healthy support settings for people with ID. For example, by translating the Healthy Schools approach to ID support organizations.

Research

- Use the DIHASID tool in action research to improve the health-promoting capacities in ID support settings.
- Use the DIHASID tool to provide an overview of the implementation context in which health promotion interventions are implemented.
- Apply insights on stakeholder involvement processes in future studies to optimise collaboration with stakeholders in research.

Samenvatting

Hoofdstuk 1

Hoofdstuk 1 omvat een introductie op het proefschrift. Er wordt een overzicht gegeven van de (gezondheids-) karakteristieken van mensen met een verstandelijke beperking (VB) en de omgevingsfactoren die hun leefstijl beïnvloedt. Daarnaast wordt het concept gezondheidsbevordering geïntroduceerd en een model dat inzicht geeft in de verschillende lagen van omgevingsfactoren die invloed hebben op gezondheidsgedrag. Verder biedt het hoofdstuk een overzicht van hoe gezondheidsbevordering voor mensen met een VB in de laatste jaren is toegepast in de praktijk en onderzoek. Uit de literatuur komt naar voren dat een multidimensionale aanpak nodig is om gezondheidsbevordering voor mensen met een VB te verbeteren. Bij een multidimensionale aanpak is er aandacht voor het normaliseren van gezondheidsbevordering in de cultuur van de organisatie. De zogenoemde settingsaanpak voor gezondheidsbevordering is een dergelijke aanpak welke zich op verschillende omgevingsdeterminanten richt.

Drie belangrijke principes van de settingsaanpak worden toegepast in dit proefschrift:

- Betrekken van stakeholders bij het ontwerpen en implementeren van acties gericht op gezondheidsbevordering. Door de gezamenlijke acties wordt een systeem-brede verandering in de praktijk in gang gezet.
- Een systeemaanpak waarbij aandacht is voor de verschillende niveaus van contextfactoren die van invloed zijn op gezondheid. Met als resultaat dat deze acties voor gezondheidsbevordering worden ingebed in het systeem.
- Een setting wordt benaderd als een complex systeem dat continue verandert. Acties richten zich op de kern; acties die organisatieverandering teweeg brengt dat bijdraagt aan gezondheidsbevordering. Bij het ontwikkelen van acties moet er aandacht zijn voor de huidige situatie en de te verwachte veranderingen in de toekomst.

Dit proefschrift richt zich op fysieke activiteit en gezonde voeding binnen Nederlandse zorgorganisaties voor mensen met een matig tot zeer ernstige VB. Het doel van dit proefschrift is om; 1) inzicht te krijgen in contextuele factoren die gezond leven van mensen met een VB stimuleren, en 2) een omgevingsscan voor de praktijk te ontwikkelen waarmee locaties van zorgorganisaties voor mensen met een VB verbeteringen kunnen doorvoeren op het gebied van gezondheidsbevordering.

De drie onderzoeksvragen zijn:

1. Wie zijn stakeholders in de dagelijkse praktijk van gezondheidsbevordering voor mensen met een VB en hoe kunnen zij betrokken worden in onderzoek naar een toepassing van de settingsaanpak in de praktijk? *(Deel I: hoofdstuk 2,3,4)*
2. Welke concepten en hulpbronnen in de omgeving zijn belangrijk voor het conceptualiseren van een gezonde leefomgeving voor mensen met een VB? *(Deel II: hoofdstuk 5&6)*
3. Kan de omgevingsscan een veelomvattend en bondig overzicht geven van aanwezige hulpbronnen voor gezond leven op locaties van zorgorganisaties voor mensen met een VB? En levert het gebruik van de omgevingsscan kennis op waarmee stakeholders in de praktijk acties kunnen inzetten om te werken aan een gezonde(re) leefomgeving? *(Deel III: hoofdstuk 7&8)*

Deel I: Stakeholder analyse en stakeholder betrokkenheid in onderzoek

Hoofdstuk 2

Hoofdstuk 2 presenteert een stakeholderonderzoek naar verwachtingen, rollen, verantwoordelijkheden, en ervaren faciliterende en belemmerende factoren voor gezondheidsbevordering voor mensen met een VB. Als eerste stap werden er vier workshops gehouden om stakeholders te identificeren die mensen met een VB ondersteunen bij gezond leven. Daarna werden er 29 semigestructureerde interviews gehouden met stakeholders zoals dagelijks begeleiders, familie van mensen met een VB, fysiotherapeuten, diëtisten en managers. Uit deze interviews bleek dat stakeholders een gebrek aan helderheid ervoeren over hun (eigen) rollen en verantwoordelijkheden in het ondersteunen van een gezonde leefstijl van mensen met een VB. De stakeholders vonden dagelijks begeleiders de belangrijkste en invloedrijkste stakeholder in de ondersteuning van een gezonde leefstijl van mensen met een VB. Echter zijn dagelijks begeleiders niet opgeleid om een gezonde leefstijl van mensen met een VB te ondersteunen. Gezondheidsprofessionals, zoals diëtisten, fysiotherapeuten en bewegingsagogen, hebben kennis en vaardigheden op dit gebied, maar zij zijn niet betrokken in de dagelijks zorg en werken voornamelijk aan gezondheidsproblemen. De bevindingen van dit hoofdstuk laten zien dat er een cultuurverandering binnen zorgorganisaties nodig is waarin gezond leven de norm wordt en wordt ondersteund in het dagelijks leven. Dit vraagt om een gedeelde visie en een systeem waarin stakeholders hun rollen en verantwoordelijkheden kennen en een gezondheidsbevorderend steunnetwerk faciliteren.

Hoofdstuk 3

Hoofdstuk 3 beschrijft het proces van een inclusief onderzoekteam (onderzoekers met en zonder een VB) om gezondheidsvragenlijsten aan te passen voor gebruik onder mensen met een lichte VB. Allereerst werden de vragenlijsten voor zitgedrag, fysieke activiteit, en gezondheid aangepast voor mensen met een lichte VB door het inclusieve onderzoeksteam. De belangrijkste aanpassingen op de vragenlijsten waren; het gebruik van makkelijke woorden, korte zinnen en eenvoudige antwoordopties. Daarna werden de vragenlijsten getest door mensen met een lichte VB op bruikbaarheid (n=40) en test-hertest betrouwbaarheid (n=15). Uit het testen kwam naar voren dat de aangepaste vragenlijst voor fysieke activiteit bruikbaarder was dan de aangepaste vragenlijst voor zitgedrag voor mensen met een lichte VB. Test-hertest betrouwbaarheid varieerde tussen slecht en bijna perfect. Tenslotte werden de resultaten van de test bediscussieerd in een groep van onderzoekers met een VB. Gebaseerd op de testresultaten en de adviezen vanuit de groepsdiscussie werden andere antwoordopties voor de aangepaste zitgedrag vragenlijst geadviseerd. Antwoordopties die minder gedetailleerde herinneringen en berekeningen vragen lijken bruikbaarder en passender bij de cognitieve vaardigheden van mensen met een lichte VB. Alhoewel de aangepaste vragenlijsten bruikbaar zijn voor de doelgroep mensen met een lichte VB, kunnen de aanpassingen een negatief effect hebben op de meetnauwkeurigheid. De resultaten van deze studie dragen bij aan de besluitvorming rondom het aanpassen en gebruik van vragenlijsten bij mensen met een lichte VB.

Hoofdstuk 4

Hoofdstuk 4 beschrijft een reflectie van het inclusieve onderzoeksteam, dat betrokken was bij de uitvoer van dit proefschrift, op hun besluitvorming in vier onderzoeksprojecten. Voor de reflectie werd documenten van het inclusieve onderzoeksteam gebruikt en werden teamleden individueel geïnterviewd. De reflectie resulteerde in; 1) een overzicht van type beslissingen die samen gemaakt kunnen worden, 2) informatie en processen die nodig zijn voor gezamenlijke besluitvorming, en 3) inzicht in de impact van de beslissingen op het onderzoek. Voor alle stappen van het onderzoeksproces identificeerde het onderzoeksteam de beslissingen die zij samen hadden genomen. Deze beslissingen hadden te maken met de inhoud en procedures van de studies en rolverdeling in het team. Ook werden belangrijke componenten van gezamenlijke besluitvorming geïdentificeerd, zoals kennisuitwisseling en rolverdeling. Daarnaast geeft dit hoofdstuk inzicht in de percepties van het inclusieve onderzoeksteam op de impact van gezamenlijke besluitvorming; 1) kwaliteitsverbetering van onderzoek en 2) het op een waardevolle manier betrekken van mensen met een VB. Kortom, dit hoofdstuk geeft een overzicht van mogelijkheden en belangrijke componenten voor gezamenlijke besluitvorming in inclusief onderzoek. Voor de praktijk levert dit onderzoek inzichten op die inclusieve onderzoeksteams kunnen inzetten om op een succesvolle manier samen beslissingen te maken.

Deel II: Conceptualiseren van gezonde leefomgeving voor mensen met een VB

Hoofdstuk 5

Hoofdstuk 5 beschrijft de ontwikkeling van een conceptueel kader van de gezonde leefomgeving voor mensen met een VB. Een internationale en multidisciplinaire groep van 41 onderzoekers deed mee aan dit concept mapping onderzoek. Deze onderzoekers zijn gespecialiseerd in gezondheidszorg voor mensen met een VB of de settingsaanpak voor gezondheidsbevordering, Fase één bestond uit een (online) brainstormsessie waarin uitspraken van deelnemers werden verzameld over hoe een (gezonde) leefomgeving voor mensen met een VB eruit ziet. Fase twee bestond uit het sorteren van de uitspraken in clusters en het beoordelen van de uitspraken op mate van belangrijkheid. Dit resulteerde in en conceptueel kader van 13 clusters welke wij "Healthy Settings for People with Intellectual Disabilities" (HeSPID framework) hebben genoemd. De clusters zijn onder te verdelen in de fysieke omgeving, de sociale omgeving, en maatschappelijke voorwaarden voor gezond leven.

Clusters gerelateerd aan de fysieke omgeving zijn; *Gezonde thuisomgeving, Faciliterende omgeving, Op maat gemaakte omgeving* en *Toegankelijkheid*. De clusters *Gezonde thuisomgeving* en *Faciliterende omgeving* gaan over de hulpbronnen op en rondom een locatie die bijdragen aan gezond leven. De clusters *Op maat gemaakte omgeving* en *Toegankelijkheid* beschrijven de barrières en hulpbronnen die specifiek voor mensen met een VB nodig zijn. Dit laat zien dat er een goede match nodig is tussen hulpbronnen in de omgeving en wat mensen met een VB nodig hebben. De onderlinge verbondenheid van de fysieke en sociale omgeving is zichtbaar in het cluster *Huiselijke omgeving*, waar uitspraken zowel met mensen als plekken te maken hebben.

De clusters die te maken hebben met de sociale omgeving beschrijven het sociale netwerk (*Ondersteunende omgeving*) en voorwaarden voor het netwerk om gezondheidsbevorderend te zijn (*Waarden over gezond leven, Een open gesprek, Eigen keuzes maken,* en *Ondersteunende hulp*). Opvallend is de belangrijke rol van het sociale netwerk om mensen met een VB in staat te stellen om gezond te leven.

Clusters die te maken hebben met voorwaarden voor gezond leven in de maatschappij zijn; *Financiële aspecten, Gezondheidszorg en preventie*, en *Meedoen in de maatschappij*. Dit gaat over aspecten zoals geld voor gezonde voeding, toegang tot gezondheidsprofessionals en (niet) dezelfde mogelijkheden hebben als iedereen in de maatschappij.

De clusters laten zien waar maatwerk nodig is in het creëren van een gezonde leefomgeving voor mensen met een VB.

Hoofdstuk 6

In hoofdstuk 6 zijn perspectieven verzameld van mensen met een VB over wat hulpbronnen in de gezonde leefomgeving voor gezonde voeding en beweging zijn. Dit geeft een verdere invulling en aanvullingen op het conceptuele kader (HeSPID framework). Eenenvijftig

mensen deden mee aan deze nominale groepstechniek studie; 4 groepen van mensen met een licht/matige VB en 5 groepen vertegenwoordigers van mensen met een (zeer) ernstige VB. Elke groep kwam twee keer samen om onder begeleiding van een inclusief onderzoeksteam ideeën te verzamelen en te beoordelen op mate van belangrijkheid. In totaal werden er 185 hulpbronnen geïdentificeerd. Deze hulpbronnen passen goed binnen de clusters van het eerder ontwikkelde conceptuele kader (HeSPID framework). Daarnaast geven de hulpbronnen een gebruikersperspectief op hulpbronnen die nodig zijn voor fysieke activiteit en gezonde voeding op locaties van zorgorganisaties voor mensen met een VB. Ten aanzien van het sociale netwerk benoemden deelnemers diverse ideeën hoe ondersteunende hulp gegeven kan worden en wat nodig is voor een open gesprek over gezond leven. Ook werden benodigde factoren voor een ondersteunend sociaal netwerk benoemd. En werden manieren in kaart gebracht hoe begeleiders zowel aandacht kunnen hebben voor het ondersteunen van autonomie als het ondersteunen van een gezonde leefstijl. Hulpbronnen in de fysieke omgeving geven inzicht in het perspectief van gebruikers van de locatie op wat voor hulpmiddelen en faciliteiten behulpzaam zijn bij het creëren van een gezonde omgeving die toegankelijk en op maat gemaakt is voor mensen met een VB. Hulpbronnen gerelateerd aan maatschappelijke voorwaarden voor gezond leven geven inzicht in hoe gezondheidsprofessionals kunnen bijdragen aan de gezondheidszorg en preventie. Ook werden er verschillende financiële niveaus benoemd waar vanuit gezond leven ondersteund kan worden. Een nieuw cluster *Gezondheidsbevorderend beleid* van zorgorganisaties gaat over hulpbronnen op het niveau van zorgorganisaties zoals de visie en missie van een organisatie en het uitdragen van het belang van gezond leven binnen de organisatie. De resultaten van dit hoofdstuk geven inzicht in omgevingsfactoren die nodig zijn voor het ontwikkelen van een gezonde leefomgeving voor mensen met een VB. Deze studie laat de onderlinge verbondenheid van hulpbronnen en clusters zien. Dit laat het belang zien voor een integrale aanpak om op een duurzame manier gezondheidsbevordering te integreren in de setting waar mensen met een VB veel gebruik van maken, d.w.z. woon- en dagbestedingslocaties van zorgorganisaties voor mensen met een VB.

Deel III: Werken aan een gezonde(re) leefomgeving in de praktijk

Hoofdstuk 7

Hoofdstuk 7 gaat over de ontwikkeling van de omgevingsscan (DIHASID tool). De omgevingsscan heeft als doel om inzicht te verschaffen aan stakeholders in de praktijk hoe hulpbronnen voor gezonde voeding en fysieke activiteit in een woon- of dagbestedingslocatie (setting) voor mensen met een matige tot zeer ernstige VB worden ervaren. Ook geeft de tool inzicht in verbeterpunten om toe te werken naar een gezonde(re) leefomgeving. Een eerste ontwerp van de omgevingsscan werd gebaseerd op de resultaten van hoofdstuk 5 en 6. Vervolgens werd dit doorontwikkeld met inbreng

vanuit interviews met experts rondom gezondheidsbevordering in de praktijk (n=7), cognitieve interviews met eindgebruikers (mensen met een VB, vertegenwoordigers van mensen met een VB en begeleiders, n=7) en een pilot onder eindgebruikers van drie locaties (n=16). De volledigheid van de omgevingsscan werd verbeterd door het toevoegen of veranderen van vragen en antwoordopties, toevoegen van instructies en het personaliseren van vragen naar drie verschillende groepen eindgebruikers. Helderheid van de tool werd verbeterd door het aanpassen van instructies, aanpassen van pictogrammen, vervangen van technische of onduidelijke woorden met eenvoudige woorden, aanpassen van woordvolgorde, verwijderen of toevoegen van antwoordopties en veranderen van gevoelige woorden. De pilot test leverde informatie op over de ervaren gebruiksvriendelijkheid en gaf een aantal laatste verbeterpunten. De meeste pilot deelnemers vonden de uitleg, duidelijkheid, gemak en invultijd van de omgevingsscan goed. Pilotdeelnemers vonden de omgevingsscan behulpzaam voor het vergroten van bewustzijn van hoe de omgeving van invloed is op leefstijl. Ook gaven zij aan dat de omgevingsscan kan helpen bij het onder de aandacht brengen van een gezonde leefstijl bij betrokkenen op de locatie. Bovendien vonden deelnemers dat de omgevingsscan een goed overzicht geeft van bestaande hulpbronnen, wat gebruikt kan worden om verandering in de organisatie teweeg te brengen. Deelnemers vonden dat een samenvatting van de uitkomsten nodig was om op basis van de omgevingsscan acties te kunnen gaan inzetten. De definitieve omgevingsscan bestaande uit 37 vragen over; deelnemerskarakteristieken, karakteristieken van de setting, aanwezigheid van, tevredenheid met en dromen over sociale, fysieke, beleids- en financiële hulpbronnen. De omgevingsscan kan ingevuld worden door cliënten met een matige VB, vertegenwoordigers van mensen met een VB, begeleiders en teamleiders op een woon- of dagbestedingslocatie in circa 30 minuten. Samengevat, de omgevingsscan is een veelomvattend, duidelijk en bruikbaar hulpmiddel wat mensen met een VB en begeleiders helpt om hulpbronnen voor gezond leven op een woon- of dagbestedingslocatie in kaart te brengen. De perspectieven van eindgebruikers op wat aanwezig is, wat ze ervan vinden en verbeterwensen kunnen gebruikt worden om te werken aan een gezonde(re) leefomgeving voor mensen met een VB.

Hoofdstuk 8

Hoofdstuk 8 gaat over de implementatie van de, in hoofdstuk 7 beschreven, omgevingsscan bij vier woon- en/of dagbestedingslocaties van vier verschillende zorgorganisaties voor mensen met een VB. Zevenenvijftig gebruikers van de vier locaties deden mee; mensen met een licht/matige VB, vertegenwoordigers van mensen met een (zeer) ernstige VB, begeleiders en teamleiders. Zij vulden de omgevingsscan in die ging over de beschikbaarheid, tevredenheid met, en dromen over sociale, fysieke, beleids- en financiële hulpbronnen. Gebaseerd op deze informatie werd een samenvatting ontwikkeld voor elke locatie die gecontroleerd werd door de deelnemers in een groepsgesprek. Het toepassen van de omgevingsscan bevestigde dat de omgevingsscan

een volledig beeld geeft van hoe gebruikers van een locatie denken over sociale, fysieke, beleids- en financiële hulpbronnen voor gezond leven op een woon- en/of dagbestedingslocatie voor mensen met een VB. Tijdens het groepsgesprek werd door de deelnemers bevestigd dat de omgevingsscan kennis oplevert die je direct in kunt zetten om toe te werken naar een gezonde(re) locatie voor mensen met een VB. Deze kennis omvat; 1) hoe beschikbare hulpbronnen aangepast kunnen worden aan wat gebruikers nodig hebben, 2) hoe beschikbare hulpbronnen op een andere/betere manier gebruikt kunnen worden, en 3) welke hulpbronnen toegevoegd zouden moeten worden aan de setting. Deze inzichten zijn belangrijk voor zorgorganisaties voor mensen met een VB om de huidige context mee te nemen in het toepassen van de settingsaanpak. Op deze manier kan gezondheidsbevordering verder geïntegreerd worden in de locaties en zorgorganisatie.

Hoofdstuk 9

Hoofdstuk 9 bevat de algemene discussie van dit proefschrift. Hierin wordt een overzicht gegeven van de belangrijkste bevindingen. Ook wordt de toepassing van de setting aanpak in dit proefschrift bediscussieerd aan de hand van de volgende principes:

1. Processen voor het betrekken van en samenwerken met stakeholders in onderzoek, Het belang van de verbondenheid van mensen, plekken en voorwaarden voor gezond leven meenemen in een aanpak om te werken aan een gezonde(re) leefomgeving voor mensen met VB (systeemaanpak),
2. Inbedding van gezondheidsbevordering in het systeem van zorgorganisaties en locaties voor mensen met VB. Dit door stakeholders te betrekken in het verzamelen van toepasbare kennis rondom gezondheidsbevordering en dit toe te passen in de praktijk.

Stakeholderbetrokkenheid werd in dit proefschrift toegepast door het samenwerken als inclusief onderzoeksteam en de betrokkenheid van de klankbordgroep. Dit gaf inzicht in mogelijke processen voor stakeholder betrokkenheid in onderzoek naar gezondheidsbevordering voor mensen met een VB. De inzet van de klankbordgroep in groepsdiscussies en het geven van feedback droeg bij aan het toepasbaar maken van studieontwerpen, studieresultaten en hulpmiddelen voor de praktijk. Wekelijks werkte het inclusieve onderzoeksteam samen. In elke fase van de studies maakte het team samen beslissingen over rolverdeling en de inhoud en procedures van de studies. Informatie en processen die het inclusieve onderzoeksteam gebruikte voor gezamenlijke besluitvorming zijn: 1) identificeren van beslissingen om te maken, 2) kennisoverdracht van wetenschappelijke- en ervaringskennis, 3) eigen waarden en voorkeuren benoemen op basis van interesses, competenties en vaardigheden, 4) overleggen en deelnemen aan besluitvorming met specifieke aandacht voor rolverdeling in inclusieve dataverzameling en analyse, en 5) implementeren van de beslissing. Het inclusieve onderzoeksteam

benoemde als impact van stakeholder betrokkenheid een verbeterde kwaliteit van de studies en het in de eigen kracht staan van mensen met een VB. Zo hielpen de stakeholders om het onderzoeksproject aan te passen om stakeholders, en in het bijzonder mensen met een VB, op een betekenisvolle manier te laten deelnemen aan onderzoek. Ook hielpen zij bij de ontwikkeling van studies en hulpmiddelen die relevant zijn voor gezondheidsbevordering in de praktijk. De omgevingsscan activeert de betrokkenheid van stakeholders, zoals mensen met een VB, in gezondheidsbevordering.

Ten tweede kan het in dit proefschrift ontwikkelde conceptuele kader (HeSPID framework) gebruikt worden om een systeemaanpak toe te passen in gezondheidsbevordering voor mensen met een VB. Het conceptuele kader geeft inzicht in hoe veelzijdig en onderling verbonden hulpbronnen voor gezonde voeding en fysieke activiteit van mensen met een VB in een setting zijn. Het conceptuele kader benadrukt de verbondenheid tussen gebruikers en hulpbronnen in de setting en het belang van het passend maken van de omgeving voor specifieke gebruikersgroepen. De omgevingsscan is ontwikkeld om een gebruikersperspectief te verkrijgen op hoe bestaande hulpbronnen voor gezond leven worden ervaren en wat verbeterwensen zijn. Dit gebruikersperspectief kan gebruikt worden om een passend aanbod voor gezondheidsbevordering in een bepaalde setting te ontwikkelen door rekening te houden met de wensen van de gebruikers. Dit draagt bij aan de toenemende vraag om gezondheidsbevordering vanuit systeemdenken te benaderen waarbij de wisselwerking tussen mensen en de setting waarin zij zich begeven wordt meegenomen. Daarnaast komt ook uit dit proefschrift naar voren dat hulpbronnen in een setting verbonden moeten worden aan elkaar om het gezondheidsbevorderend potentieel van de setting te optimaliseren. Ook moeten hulpbronnen in een setting verbonden worden met bredere omgevingsdeterminanten buiten de setting. Naast dat omgevingsscan zich richt op het niveau van woon- en dagbestedingslocaties wordt er ook informatie mee verzamelt over de fysieke omgeving, financiën en beleid van de organisatie waar zorgorganisaties en gemeenten actie op kunnen ondernemen.

Ten derde, de omgevingsscan werd in dit proefschrift ontwikkeld om toepasbare kennis bij stakeholders te verzamelen om zo gezondheidsbevordering beter in te kunnen bedden in woon- en dagbestedingslocaties voor mensen met een VB. De omgevingsscan helpt lokale stakeholders om vanuit het perspectief van gezondheidsbevordering naar de locatie te kijken en zo te identificeren wat nodig is voor een gezondere leefomgeving. De omgevingsscan stelt gebruikers van een locatie in staat om een volledig beeld te verkrijgen van aanwezige sociale, fysieke, beleid, en financiële hulpbronnen. Gecombineerd met informatie over gebruikerstevredenheid en verbeterwensen geeft dit toepasbare kennis op welke gebieden en op welke manier er gewerkt kan worden aan een gezondere leefomgeving. Deze kennis kan stakeholders helpen om tot een gezamenlijk actieplan te komen. De kracht van deze aanpak ligt in het faciliteren van bottom-up verandering die past bij wat gebruikers nodig hebben en hun wensen. Ook wordt door deze aanpak

gebruik gemaakt van bestaande hulpbronnen en wordt gezondheidsbevordering ingebed in de locatie wat bijdraagt aan duurzame gezondheidsbevordering.

Naast de discussie over de toepassing van principes van de settingsaanpak, worden in dit hoofdstuk ook methodologische overwegingen en implicaties voor de praktijk, beleid en toekomstig onderzoek besproken. De methodologische overwegingen gaan over methode- en databron triangulatie, uitdagingen rondom het betrekken van mensen met een VB als onderzoekdeelnemers en de sterke punten en beperkingen van het toepassen van de settingsaanpak in dit proefschrift. Op de volgende pagina wordt een puntsgewijze samenvatting gegeven van de implicaties voor praktijk, beleid en toekomstig onderzoek.

Aanbevelingen voor de praktijk

- Gebruik een systeemaanpak voor gezondheidsbevordering binnen zorgorganisaties voor mensen met een verstandelijke beperking (VB). Factoren die gezond leven van mensen met een VB ondersteunen zijn veelzijdig en onderling verbonden. Gebruik de volgende actiegebieden:

  1. Een eigen visie creëren op gezondheidsbevordering als zorgorganisatie.
  2. Beleid op gezondheidsbevordering ontwikkelen en inbedding in de organisatie.
  3. Plannen op maat maken; betrek cliënten en begeleiders want op elke locatie is wat anders nodig.
  4. Netwerkvorming en rol- en taakverdeling van betrokkenen bij ondersteuning van gezond leven.
  5. Trainingsmogelijkheden van personeel.
  6. Toegankelijke en passende hulpmiddelen, activiteiten en faciliteiten die gezond leven ondersteunen.
  7. (extra) tijd voor begeleiders om cliënten in het dagelijks leven te ondersteunen.

- Gebruik de omgevingsscan voor een bottom-up aanpak op het niveau van woon- en dagbestedingslocaties. Gebruikers van locaties brengen samen in kaart wat aanwezig is, hoe dit ervaren wordt en wat dromen voor verbetering zijn. Zo kan een gezamenlijk lokaal actieplan worden opgesteld om te werken aan een gezondere leefomgeving. De webapplicatie van de omgevingsscan en handleiding voor het actiegesprek om een actieplan op te stellen zijn te vinden op de projectwebsite: *dekrachtengebundeld.nl*

Aanbevelingen voor beleid

- Algemeen: erken de rol van omgevingsfactoren in het dagelijks leven die van invloed zijn op leefstijlgedrag. Creëer meer aandacht voor het werken aan een gezonde(re) leefomgeving voor mensen met een VB.
- Zorgorganisaties voor mensen met een VB: ondersteun personeel en financiële inzet op basis van de zeven actiegebieden zoals hierboven geformuleerd. Ondersteun het gebruik van de omgevingsscan en het implementeren van lokale actieplannen om te werken aan een gezonde(re) leefomgeving voor mensen met een VB.
- Gemeenten: zet in op samenwerking tussen de gemeente en zorgorganisaties voor mensen met een verstandelijke beperking voor passend aanbod van gezondheidsbevordering in de buurt en een gezonde leefomgeving.
- Nationaal: zet stimuleringsmaatregelen in voor het werken aan een gezonde leefomgeving binnen zorgorganisaties voor mensen met een verstandelijke beperking. Bijvoorbeeld door de Gezonde School aanpak door te vertalen en toe te passen voor zorgorganisaties voor mensen met een VB.

Aanbevelingen voor onderzoek

- Gebruik de omgevingsscan in actieonderzoek om te werken aan een gezonde(re) woon- en dagbestedingslocaties voor mensen met een VB.
- Gebruik de omgevingsscan om een overzicht te krijgen van de implementatie-context bij het implementeren van leefstijlinterventies.
- Gebruik de inzichten voor het betrekken van stakeholders in toekomstig onderzoek om zo samenwerking met stakeholders te optimaliseren.

CHAPTER

11

Dankwoord (acknowledgements)

Wat begon als een stage in 2015 bij Geneeskunde voor Mensen met een Verstandelijke Beperking (GMVB) resulteerde in dit proefschrift. Tijdens die stage groeide mijn interesse in gezondheidsbevordering uit tot de wens om een promotieonderzoek te starten over gezond leven voor mensen met een verstandelijke beperking. In 2017 werd dit mogelijk door financiering van ZonMw, Gewoon Bijzonder en de academische werkplaats Sterker op eigen benen. Terugkijkend op deze leerzame periode ben ik dankbaar voor de steun van velen. Dit hoofdstuk is dan ook speciaal voor jullie!

Als eerste; co-onderzoekers Anneke van der Cruijsen en Henk Jansen. Wat hebben we samen veel geleerd. Elke week werkten we samen aan het onderzoek. Hoe kunnen mensen met een verstandelijke beperking goed meedoen in onderzoek? Wat hebben zij nodig? En in welke woorden kunnen we uitleggen wat het onderzoek oplevert? Samen puzzelden we wat af. We gingen samen op pad voor groepsgesprekken. De informatie analyseerden we op een creatieve manier. De muren van onze werkruimte zijn wat volgeplakt met post-its en afbeeldingen! Bedankt voor jullie eerlijkheid, enthousiasme en geduld. Wat hebben jullie mij veel geleerd over onderzoek passend maken. En erover praten en schrijven in makkelijke taal. Ik ga jullie missen. Gelukkig kan ik alles wat ik van jullie heb geleerd meenemen en blijven inzetten.

Associate prof. Jenneken Naaldenberg, mijn dagelijks begeleider en copromotor, bedankt voor de fijne samenwerking. Tijdens onze tweewekelijkse overleggen hielp jij me door de juiste vragen te stellen. Wanneer ik tijdens het schrijfproces mijn enthousiasme wel eens verloor, daagde jij me uit en gaf me nieuwe moed om nog even de puntjes op de ï zetten. Bedankt voor je vertrouwen, steun, humor en alle kletspraatjes over paarden!

Assistant prof. Thessa Hilgenkamp, mijn copromotor op afstand, dank voor je betrokkenheid, zowel inhoudelijk als persoonlijk. De fysieke afstand wisten we goed te overbruggen via Skype overleggen. Al waren die momenten altijd vroeg in de ochtend voor jou, je was er niet minder scherp door. Ik kon altijd rekenen op jouw analytisch vermogen en hulp om er vanuit helikopterperspectief naar te kijken. In het schrijfproces hielp jij me om tot de kern te komen.

Prof. dr. Geraline Leusink, wat leuk om de eerste promovenda te zijn waar jij promotor van bent. Dank voor de vrijheid en mogelijkheden die jij me gaf. Nog geen financiering voor je promotieonderzoek? Dan help je me toch gewoon eerst bij de uitbreiding en professionalisering van de academische werkplaats! Zo creëerde je een functie als coördinator voor mij, waarin ik veel van je bestuurlijke vaardigheden heb kunnen leren. Later waren er de promotoren-overleggen waarin jij altijd veel humor en energie in bracht.

Prof. dr. Koos van der Velden, jij bracht als promotor het public-health perspectief in! Doordat de gehandicaptensector vrij nieuw voor je was, stelde je vaak interessante vragen en trok je vergelijkingen met andere sectoren. Dit heeft mij vaak aan het denken gezet. Zoals zo vaak naar voren kwam in onze overleggen; er zijn nog genoeg kansen om bruggen te bouwen tussen public health en gezondheidsbevordering binnen zorgorganisaties voor mensen met een verstandelijke beperking. Vanwege je rol was je nooit ver weg van Den Haag en had je altijd wel een mooi verhaal zo aan het begin van een promotorenoverleg.

De leden van de manuscriptcommissie, Prof dr. Stefan Listl, Prof dr. Nanne de Vries en Prof dr. Petri Embregst, hartelijk dank voor het lezen en beoordelen van mijn manuscript. Ook dank ik de aanvullende leden van de promotiecommissie, Alyt Oppewal, Gerdine Fransen en Pim Assendelft, voor het lezen van mijn manuscript en uw bijdrage tijdens de verdediging. Ik kijk uit naar onze discussie tijdens de verdediging.

Partners van de Academische Werkplaats Sterker op eigen benen, bedankt voor jullie financiële en inhoudelijke bijdrage aan dit proefschrift. Door de samenwerking tussen het Radboudumc en Dichterbij, Driestroom, s Heeren Loo, Koraal, ORO, Philadelphia, Pluryn, Siza en de Twentse Zorgcentra werd dit onderzoek mogelijk gemaakt. Cliënten en medewerkers van deze organisaties; jullie hielpen bij het werven van onderzoekdeelnemers of deden zelf mee aan onderzoek. Alleen door jullie hulp was het mogelijk om de ideeën van mensen met een verstandelijke beperking en begeleiders te verzamelen. Een speciaal dank aan de klankbordgroep Gezonde Leefomgeving. Edwin Mulder, Hanneke Goosen-Kramer, Jane van Geenen, Marco Bruggeman, Marco Buurman, Marion Bulkens, Monique Harink en Nenette Bosveld-Hendriks. Bedankt voor jullie enthousiasme en inzet van jullie ervarings- en praktijkkennis. Jullie hielpen mij, Anneke en Henk bij het toepasbaar maken van onderzoek in de praktijk. Samen pasten we onderzoeksmethoden aan, bedachten we hoe we onderzoekdeelnemers konden vinden en uitnodigen en maakten we makkelijk leesbare informatie. Met jullie hulp konden we een gebruiksvriendelijke omgevingsscan maken en andere praktijkproducten. Zonder jullie was dit proefschrift er niet geweest. Ik hoop dat ik met de ontwikkelde producten en aanbevelingen voor de praktijk jullie iets terug kan geven dat bijdraagt aan een gezonde leefomgeving voor mensen met een verstandelijke beperking.

Programmacommissie Gewoon Bijzonder van ZonMw dank voor de financiering van dit project en jullie inbreng tijdens site-visits. In het bijzonder wil ik jullie bedanken voor de stimulering die jullie als programma geven aan de inzet van co-onderzoekers in onderzoek. Dank voor jullie vertrouwen en flexibiliteit om aanpassingen in het projectplan toe te laten. Zo konden we de inbreng van co-onderzoekers écht omzetten in acties die een waardevolle bijdrage opleverde van mensen met een verstandelijke beperking aan onderzoek.

Leden van de stuurgroep en organisaties in het kernteam, gebruikersnetwerk en de kennisnetwerkpartners van De Krachten Gebundeld; bedankt voor jullie betrokkenheid en enthousiasme voor het project. Leden van het projectteam Annelies Overwijk, Aly Waninge, Annette van der Putten, Jenneken Naaldenberg en Thessa Hilgenkamp, fijn om in dit project met jullie te kunnen optrekken. Samen zetten we de schouders eronder om mooie projectrapportages op te leveren, bijeenkomsten te organiseren en het project succesvol af te ronden. Aly Waninge, wat was jij een betrokken en proactieve projectleider. Dank voor jouw inzet en enthousiasme voor dit project. Annette van der Putten, dank voor het delen van jouw expertise en adviezen tijdens de project overleggen van De Krachten Gebundeld. Annelies Overwijk, mijn Groningse collega-promovenda, wat bijzonder om deze 4 jaar samen met jou op te kunnen trekken in dit project en de VIMP. Wat waren we een goed team. Taken verdelen konden we goed: jij communicatie, ik inclusief onderzoek. Maar ook de intensieve samenwerking rondom dataverzameling, presentaties en rapportages ging ons goed af. Dit ambitieuze project met de vele praktijkpartners en nevenactiviteiten wisten we samen binnen de strakke planning te houden. Het is ons gelukt! Jammer dat onze samenwerking nu stopt, maar wie weet maken we ooit nog een carrière-switch en gaan we samen verder als duo-presentators.

Mijn GMVB collega's Anne, Anja, Anneke, Bianca, Esther, Fleur, Henk, Jenneken, Joep, Geraline, Julia, Katrien, Kris, Maarten, Marian, Mathilde, Marloes, Monique, Milou, Natascha, Tim en Tonnie bedankt voor de gezelligheid op de werkvloer en tijdens online koffiemomentjes toen we vanuit huis werkten. Ook dank aan mijn oud collega's Cis, Corine, Henny, Noortje en Tessa hiervoor. Met vele van jullie heb ik veel plezier beleefd tijdens congressen en ELG- en GMVB-uitjes. Esther, fijn dat we zoveel met elkaar konden delen tijdens de uurtjes die we samen in de auto zaten van en naar Nijmegen. Noortje, bedankt voor het vertrouwen en de mogelijkheden die jij me gaf om binnen jouw PhD project al veel te kunnen leren over gezondheidsbevordering. Tessa, het was fijn om vanuit jouw pionierswerk verder te kunnen bouwen aan inclusief onderzoek. Bedankt voor al jouw inzichten en je betrokkenheid bij onze reflectiestudie. Monique, bedankt voor je hulp bij de dataverzameling en analyse van de groepsgesprekken met mensen met een verstandelijke beperking. Het was gezellig om daarvoor samen met jou, Anneke en Henk op pad te zijn. Kris, het was leerzaam om samen met jou de stagiaires van het Supermarktsafari project te begeleiden. Ik leerde veel van je over het toepassen van theorieën in de opzet van interventies. Dankjewel voor de steun en mogelijkheden die je me gaf in de uitvoer van de monitoring van het lokale preventie-akkoord en de laatste loodjes van het reflectiepaper. Gelukkig blijven we elkaar via AMPHI in de toekomst nog tegenkomen!

Oud-docenten Lenneke Vaandrager en Hilde Tobi, wat was het leerzaam om met jullie samen te werken aan onderzoek! Lenneke, bedankt dat je bereid was je netwerk en

expertise in te zetten om zo met een internationale groep experts zicht te krijgen op de gezonde leefomgeving voor mensen met een verstandelijke beperking. Hilde, bedankt voor je betrokkenheid en dat je me veel methodologische kennis hebt bijgebracht.

Stagiaires Rivka Siebesma en Berfin Bulut bedankt voor jullie inzet voor de analyse van de omgevingsscan data. Betrokkenen en stagiaires van het Supermarktsafari project: Edwin Mulder, Fieke Wolters, Giulieta Nalbandyan, Kris Bevelander, Loreen Loman, Lieke van de Braak, Marieke de Vries, Marleen Willemsen, Milou Spirou en Tamara Willemsen, het was erg leuk en leerzaam om samen met jullie deze praktijkinterventie op te kunnen zetten en te evalueren. Nenette Bosveld-Hendriks onze samenwerking ging een stuk verder dan alleen de klankbordgroep. Wat waardeer ik jouw bevlogenheid. Samen met stagiaires Kevin van Zanten, Koos Vink, Damian Schipper en Amber van Dorp konden we toekomstplannen verkennen van de Gezonde-zorgorganisatie aanpak. Ik kijk er naar uit om vanaf de zijlijn mee te krijgen hoe je hier met Tim verder vorm aan gaat geven.

Ook een bijzonder dank aan allen die betrokken waren bij de verspreidings- en implementatie impuls van de praktijkproducten van De Krachten Gebundeld: Annelies Overwijk, Elske ten Vergert, Elles van der Meer, Ichelle van der Zee, Idske Meijer, Marjolein Penninga, Mirjam Bijlsma en Sanne van der Hagen. Mooi om samen met jullie op te kunnen trekken in het implementeren en borgen van de producten binnen de zorgorganisaties. In deze afrondingsperiode van mijn PhD gaven de positieve reacties uit het veld me veel energie om mijn proefschrift af te ronden.

Lieve vrienden en familie bedankt voor jullie steun, interesse in mijn onderzoek en gezellige momenten waardoor ik het werk even helemaal los kon laten. Lieve pap en mam, al vanaf jongs af aan stimuleerden jullie mij om dingen die ik graag wilde, maar spannend vond, gewoon te proberen. Dankzij jullie durf ik uitdagingen zoals dit promotietraject aan te gaan. Anne en Geke wat ben ik blij dat jullie als paranimfen aan mijn zijde staan tijdens de verdediging. Anne door jouw liefde voor de natuur en heerlijke humor zitten onze wandelingen altijd vol bewondering en ontspanning. En Geke, wat is het fijn om een goede vriendin te hebben die op fietsafstand woont. Jij staat altijd voor me klaar met een luisterend oor. En we wandelen wat af om naast het bijkletsen ook in beweging te blijven. Paardenvriendinnen Dalith, Sascha en Selma, wat is het heerlijk om samen met jullie te genieten van de paarden en het bos. BONT vriendinnen, wat bijzonder dat we met vijf van ons aan het promoveren zijn/waren. Laura en Anneloes jullie; gingen me voor. En Alanya en Marijke; zet hem op, jullie mooie boekjes komen er vast ook snel aan.

Tenslotte Marnix, mijn liefste! Bedankt voor je rotsvaste vertrouwen in mijn kunnen. Jij was er altijd voor me aan het einde van een lange werkdag en als het weer eens anders liep dan gepland of gehoopt. Wat waardeer ik jouw geduld, nuchtere blik en droge

humor. Je weet maar al te goed wat promoveren betekent omdat jij het allemaal al hebt meegemaakt. In mijn promotie-periode werden we ouders van onze lieve meid Noémi. Wat is het samen genieten! Nu dit boek klaar is komt er vast meer energie en tijd om er samen op uit te gaan.

CHAPTER

12

Publications, CV and Portfolio

List of publications
Curriculum Vitae (English|Nederlands)
RIHS PhD portfolio

List of publications

Peer reviewed publications

Vlot-van Anrooij, K.; Naaldenberg, J.; Hilgenkamp, T.I.M.; Overwijk, A.; van der Velden, K.; Leusink, G.L. (2021) Gaining actionable knowledge to improve local health-promoting capacities in long-term care support settings for people with intellectual disabilities. *Patient education and counselling doi.org/10.1016/j.pec.2021.05.033*

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Kuijken, N. M. J.; Naaldenberg, J.; **Vlot-van Anrooij, K.;** Nijhuis-van der Sanden, M. W.; Van Schrojenstein Lantman-de Valk, H. M. J.; & Leusink, G. L. (2020) Integrating health promotion in Everyday life of people with ID – extent to which current initiatives take context into account. *Intellectual and developmental disabilitie*s doi:10.1352/1934-9556-58.2.170

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Forthcoming

Vlot-van Anrooij, K.; Frankena, T.K.; van der Cruijsen, A.; Jansen, H.; Bevelander, K.E. Naaldenberg,J.; Shared decision-making in inclusive research: reflections from an inclusive research team *Under review*

Overwijk, A.; Hilgenkamp, T. I. M.; Van der Schans, C. P.; **Vlot-van Anrooij, K**.; Van der Putten, A. A. J.; Waninge, A. Implementation of a training/education program to support direct support professionals to promote a healthy lifestyle for people with intellectual disabilities. *Submitted*

Breuer, M.E.J.; Bakker-van Gijssel, E.J.; **Vlot-van Anrooij, K.;** Tobi, H. Leusink, G.L.; Naaldenberg, J. Towards a shared conceptualization of medical care for people with intellectual disabilities. *Submitted*

Other

Hilgenkamp, T.I.M.; Naaldenberg, J.; van der Putten, A.A.J.; **Vlot-van Anrooij, K**.; Overwijk, A..; Waninge, A. (2021) De Krachten Gebundeld; Ondersteunen van een gezonde leefstijl voor mensen met een verstandelijke beperking. Wetenschappelijk rapport voor beleid en overheid (*Dutch scientific report for policy and government*)

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Curriculum Vitae (English|Nederlands)

English Curriculum Vitae

Kristel Vlot-van Anrooij was born in 's-Hertogenbosch (The Netherlands) on the 9th of May, 1992 and grew up in the village Giessen. After completing secondary school at the 'Altena College' in Sleeuwijk in 2010, she moved to Wageningen. There she studied 'Health and society' (BSc and 2-year MSc) at Wageningen University, a study focused on prevention, health promotion and healthcare systems. During her studies she worked as research methodology lecturer at Wageningen University. Also she worked as a personal and group coach at a care farm (Zorgboerderij Enghoeve) and day-activity centre of an ID support provider (Syndion). For her BSc-minor she studied 'International development and environmental studies' at the Norwegian University of Life Sciences in Ås. For her BSc-thesis she performed a qualitative study at the Asylum Seeker's Health Centre. During her 2-years master program she wrote her thesis about child marriages at the Research and Advocacy Unit in Harare, Zimbabwe. During her MSc internship she performed a study on health promotion initiatives from support providers for people with intellectual disabilities at the research group Intellectual Disabilities and Health from Radboudumc. After obtaining her master in 2015 she started working as research assistant and coordinator of the academic collaborative Stronger on Your own Feet (*Sterker op eigen benen*) at the same research group. As coordinator (2015-2018) she was involved in writing grant proposals and professionalizing the collaboration with the research group and nine ID support providers. Three grant proposals she was involved in were approved (in total 465k from *ZonMw Gewoon Bijzonder voor De krachten gebundeld (DKG) voor gezond leven, ZonMw verspreidings en implementatieimpuls voor praktijkproducten DKG*, en Stichting SPZ voor werkplaats bewegen). This allowed Kristel to start her PhD trajectory in January 2017. As of June 2021 works as a project leader at the GGD Gelderland-Zuid. Kristel lives together with her husband Marnix and daughter Noémi in Nijmegen.

Nederlands Curriculum Vitae

Kristel Vlot-van Anrooij is geboren in 's-Hertogenbosch (The Netherlands) op 9 mei 1992 en groeide op in Giessen. In 2010 behaalde ze haar VWO diploma op de middelbare school Altena College te Sleeuwijk. Daarna verhuisde zij naar Wageningen om 'Gezondheid en Maatschappij' te studeren aan de Wageningen Universiteit (BSc en MSc). Deze studie richt zich op preventie, gezondheids-bevordering en gezondheidszorgsystemen. Tijdens haar studie werkte ze als werkcollege docent onderzoeksmethodologie bij de Wageningen University. Ook werkte ze als individueel- en groepsbegeleiders bij zorgboerderij de Enghoeve en een dagbestedingslocatie van Syndion, een zorgorganisatie voor mensen met een verstandelijke beperking. Tijdens haar bachelor deed ze een minor in internationale ontwikkelings- en omgevingswetenschappen bij de Norwegian University of Life Sciences in Ås. Voor het bachelor thesis deed ze een kwalitatieve studie over de zorg voor asielzoekers bij het Gezondheiscentrum Asielzoekers (nu Arts en Zorg). Tijdens haar 2-jarige master schreef Kristel haar thesis over kind huwelijken bij de Reasearch and Advocacy Unit in Harare, Zimbabwe. Tijdens haar stageperiode bij de leerstoel 'Geneeskunde voor mensen met een verstandelijke beperking' van het Radboudumc deed Kristel onderzoek naar initiatieven van zorgorganisaties voor mensen met een verstandelijke beperking op het gebied van gezondheidsbevordering. Na het behalen van haar diploma in 2015 kreeg Kristel een baan als onderzoeksassistent en coördinator van de academische werkplaats Sterker op eigen benen bij dezelfde leerstoel. Als coördinator (2015-2018) was ze betrokken bij de verdere professionalisering van de samenwerking van de onderzoeksgroep met negen zorgorganisaties. Ook was ze betrokken bij subsidieaanvragen waarvan er drie werden gehonoreerd (in totaal 465k voor *ZonMw Gewoon Bijzonder voor De krachten gebundeld (DKG) voor gezond leven, ZonMw verspreidings en implementatieimpuls voor praktijkproducten DKG*, en Stichting SPZ voor werkplaats bewegen). Dit maakte het voor Kristel mogelijk om in januari 2017 te starten met haar promotieonderzoek. Sinds juni 2021 werkt Kristel bij de GGD Gelderland-Zuid als projectleider verbinding sociaal en medisch domein. Ze woont samen met haar man Marnix en dochter Noémi in Nijmegen.

RIHS PhD portfolio

Institute for Health Sciences
Radboudumc

Name PhD candidate:
K., Vlot-van Anrooij
Department:
Primary and Community Care
Graduate School:
Radboud Institute for Health Sciences

PhD period:
01-01-2017 – 28-05-2021
Promotors:
Prof. G. Leusink,
Prof. K. van der Velden
Co-promotors:
Associate prof. J. Naaldenberg
Assistant prof. T.I.M. Hilgenkamp

	Year(s)	ECTS
TRAINING ACTIVITIES		
Courses & Workshops	2017	3.0
- Designing a PhD research project	2017	1.0
- Introductory course of graduate school (RIHS)	2017	0.5
- HARRIE training (supporting people with a disability in work)	2017	3.0
- Effective writing strategies	2017	0.5
- CABRIO training (collaboration in inclusive research)	2017	8.0
- Summercoure European Training Consortium in Public Health and Health promotion: Mapping and mobilising health assets, Alicante, Spain		
- Scientific integrity	2018	1.0
- Workshop Appreciative Inquiry	2018	0.2
- BROK course	2019	2.0
- Perfecting your academic writing skills	2019	1.5
- Loopbaanmanagement voor promovendi	2019	1.0
- Masterclass implementatie van E-Health	2019-2020	3.0
- Opfriscursus statistiek	2020	2.0
Seminars & lectures	2017	
- Radboud Grand Rounds and Research rounds	2017	0.4
- ZinTern Eerstelijnsgeneeskunde (oral)	2017	0.1
- Kick-off project 'De krachten gebundeld!' (oral)	2017	0.25
- VGN Werkbijeenkomst	2018	0.1
- Bijeenkomst samenwerken aan kennis in de gehandicaptenzorg	2018	0.1
- Lezing Gezonde Leefomgeving bij Leersaam dag van Prader-willi stichting (oral)	2019	0.3
- Workshop Gezond Leven bij Triade (workshop)	2019	0.3
- Programmadag Gewoon Bijzonder	2019	0.2

Symposia & congresses		
- IASSIDD World Congres in Melbourne (oral, preparation for PhD)	2016	1.5
- Symposium Integraal Gericht Werken (oral)	2017	0.1
- Topcare symposium Kennisontwikkeling voor de ouderenzorg (workshop)	2017	0.3
- Studiedag LVB en Leefstijl, Leidscongresbureau	2017	0.5
- Werkconferentie Nijmegen groen gezond en in beweging	2017	0.2
- IASSIDD Health SIRG conference Belfast (poster presentation)	2017	1.5
- Symposium Medische zorg voor mensen met een verstandelijke beperking: een gezamenlijke zorg	2017	0.2
- Werkconference Nijmegen groen gezond en in beweging	2017	0.2
- Congres Unieke sporter, (workshop)	2018	0.4
- Congres Focus op Onderzoek (oral)	2018	0.4
- Symposium public health/afscheidsrede van der Velden	2018	0.15
- IUHPE conference Implementing Health Promotion in the Life Course - User Involvement in Practice and Research (2 orals, 1 workshop)	2018	1.5
- Symposium medische zorg voor mensen met een verstandelijke beperking	2018	0.15
- Eerstelijnsgeneeskunde onderzoekerssymposium E-Health (workshop)	2018	0.1
- Symposium Inclusief Onderzoek in t Eggie	2019	0.2
- Zoek het Uit_Praktijk en wetenschap dichterbij elkaar (workshop)	2019	0.4
- Jaarcongres Alles is gezondheid	2019	0.2
- IASSIDD World Congress Glasgow (2 orals)	2019	2.0
- Karavaanbijeenkomst De Krachten Gebundeld (1 oral, 2 workshops)	2019	0.8
- Organisatie Onderzoekssymposium Eerstelijnsgeneeskunde Kwetsbaar maar Krachtig (workshop)	2019	0.3
- Congres Diagnose Voeding en Gezondheid	2019	0.3
- Concha Colomer Symposium ETC PHHP	2020	0.1
- Slotsymposium De Krachten Gebundeld (oral, workshop)	2021	0.8
Other		
- Scientific seminars of the department of primary and community care 'Refereer' (2 orals)	2017-2021	1.0
- Vakgroepbijeenkomst Movere bewegingsagogiek (oral)	2017	0.1
- ID physician regional meeting Arnhem/Nijmegen (oral)	2018	0.1
- Sitevisits and Network meetings ZonMw (orals)	2017-2020	0.3
- Kenniskring Academic Collaborative Stronger on Your Own Feet (orals)	2017-2020	0.3
- Review of 3 scientific publications (Health Promotion International and Evaluation and Program Planning)	2019-2020	0.3
TEACHING ACTIVITIES		
Lecturing		
- Lecture on concept mapping during ETC-PHHP summercourse	2017	0.1
- Lecture on concept mapping for Research Methodology course at Wageningen University	2017	0.25
Supervision of internships		
- Supervision of 7 research interns (from Radboud University, Wageningen university and HAN) on PhD project, Supermarktsafari project and Healthy care organisation project	2019-2020	7.5
TOTAL		**50.7**

CHAPTER

13

Appendices

Research data management
DIHASID tool in English
Omgevingsscan in Nederlands

Research data management

This thesis is based on data gathered during a PhD project at the Department of Primary and Community Care at the Radboud university medical center. Data are archived according to the Findable, Accessible, Interoperable and Reusable (FAIR) principles (Wilkinson et al., 2016). All studies involved human participants and were conducted in accordance with the principles of the Declaration of Helsinki. The research ethics committee of the Radboud University Nijmegen declared that the studies in this thesis do not fall within the remit of the Medical Research Involving Human Subjects Act (WMO). The ethics committee reviewed the studies using the Dutch code of conduct for health research and responsible use and the Dutch Personal Data Protection Act, replaced in May 2018 by the EU General Data Protection Regulation. The studies received a positive judgement from the ethics committee.

Study participants in all studies received study information and gave informed consent. For participants with intellectual disabilities easy read study information and informed consent forms were used. After completion of the study the physical consent forms were archived following department procedures and registration in the department quality system.

During this project the raw data, edited data and documentation about the data was stored in separate study folders on the Radboudumc department server or the Digital Research Environment (DRE) from the Radboudumc. After introduction of the DRE the data was stored there (from Chapter 4 onwards). Access to the study folders at the department server and DRE is restricted to team members after registry. The privacy of the participants in this study is guaranteed by use of encrypted individual subject codes. These codes are stored separately from the study data on the department server and are only accessible by the primary researcher.

After completion of the studies, the data is saved following local procedures for 10 years at the Radboudumc at the departments archive server for Chapter 2 and 3 and at DRE for Chapters 4-7. Access to these study folders in the archive is restricted. The datasets (excluding participant data) analyzed during thesis studies are available from the corresponding author on reasonable request. Participant data can only be shared for the participants who gave additional consent for using participant data in future studies that are about (supporting) healthy living of people with ID. For participants and studies who do not meet this criteria, renewed permission by the participants is needed to use participant data.

Wilkinson MD, Dumontier M, Aalbersberg IJ, et al. The FAIR Guiding Principles for scientific data management and stewardship. Sci Data 2016; 3: 160018.

DIHASID tool in English

Healthy environment survey

The survey can be used by clients, client representatives, care professionals, and team leaders at ID support organizations.

For convenience and clarity, the questions in the online survey are automatically adapted to the target audience. There are six types of surveys available in Dutch. Three for residential support centers and three for daytime support centers. For each location, there is one for clients, one for client representatives, and one for care professionals and team leaders.

This version of the survey is a combination of them, and the differences between the six surveys are as follows:

⟶ Per target group and location, the different options are provided in square brackets [...], for the client, client representative, and care professionals or team leader respectively.

Example: How old [are you/is the person you represent/are the clients]?

The images in this survey are used under the Creative Commons Licence 2.0. The colored pictures are made by the author. The black and white pictures are from Sclera.be and the following contributors to the Noun project; Andrew Doane, Hea Poh Lin, Alvaro Cabrera, Corpus Delicti, John T. Garcia, Yu Luck, Parkjisun, Gan Khoon Lay, Björn Andersson, Luis Prado, Gan Khoon Lay, Studio Het Mes.

Healthy environment survey

This survey is about healthy living. Healthy living is:

Healthy food and drink

Physical activity and sports

Complete the questions for a residential or a daytime care location. The survey consists of 4 parts:

1. Questions about you (or the person/persons you represent).
2. How people help with healthy living.
3. How places help with healthy living.
4. How plans and money from the organization help with healthy living.

Everyone must complete parts 1, 2, and 3. Part 4 only needs to be completed by representatives and care professionals.

There are 3 types of questions in the survey.
Questions about what already exists, what you think about it, and what your wishes and dreams are. When you write about what already exists, you may think of things that you want. Write those things down for the questions about dreams and wishes.

If you do not know the answer to a question, check "I do not know".
If the question does not apply to you/your client(s), check "not applicable".
For example, the question about talking with a client if they are unable to speak.

Part 1: General questions

1. I am:

Check one box.

- ○ A client.
- ○ A person filling in the list on behalf of one client.
- ○ An attendant.

Care professionals only When you complete the survey, think about all clients you care for in this location.

B1 *Care professionals only* **How many clients are there at the residential or daytime care group?**

V1 *Representatives only* **What is your relationship with the resident or participant in the daytime care activities on whose behalf you are filling out this list?**

- ○ Parent
- ○ Brother/sister
- ○ Daily attendant
- ○ Other;

○ Man

○ Woman

3. How old [are you/is the person you represent/are the clients]?

4. I am completing this survey for:

Check one of the boxes

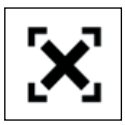
- ○ A home. The building is in a residential area.
- ○ A home. The building is on the grounds of a care organization complex.
- ○ A daytime care location or workplace. The building is in a residential area.
- ○ A daytime care location or workplace. The building is on the grounds of a care organization complex.

5. [Do you have/Does the person you represent have/Do one or more clients have] any of the following disabilities?

Check all that apply.

- ○  I do not know. Or: I prefer not to say.
- ○  [I use/The person I represent uses/One or more clients use] a wheelchair. [I can move myself/The person I represent can move themselves/One or more clients can move themselves] in a manually operated wheelchair.
- ○  [I use/The person I represent uses/One or more clients use] a wheelchair. [I can move myself/The person I represent can move themselves/One or more clients can move themselves] in an electric wheelchair.
- ○  [I am/The person I represent is/One or more clients are] not allowed on the road by [myself/themselves/themselves].
- ○  [I have/The person I represent has/One or more clients have] spasms. *Example: you have an arm or a leg that you cannot fully use. Because of stiff muscles or muscles that suddenly contract.*
- ○  [I have/The person I represent has/One or more clients have] epilepsy. *Example: your brain can short-circuit. When this happens you will notice things like strange movements, convulsions, falling down, or even falling unconscious.*

-  [I have/The person I represent has/One or more clients have] difficulty processing stimuli (autism).
  Example: You cannot deal with a lot of noise or lots of people around you.

-  [I have/The person I represent has/One or more clients have] a feeding tube.
  Example: You receive food through a tube in your stomach.
-  [I have impaired vision or am blind/The person I represent has impaired vision or is blind/One or more clients have impaired vision or are blind.] Even when wearing glasses.
-  [I am hard of hearing/The person I represent is hard of hearing/One or more clients are hard of hearing.] Even when wearing a hearing aid.
-  [I have/The person I represent has/One or more clients have] no impairments.
- Other:

Part 2: People

Healthy living is:

Healthy food and drink

Physical activity and sports

Maybe different people support you.
This question is only about the people who help you with healthy living.

6. Who helps [you/the person you represent/the clients] [in daytime care/at home] with healthy living?

Check all that apply.

- ○ Care professionals
- ○ Family
- ○ Clients or fellow residents
- ○ Friends
- ○ Volunteers
- ○ A care professional who specifically helps with healthy living.

Explanation: Healthy living awareness specialist

- ○ Doctor
- ○ Physiotherapist

Explanation: This is someone who helps with specific exercises for movement.

- ○ Exercise specialist

Explanation: Someone who helps with physical activities and exercise.

- ○ Occupational therapist

Explanation: Someone who gives you exercises or helps with adapting your home. Things such as adding a chair in the shower or adjusting the height of the kitchen.

- ○ Masseur

Explanation: Someone who relaxes your muscles.

- ○ Dietician

Explanation: Someone who gives you tips about healthy food and drink.

- ○ Speech therapist

Explanation: Someone who can help when eating and drinking is difficult.

- ○ Someone else, answer:
- ○ I do not know. Or I prefer not to say.

BV1 *Representatives and care professionals only* **Do care professionals at this location have time to motivate the clients to be physically active?**

- Never
- Sometimes
- Often
- Always
- I do not know

BV2 *Representatives and care professionals only* **Do care professionals at this location have time to sufficiently focus on food and provide the clients with a peaceful time to eat?**

- Never
- Sometimes
- Often
- Always
- I do not know

7. What do the people [in the daytime care/in the home] do together?

This question is about what [you do/the person you represent does/the clients do] together with the clients and/or care professionals.
You do not need to check off the things [you do/the person you represent does/the clients do] alone.

Check all that apply.

- Sports.
- Physical activity.

Example: walking, cycling, mat exercises, and exercising to music.

- Staying active throughout the day.

Example: getting a cup of coffee, taking out the trash, cleaning, dressing oneself, controlled MSE, and playing.

- Grocery shopping.
- Cooking.
- Eating together.
- Talking about healthy living.
- Making agreements about healthy living.

Example: You agree with your care professional that you will eat one piece of fruit every day.

- Nothing that has to do with healthy living.
- I do not know.
- Other:

Healthy food and drink

Physical activity and sports

8. How do others help [you/the person you represent/the clients] [at daytime care/in the home] with healthy living?

Check all that apply.

- ○ Encourage healthy living.

Example: your care professional says "have an apple today!"

- ○ Explain things about healthy living.
- ○ Support by giving tips about healthy living.
- ○ Show others what healthy living looks like.

Example: your care professional eats a healthy lunch.

- ○ Help with going to an exercise activity.
- ○ Help with getting dressed for sports.
- ○ Help choosing an exercise or sports activity.
- ○ Help choosing food and drink.

Example: creating a menu together, or offering clients two types of vegetables to choose from.

- ○ Others buy healthy food and drink.

Example: grocery shopping or ordering food.

- ○ Serve food and pour drinks.
- ○ Others prepare breakfast, lunch, and/or dinner.
- ○ The other people here do not help with healthy living.
- ○ I do not know.
- ○ Other: _____

People who know a lot about healthy living can also help. It could be the doctor, physiotherapist, exercise specialist, occupational therapist, dietician, speech therapist, etc

9. How do these people help [you/the person you represent/the clients] with healthy eating, healthy drinking, exercise, and sport?

Check all that apply.

- ○ Exercise activities.

Example: fitness and swimming

- ○ Movement exercises.

Example: from the physiotherapist

- ○ Assisted exercise.

Example: when you cannot move your leg, and someone else moves it for you.

- ○ Information and tips about exercising.

Example: The physiotherapist tells you what sports you can do.

- ○ Information and tips about healthy food and drink.

Example: The dietician tells you which food is healthy.

- ○ Cooking classes.
- ○ Giving advice when healthy eating is difficult.

Example: If swallowing is difficult, eating too much or not enough.

- ○ I do not receive this help.
- ○ I do not know.
- ○ Other: [ ]

B2a *Care professionals only* **At this location, there is enough opportunity for care professionals to get tips or advice about...:**

- ○ Exercise aids.
- ○ Exercise options and motivating clients.
- ○ Ways you can offer support for the exercises the clients have received from a physiotherapist or exercise specialist.
- ○ Inspiring materials you can use (exercise folder, exercise bag) to motivate clients to engage in physical activity.
- ○ Inspiring materials you can use (such as cooking workshops, videos, menus) to create healthy meals.
- ○ Ways to make eating easier for clients with problems swallowing.
- ○ Ways food can be fine-tuned to what the clients need.
- ○ There are no opportunities for this.
- ○ I do not know.

B2b *Care professionals only* **Who is available to provide this advice?**

- ○ Physiotherapist
- ○ Exercise specialist
- ○ Occupational therapist
- ○ Speech therapist
- ○ Dietician
- ○ General practitioner (GP)
- ○ Intellectual disability physician
- ○ I do not know
- ○ Other:

10–12. To what extent do the following people help with healthy living?

Check the boxes that are most applicable.

**People who know a lot about healthy living include: doctors, physiotherapists, exercise specialists, occupational therapists, dieticians, and speech therapists.*

	 Good	 Could be better	 Bad	 I do not know
Care professionals, clients, and volunteers	○	○	○	○
Family and friends	○	○	○	○
People who know a lot about healthy living*	○	○	○	○

B3. *Care professionals only* **Do care professionals receive assistance from healthcare professionals in the area of healthy living?**

- Very unsatisfactory
- Unsatisfactory
- Moderate
- Satisfactory
- Good
- I do not know

Healthy food and drink

Physical activity and sports

13. How do others help [you/the person you represent/the clients] make choices about healthy living?

Check what applies to you. You can check more than one box.

- Clients choose themselves; they do not receive help.
- Clients choose themselves; others give tips.

Example: care professional gives tips about what healthy drinking is; client chooses what they will do.

- Care professionals and clients choose together.

Example: creating a weekly menu together or choosing a sport.

- Care professionals say what you can choose from. Clients choose what they want.

Example: Care professional shows two vegetables. Client indicates what they want.

- Care professionals consider client preferences.

Example: Care professional chooses to take walks with clients. The care professional knows that the clients will like this.

- Care professionals make the choice for the client.

Example: Care professional makes the choice, as the client is not allowed to do so or capable of doing so.

- I do not know.

14. What do you think about the help [you receive/the person you represent receives/the client receives] in relation to making personal choices.

For example, choices about exercise, sports, healthy food, and drink?

Check the box below the smiley face that is the best match.


○ Good


○ Can be improved


○ Bad


○ I do not know


○ Not applicable

Healthy living is:


Healthy food and drink


Physical activity and sports

15. [At day care/in the residential group], clients and care professionals talk with each other about healthy living.

Check the best match:

- ○ Never
- ○ Sometimes
- ○ Often
- ○ Always
- ○ I do not know
- ○ Not applicable

16. What do you think about the way they talk about healthy living at the [daytime care group/residential group]?

Check the box below the smiley face that is the best match.


○ Good


○ Can be improved


○ Bad


○ I do not know


○ Not applicable

When we say healthy living, we mean healthy food, healthy drink, sufficient exercise and.

BV3–7 To what extent do you agree with the following statements about care professionals at this location:

	Completely disagree	Disagree	Neutral	Agree	Complete ly agree	I do not know
The team of care professionals has sufficient knowledge and skills in relation to healthy living.	○	○	○	○	○	○
The team of care professionals has sufficient knowledge about every client so that personalized support can be offered for healthy living. For example, the team knows what type of exercise is beneficial for a client with spasms.	○	○	○	○	○	○
The team has clear mutual agreements about supporting clients in relation to healthy living.	○	○	○	○	○	○
The team has clear agreements with the family of clients about providing support in relation to healthy living.	○	○	○	○	○	○
The team has a shared vision of healthy living.	○	○	○	○	○	○

People
around you

Help
from others

Healthcare

Supporting
own choices

Open
discussion

Thinking about
healthy living

A17. You have told us about how people [at daytime care/in the home] help with healthy eating, drinking, exercise, and sports.
How can people help even more with healthy living? What are your dreams, tips, or ideas?

**Clients only* You can write something in the box below. Maybe someone can help you.*

PART 3: Places and Aids

18. Which things (aids) for exercise are available [at daytime care/in the home]?

Check all that apply.

- ○ Yard in which you can do exercises.
- ○ Enough space inside to do exercises.
- ○ A hall or space for engaging in physical activity.

Example: gymnasium or fitness space at the daytime care location.

- ○ Multisensory environment (MSE room).
- ○ Stationary bicycle.
- ○ Bicycle or buddy bicycle.
- ○ Bicycle for the wheelchair.

Example: a MOTOmed, Thera Trainer, or Theravital.

- ○ Book with ideas about exercise activities.
- ○ Exercise equipment.

Example: exercise bag, mat, and jump rope.

- ○ Games in which you need to move.

Example: Wii or interactive games.

- ○ Patient lift. This is a special device for lifting someone from a wheelchair.
- ○ Building without thresholds.
- ○ Wide doors.

Example: The doors are wide enough for someone in a wheelchair.

- ○ We do not have the things mentioned above.
- ○ I do not know.
- ○ Other: _____

19. Which things (aids) for healthy eating and drinking are available [at daytime care/in the home]?

Check all that apply.

- ○ Kitchen and cooking supplies.
- ○ Meal service.

Explanation: ready-made meals are delivered.

- ○ Meal-in-a-box or groceries are provided.

Explanation: items are supplied that can be used to make food.

- ○ Vegetable garden or fruit trees.
- ○ Healthy food and drink at home.
- ○ Foods list

Explanation: a list of the food and drink that everyone likes.

- ○ Recipe book
- ○ We do not have the things mentioned above.
- ○ I do not know.
- ○ Something else.

Answer: _____

Healthy living is:

Healthy food and drink

Physical activity and sports

20. How do the things (aids) fit in with what [you need/the person you represent needs/the clients need] for healthy living?

Check the box below the smiley face that is the best match.

○ Good

○ Can be improved

○ Bad

○ I do not know

○ Not applicable

With "near", we mean on the site and/or in the area around [the home/the daytime care location].

21. Which of these are near [the daytime care/the home]?

Check all that apply.

- ○ [Home/Daytime support center]
- ○ Supermarket
- ○ Shops
- ○ Swimming pool
- ○ Hydrotherapy bath

Explanation: this is a water therapy bath.

- ○ Riding stables

Explanation: you can ride horses here.

- ○ Gymnasium, sports hall, or fitness space
- ○ Playground or outdoor exercise area
- ○ Sports field
- ○ Grounds for walking and cycling
- ○ Green space for walking or cycling

Example: walking in a park or forest

- ○ There are no places nearby that can help people with healthy living.
- ○ I do not know

22. How far is...

For each location, check the box that is best for you/your client(s).

	You can walk there (within 15 minutes)	You can cycle there (within 15 minutes)	You need a car, taxi, or bus to get there.	I do not know
[Home/Daytime sup-port center]	○	○	○	○
Supermarket	○	○	○	○
Shops	○	○	○	○
Swimming pool	○	○	○	○
Hydrotherapy bath	○	○	○	○
Riding stables	○	○	○	○
Gymnasium, sports hall, or fitness space	○	○	○	○
Playground or out-door exercise area	○	○	○	○
Sports field	○	○	○	○
Area for walking and cycling	○	○	○	○
Green space for walking or cycling	○	○	○	○

By "near", we mean on the site of and/or in the area around [the home/the daytime support center].

23. What do you think of the locations near [the daytime care location/your home] with regard to:

	Good	Could be better	Bad	I do not know
... healthy food and drink	○	○	○	○
... physical activity and sport	○	○	○	○

25. What do you think about the activities for healthy living that [you/the person you represent/clients] can participate in?

Example: You can participate in cooking lessons and fitness. Check the box below the smiley face that is the best match

Good	Can be improved	Bad	I do not know
○	○	○	○

BV8 *Attendants + representatives only* **Is healthy living sufficiently woven into the day and evening program?**

Check the box below the smiley face that is the best match.




○ Good	○ Can be improved	○ Bad	○ I do not know

By "near", we mean on the site of and/or in the area around [the home/the daytime care location].

26. How safe [do you feel/does the person you represent feel/do your clients feel] to go to nearby places?

Check the box below the smiley face that is the best match.




○ Safe	○ Can be safer	○ Needs to be safer	○ I do not know

27. How easy is it to go to nearby places?

Check the box below the smiley face that is the best match.




○ Easy	○ Could be easier	○ Needs to be easier	○ I do not know

Healthy living is:

Healthy food and drink

Physical activity and sports

28. Think about [what you need/what the person you represent needs/the clients need] for healthy living. Is that available at the [home/daytime care location]?

Check the box below the smiley face that is the best match.

○ Enough

○ Could be more

○ Needs to be more

○ I do not know

29. Think about [what you need/what the person you represent needs/the clients need] for healthy living. Is that available near the [home/daytime care location]?

Check the box below the smiley face that is the best match.

○ Enough

○ Could be more

○ Needs to be more

○ I do not know

Healthy home environment

Locations for healthy activities

Ease of travel

Tailored

You have told us about how places help with healthy food, drink, physical activity, and sport.

30. What is still needed at the [daytime care location/home] or nearby areas for healthy living?

What are your dreams, tips, or ideas?

**the following instructions for clients only* You can write something in the box below. Maybe your care professional can help you.*

C1. *Clients only* **Are there other things that can be improved?**

Care professionals are also asked questions about money and the organization's plans. Do you also want to add something about how money and the organization's plans can help with healthy living?

Write it down below.

Part 4: Policy and budget for healthy living

BV9–12 *Representatives and care professionals only* **The following questions are about financial resources**

	Very unsatisfactory	Unsatisfactory	Moderate	Satisfactory	Good	I do not know
Do the clients at this location have enough money to spend freely on exercise activities, exercise materials, movement aids, and healthy food?	○	○	○	○	○	○
Does this location have enough money to spend on healthy food and tools for healthy foods (such as kitchen utensils)?	○	○	○	○	○	○
Does this location have enough money to spend on physical activity, exercise equipment, and movement aids for clients?	○	○	○	○	○	○
Do you feel that the care organization has reserved enough in the budget and in personnel capacity to support clients with healthy living?	○	○	○	○	○	○

BV13 *Representatives and care professionals only* **What do you think about the financial resources for healthy living at this location?**

- ○ Very unsatisfactory
- ○ Unsatisfactory
- ○ Moderate
- ○ Satisfactory
- ○ Good
- ○ I do not know

Part 4: Policy and budget for healthy living

BV9–12 *Representatives and care professionals only* **The following questions are about financial resources**

	Very unsatisfactory	Unsatisfactory	Moderate	Satisfactory	Good	I do not know
What do you think about the attention paid to healthy living in the organization's policy?	○	○	○	○	○	○
What do you think about the attention paid to healthy living in the organization's communications?	○	○	○	○	○	○
To what extent does the organization align and collaborate with municipalities in relation to spatial planning and sports providers (for example, a sports service desk)?	○	○	○	○	○	○
To what extent does the policy take the wishes of the different target groups into consideration?	○	○	○	○	○	○
To what extent are clients actively involved in the creation of a healthy living environment at the locations?	○	○	○	○	○	○
To what extent is there attention for exercise and healthy food in the discussions of the client's development plan*?	○	○	○	○	○	○

	Very unsatisfactory	Unsatisfactory	Moderate	Satisfactory	Good	I do not know
Does the organization determine what knowledge employees and clients need to have in relation to lifestyle?	○	○	○	○	○	○
To what extent are care professionals provided with knowledge and coaching from other employees within the organization to support clients with healthy living?	○	○	○	○	○	○
To what extent can care professionals make use of coaching by external parties, courses, and education in relation to providing support for healthy living?	○	○	○	○	○	○

* Some organizations call the development plan a care plan, individual guidance plan, support plan, or treatment plan.

BV23 *Representatives and care professionals only* **You have just told us about the situation at this location in relation to policy and budget for healthy eating, healthy drinking, sufficient exercise, and sport?**

Do you have tips or ideas? What is needed in the policy? Which financial resources are needed?

Omgevingsscan in Nederlands

Vragenlijst gezonde omgeving

Deze vragenlijst kan gebruikt worden door cliënten, vertegenwoordigers van cliënten, begeleiders en teamleiders van woon- en dagbestedingslocaties.

Voor gebruiksgemak en duidelijkheid zijn in de online vragenlijst de vragen automatisch aangepast aan de doelgroep. In het Nederlands zijn 6 typen van de vragenlijst beschikbaar. 3 voor woon- en 3 voor dagbestedingslocaties. Per locatie is er 1 voor cliënten, 1 voor vertegenwoordigers van cliënten en 1 voor begeleiders en teamleiders.

Deze versie van de vragenlijst is een samenvoeging hiervan en geeft de verschillen tussen de 6 lijsten als volgt weer:

⟶ Per doelgroep en locatie zijn de verschillende opties aangegeven tussen rechte haakjes […] met de volgorde cliënt, vertegenwoordiger van cliënt en begeleider of teamleider.
Voorbeeld: Hoe oud [ben je/is de persoon die je vertegenwoordigd/zijn de cliënten]?

⟶ Sommige vragen hoeven niet door cliënten en/of vertegenwoordigers ingevuld te worden. Dit is te zien aan "* voor ….*" voor de vraag.
*Voorbeeld: V1.*Alleen voor vertegenwoordigers* Wat is je relatie met de bewoner of deelnemer van dagbesteding waarvoor je deze lijst invult?*

Deze vragenlijst gaat over gezond leven

Gezond leven is:

Gezond eten en drinken

Bewegen en sporten

De vragenlijst bestaat uit 4 delen:

1. Vragen over jou (of de persoon/personen die je vertegenwoordigd)
2. Hoe mensen helpen bij gezond leven.
3. Hoe plekken helpen bij gezond leven.
4. Hoe plannen en geld van de organisatie helpen bij gezond leven.

Deel 1, 2 en 3 vult iedereen in. Deel 4 vullen alleen vertegenwoordigers en begeleiders in.

In de vragenlijst zijn 3 soorten vragen.
Vragen over wat er is, wat je ervan vindt en wat voor wensen en dromen je hebt.
Bij het invullen van wat er is zie je misschien dingen die je graag zou willen.
Vul die dan in bij de vragen die gaan over je dromen en wensen.

Als je het antwoord op een vraag niet weet: kruis' weet ik niet' aan.
Als de vraag niet geldt voor jou/de cliënt(en): kruis 'niet van toepassing' aan.
Bijvoorbeeld bij de vraag over praten als een cliënt niet kan praten.

Deel 1: Algemene vragen

1. Ik ben:
Kruis 1 hokje aan.

- ○ Een cliënt.
- ○ Iemand die namens één cliënt de vragenlijst invult.
- ○ Een begeleider.

Alleen voor begeleiders Denk bij het invullen van de vragenlijst aan alle cliënten die je op deze plek begeleid.

B1 *Alleen voor begeleiders* **Hoeveel cliënten zijn er op de woon- of dagbesteding groep?**

V1 *Alleen voor vertegenwoordigers* **Wat is je relatie met de bewoner of deelnemer van dagbesteding waarvoor je deze lijst invult?**

- ○ Ouder
- ○ Broer/zus
- ○ Dagelijks begeleider
- ○ Overig, namelijk:

2. [Ik ben een/De persoon waarvoor ik de vragenlijst invul is/De cliëntengroep betaat uit]:

○ Man

○ Vrouw

3. Hoe oud [ben je/is de persoon die je vertegenwoordigd/zijn de cliënten]?

4. Ik vul deze vragenlijst in voor:
Kruis 1 van de hokjes aan

- ○ Woning. Het gebouw staat in een woonwijk.
- ○ Woning. Het gebouw is op een terrein van de zorgorganisatie.
- ○ Dagbesteding of werkplek. Het gebouw staat in een woonwijk.
- ○ Dagbesteding of werkplek. Het gebouw is op een terrein van de zorgorganisatie.

5. [Heb je/Heeft de persoon die je vertegenwoordigd/Hebben één of meerdere cliënten] de volgende beperking(en)?
Klik op alle hokjes die kloppen.

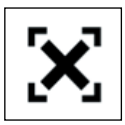
- ○  Weet ik niet. Of: Wil ik niet vertellen.
- ○  [Ik zit/De persoon die ik vertegenwoordig zit/Een/meerdere cliënten zitten] in een rolstoel. [Ik kan me /De persoon die ik vertegenwoordig kan zich/ Een/meerdere cliënten kunnen zich] voortbewegen in een handbewogen rolstoel.
- ○  Ik zit/De persoon die ik vertegenwoordig zit/Een/meerdere cliënten zitten] in een rolstoel en iemand anders moet de stoel duwen om ergens te komen.
- ○  [Ik mag/De persoon die ik vertegenwoordig mag/Een/meerdere cliënten mogen] niet alleen over straat.
- ○  [Ik heb/De persoon die ik vertegenwoordig heeft/Een/meerdere cliënten hebben] spasme.
Voorbeeld: je hebt een arm of been dat je minder kunt gebruiken. Door stijve spieren of spieren die soms opeens samentrekken.
- ○  [Ik heb/De persoon die ik vertegenwoordig heeft/Een/meerdere cliënten hebben] epilepsie.
Voorbeeld: je kunt kortsluiting in je hersenen krijgen. Dat zie je aan vreemde bewegingen, schokken, vallen of even buiten bewustzijn raken.

-  [Ik heb/De persoon die ik vertegenwoordig heeft/Een/meerdere cliënten hebben] moeite met prikkels verwerken (autisme).
  Voorbeeld: Je kunt niet tegen veel geluiden of mensen om je heen.

-  Ik heb/De persoon die ik vertegenwoordig heeft/Een/meerdere cliënten hebben] sondevoeding.
  Voorbeeld: Je krijgt je eten via een spuit in je buik.

-  [Ik zie slecht of helemaal niet/De persoon die ik vertegenwoordig ziet slecht of helemaal niet/Een/meerdere cliënten zijn slechtziend of blind.] Ook bij het dragen van een bril.

-  [Ik hoor slecht/De persoon die ik vertegenwoordig hoort slecht/Er zijn een/meerdere cliënten zijn slechthorend.] Ook bij het dragen van een gehoorapparaat.

-  [Ik heb/De persoon die ik vertegenwoordig heeft/Een/meerdere cliënten hebben] geen beperking.

- Anders, namelijk:

Deel 2: Mensen

Gezond leven is:

Gezond eten en drinken

Bewegen en sporten

Misschien helpen verschillende mensen jou.
Deze vraag gaat alleen over wie jou helpt bij gezond leven.

6. Wie helpt [jou/de persoon die je vertegenwoordigd/de cliënten] [op dagbesteding/in de woning] bij gezond leven?

Klik op alle hokjes die kloppen.

- ○ Begeleiders
- ○ Familie
- ○ Cliënten of medebewoners.
- ○ Vrienden
- ○ Vrijwilligers
- ○ Een begeleider die extra helpt bij gezond leven.

Uitleg: Aandacht functionaris gezond leven

- ○ Dokter
- ○ Fysiotherapeut

Uitleg: Dat is iemand die helpt met oefeningen voor bewegen.

- ○ Bewegingsagoog

Uitleg: Dat is iemand die helpt met beweegactiviteiten en oefeningen.

- ○ Ergotherapeut

Uitleg: Dat is iemand die je oefeningen geeft of helpt met aanpassingen in huis.
Zoals een douchestoel of hoogte keuken veranderen.

- ○ Masseur

Uitleg: Dat is iemand die je spieren los maakt.

- ○ Diëtiste

Uitleg: Dat is iemand die tips geeft over gezond eten en drinken.

- ○ Logopedist

Uitleg: Dat is iemand die kan helpen als eten en drinken niet zo goed lukt.

- ○ Iemand anders, antwoord:

- ○ Weet ik niet. Of wil ik niet vertellen.

BV1 *Alleen voor vertegenwoordigers +begeleiders* **Hebben begeleiders op deze locatie tijd om cliënten te activeren tot bewegen?**

- ○ Nooit
- ○ Soms
- ○ Vaak
- ○ Altijd
- ○ Weet ik niet

BV2 *Alleen voor vertegenwoordigers +begeleiders* **Hebben begeleiders op deze locatie tijd om voldoende aandacht aan eten te besteden en cliënten een rustig eetmoment aan te bieden?**

- ○ Nooit
- ○ Soms
- ○ Vaak
- ○ Altijd
- ○ Weet ik niet

7. Wat doen mensen [op dagbesteding/in de woning] samen?

Deze vraag gaat over wat [je/de persoon die je vertegenwoordigd/ de cliënten] samen met cliënten en/of begeleiders [doet/doet/doen]. De dingen die [je alleen doet /de persoon die je vertegenwoordigd alleen doet/de cliënten alleen doen] hoef je hier niet aan te kruisen.

Klik op alle hokjes die kloppen.

- ○ Sporten
- ○ Beweegactiviteiten.

Voorbeeld: wandelen, fietsen, bewegen op de mat en bewegen op muziek.

- ○ Bewegen door de dag heen.

Voorbeeld: kopje koffie halen, vuilnis wegbrengen, schoonmaken, zelf aankleden, snoezelen en spelen.

- ○ Boodschappen doen.
- ○ Koken
- ○ Samen eten.
- ○ Praten over gezond leven.
- ○ Afspraken maken over gezond leven.

Voorbeeld: Je spreekt af met je begeleider dat je elke dag 1 stuk fruit eet.

- ○ Niets wat te maken heeft met gezond leven.
- ○ Weet ik niet.
- ○ Iets anders, antwoord: [ ]

Gezond leven is

Gezond eten en drinken

Bewegen en sporten

8. Hoe helpen anderen [jou/de persoon die je vertegenwoordigd/ de cliënten] [op dagbesteding/in de woning] bij gezond leven?

Klik op alle hokjes die kloppen.

- ○ Aanmoedigen om gezond te leven.

Voorbeeld: je begeleider zegt "eet eens een appeltje vandaag!"

- ○ Dingen uitleggen over gezond leven.
- ○ Hulp door tips geven over gezond leven.
- ○ Anderen laten zien hoe je gezond kan leven.

Voorbeeld: begeleider eet een gezonde lunch.

- ○ Hulp om naar beweegactiviteit te gaan.
- ○ Hulp bij omkleden bij sporten.
- ○ Hulp bij beweeg- of sportactiviteiten kiezen.
- ○ Hulp bij kiezen van eten en drinken.

Voorbeeld: samen een eetmenu maken, of cliënten mogen uit 2 soorten groente kiezen.

- ○ Anderen kopen gezond eten en drinken.

Voorbeeld boodschappen doen of eten bestellen.

- ○ Eten opscheppen en drinken inschenken.
- ○ Anderen maken ontbijt, lunch en/of avondeten klaar.
- ○ Andere mensen helpen hier niet bij gezond leven.
- ○ Weet ik niet.
- ○ Iets anders, antwoord: _____

Mensen die veel weten over gezond leven kunnen je ook helpen.
Bijvoorbeeld de dokter, fysiotherapeut, bewegingsagoog, ergotherapeut, diëtiste en logopediste.

9. Hoe helpen deze mensen[jou/de persoon die je vertegenwoordigd/de cliënten] bij gezond eten, gezond drinken, bewegen en sporten?

Klik op alle hokjes die kloppen.

- ○ Beweegactiviteiten.

Voorbeeld: fitness en zwemmen

- ○ Beweegoefeningen.

Voorbeeld: van de fysiotherapeut

- ○ Bewogen worden.

Voorbeeld: als je je been niet kan bewegen en iemand anders je been beweegt.

- ○ Informatie en tips geven over bewegen.

Voorbeeld: De fysiotherapeut vertelt wat je aan sport kan doen.

- ○ Informatie en tips geven over gezond eten en drinken.

Voorbeeld: De diëtiste vertelt welk eten gezond is.

- ○ Kookles.
- ○ Advies geven als gezond eten moeilijk is.

Voorbeeld: Als je moeilijk kan slikken, te weinig eet of te veel eet.

- ○ Ik krijg deze hulp niet.
- ○ Weet ik niet.
- ○ Iets anders, antwoord: [ ]

B2a *Alleen voor begeleiders* **Er is op deze locatie voldoende mogelijkheid om als begeleider tips of advies te krijgen over...:**

- ○ Beweeghulpmiddelen
- ○ Bewegingsmogelijkheden en activering van cliënten.
- ○ Hoe u ondersteuning kunt bieden bij oefeningen die cliënten van de fysiotherapeut of bewegingsagoog krijgen.
- ○ Inspiratiemateriaal dat u kunt gebruiken (beweegmap, beweegtas) om cliënten te activeren tot bewegen.
- ○ Inspiratiemateriaal dat u kunt gebruiken (zoals kookworkshops, filmpjes, eetmenu's) geeft om gezonde maaltijden samen te stellen.
- ○ Hoe het eten van cliënten met slikproblemen vergemakkelijkt kan worden.
- ○ Hoe voeding afgestemd kan worden op wat cliënten nodig hebben.
- ○ Daar zijn geen mogelijkheden voor.
- ○ Weet ik niet.

B2b *Alleen voor begeleiders* **Wie is er beschikbaar om dit advies te geven?**

- ○ Fysiotherapeut
- ○ Bewegingsagoog
- ○ Ergotherapeut
- ○ Logopedist
- ○ Diëtiste
- ○ Huisarts
- ○ AVG
- ○ Weet ik niet
- ○ Overig, namelijk: _____

10–12. Hoe helpen de volgende mensen bij gezond leven?

Klik de hokjes aan die het beste passen.

	 Goed	 Kan beter	 Slecht	 Weet ik niet
Begeleiders , cliënten, vrijwilligers	○	○	○	○
Familie en vrienden	○	○	○	○
Mensen die veel weten over gezond leven*	○	○	○	○

**Mensen die veel weten over gezond leven zijn: dokter, fysiotherapeut, bewegingsagoog, ergotherapeut, diëtiste en logopediste.*

B3. *Alleen voor begeleiders* **Krijgen begeleiders hulp van gezondheidsprofessionals bij gezond leven?**

- ○ Zeer onvoldoende
- ○ Onvoldoende
- ○ Matig
- ○ Voldoende
- ○ Goed
- ○ Weet ik niet

Gezond leven is

Gezond eten en drinken

Bewegen en sporten

13. Hoe helpen anderen [jou/de persoon die je vertegenwoordigd/ cliënten] met kiezen over gezond leven?

Kruis aan wat bij jou past. Je mag meer dan 1 hokje aankruisen.

- ○ Cliënten kiezen zelf, ze krijgen geen hulp met kiezen.
- ○ Cliënten kiezen zelf, anderen geven tips.

Voorbeeld: begeleider geeft tips over wat gezond drinken is, cliënt kiest zelf wat hij/zij doet.

- ○ Begeleiders en cliënten kiezen samen.

Voorbeeld: samen een weekmenu maken of een sport kiezen.

- ○ Begeleiders vertellen waar je uit kunt kiezen. Cliënten kiezen wat ze willen.

Voorbeeld: Begeleider laat 2 groentes zien. Cliënt wijst aan wat hij/zij wil.

- ○ Begeleiders houden rekening met wat cliënten fijn vinden.

Voorbeeld: Begeleider kiest om te gaan wandelen met cliënten. De begeleider weet dat de cliënten dat fijn vinden.

- ○ Begeleiders kiezen voor cliënten.

Voorbeeld: Begeleider kiest want cliënt mag of kan niet kiezen.

- ○ Weet ik niet.

14. Wat vindt je van de hulp die [je krijgt /de persoon die je vertegenwoordigd krijgt/ de cliënten krijgen] bij zelf kiezen.
Bijvoorbeeld bij bewegen, sporten, gezond eten en drinken?

Klik het hokje aan onder de smiley die het beste past.

○ Goed

○ Kan beter

○ Slecht

○ Weet ik niet

○ Niet van toepassing

Gezond leven is

Gezond eten en drinken

Bewegen en sporten

15. [Op dagbesteding/in de woongroep] praten cliënten en begeleiders met elkaar over gezond leven.

Kruis aan wat het beste past:

- ○ Nooit
- ○ Soms
- ○ Vaak
- ○ Altijd
- ○ Weet ik niet
- ○ Niet van toepassing

16. Wat vindt je van het praten op de dagbestedinggroep/in de woongroep] over gezond leven?

Klik het hokje aan onder de smiley die het beste past.

○
Goed

○
Kan beter

○
Slecht

○
Weet ik niet

○
Niet van toepassing

Met gezond leven bedoelen we gezond eten, gezond drinken, voldoende bewegen en sporten.

BV3–7 In hoeverre bent u het eens met de volgende stellingen over begeleiders op deze locatie:

	Helemaal mee oneens	Oneens	Neutraal	Eens	Helemaal mee eens	Weet ik niet
Het team van begeleiders heeft voldoende kennis en vaardigheden met betrekking tot gezond leven.	○	○	○	○	○	○
Het team van begeleiders heeft voldoende kennis over elke cliënt zodat voor hem/haar op maat gemaakte steun kan worden gegeven bij gezond leven. Bijvoorbeeld dat het team weet wat voor beweging goed zijn voor een cliënt met spasticiteit.	○	○	○	○	○	○
Het team heeft onderling duidelijke afspraken over de ondersteuning van cliënten bij gezond leven.	○	○	○	○	○	○
Het team heeft met de familie van cliënten duidelijke afspraken over de ondersteuning van cliënten bij gezond leven.	○	○	○	○	○	○
Het team heeft een gezamenlijke visie op gezond leven.	○	○	○	○	○	○

Mensen
om je heen

Hulp
van anderen

Gezondheidszorg

Eigen keuzes
ondersteunen

Open
gesprek

Denken over
gezond leven

A17. Je hebt verteld hoe mensen [op dagbesteding/in de woning] helpen bij gezond eten, drinken, bewegen en sporten.
Hoe kunnen mensen nog beter helpen bij gezond leven?
Wat zijn jouw dromen,tips of ideeën?

**alleen voor cliënten* In dit vak hieronder kun je iets opschrijven. Misschien kan iemand je helpen.*

DEEL 3: Plekken en hulpmiddelen

18. Welke dingen (hulpmiddelen) voor bewegen zijn er [op dagbesteding/in de woning]?

Klik op alle hokjes die kloppen.

- ○ Tuin waarin je kunt bewegen.
- ○ Binnen genoeg ruimte om te bewegen.
- ○ Een zaal of ruimte waar je beweegactiviteiten kunt doen.

Voorbeeld: gymzaal of fitnessruimte op dagbesteding.

- ○ Snoezelruimte
- ○ Hometrainer
- ○ Fiets of Duofiets.
- ○ Fiets voor de rolstoel.

Voorbeeld: een MOTOmed, Thera Trainer of Theravital.

- ○ Boek met ideeën voor beweegactiviteiten.
- ○ Beweegmaterialen.

Voorbeeld: WII of interactieve spellen.

- ○ Spellen waarbij je moet bewegen.

Example: Wii or interactive games.

- ○ Tillift. Dat is een speciale lift waarmee je iemand uit een rolstoel kan tillen.
- ○ Gebouw zonder drempels.
- ○ Brede deuren.

Voorbeeld: De deuren zijn breed genoeg voor iemand in een rolstoel.

- ○ De dingen die hierboven staan hebben we niet.
- ○ Weet ik niet
- ○ Iets anders, antwoord: [ ]

19. Welke dingen (hulpmiddelen) voor gezond eten en drinken zijn er [op dagbesteding/in de woning]?

Klik op alle hokjes die kloppen.

- ○ Keuken en spullen om te koken.
- ○ Maaltijdservice.

Uitleg: kant en klare maaltijden worden bezorgd.

- ○ Maaltijdbox of boodschappen worden gebracht.

Uitleg: spullen worden gebracht waar je een maaltijd mee kan maken.

- ○ Moestuin of fruitbomen.
- ○ Gezond eten en drinken in huis.
- ○ Eetlijst

Uitleg: hierop staat welk eten en drinken iedereen lust.

- ○ Receptenboek
- ○ De dingen die hierboven staan hebben we niet.
- ○ Weet ik niet.
- ○ Iets anders. Antwoord: _____

Gezond leven is

Gezond eten en drinken

Bewegen en sporten

20. Hoe passen de dingen (hulpmiddelen) bij wat [je nodig hebt /de persoon die je vertegenwoordigd nodig heeft/ de cliënten nodig hebben voor gezond leven?

Klik het hokje aan onder de smiley die het beste past.

○ Goed

○ Kan beter

○ Slecht

○ Weet ik niet

Met in de buurt bedoelen we het terrein en/of de wijk rondom [de woning/ de dagbestedingsplek].

21. Wat is er in de buurt [van de dagbesteding/van de woning]?

Klik op alle hokjes die kloppen.

- [Thuis/Dagbestedingslocatie]
- Supermarkt
- Winkels
- Zwembad
- Hydrobad

Uitleg: dat is een therapiebad.

- Manege

Uitleg: hier kun je paardrijden.

- Gymzaal, Sportzaal of Fitnesszaal.
- Speeltuin of beweegtuin.
- Sportveld
- Terrein waar je kunt wandelen en fietsen.
- Groene omgeving waar je kunt wandelen en fietsen

Voorbeeld: wandelen in een park of bos

- Er zijn geen plekken in de buurt die kunnen helpen bij gezond leven.
- Weet ik niet

22. Hoe ver is ...

Kruis voor elke plek het hokje aan dat het beste past bij jou/de cliënt(en).

	Je kunt er naartoe lopen (binnen een kwartier)	Je kunt er naartoe fietsen (binnen een kwartier)	Je moet met de auto, taxi of bus om er te komen.	Weet ik niet
[Thuis/Dagbesteding]	○	○	○	○
Supermarkt	○	○	○	○
Winkels	○	○	○	○
Zwembad	○	○	○	○
Hydrobad	○	○	○	○
Manege	○	○	○	○
Gymzaal, Sportzaal of Fitnesszaal	○	○	○	○
Speeltuin of beweegtuin	○	○	○	○
Sportveld	○	○	○	○
Terrein waar je kunt wandelen en fietsen	○	○	○	○
Groene omgeving waar je kunt wandelen en fietsen	○	○	○	○

Met in de buurt bedoelen we het terrein en/of de wijk rondom [de woning/ de dagbestedings-plek].

23. Wat vindt je van de plekken in de buurt [van de dagbesteding/van je woning] voor:

	 Goed	 Kan beter	 Slecht	 Weet ik niet
… gezond eten en drinken	○	○	○	○
… bewegen en sporten	○	○	○	○

25. Wat vindt je van de activiteiten voor gezond leven waar [je aan mee kan doen/ de persoon die je vertegenwoordigd aan mee kan doen/cliënten aan mee kunnen doen]?

Voorbeeld: je kunt meedoen aan kookles en fitness.
Klik het hokje aan onder de smiley die het beste past.

○
Goed

○
Kan beter

○
Slecht

○
Weet ik niet

BV8 *Alleen voor begeleiders + vertegenwoordigers* **Is gezond leven voldoende ingeweven in het dag- en avondprogramma?**

Klik het hokje aan onder de smiley die het beste past.

○ Goed ○ Kan beter ○ Slecht ○ Weet ik niet

Met in de buurt bedoelen we het terrein en/of de wijk rondom [de woning/de dagbestedingsplek].

26. Hoe veilig [voelt het voor jou/voelt het voor de persoon die je vertegenwoordigd/voelt het voor de cliënten] om naar plekken in de buurt te gaan?

Klik het hokje aan onder de smiley die het beste past.

○ Veilig ○ Kan veiliger ○ Moet veiliger ○ Weet ik niet

27. Hoe makkelijk is het om bij plekken in de buurt te komen?

Klik het hokje aan onder de smiley die het beste past.

○ Makkelijk ○ Kan makkelijker ○ Moet makkelijker ○ Weet ik niet

Gezond leven is

Gezond eten en drinken

Bewegen en sporten

28. Als je kijkt naar [wat je nodig hebt/wat de persoon die je vertegenwoordigd nodig heeft/ de cliënten nodig hebben] voor gezond leven. Is dat op de [woning/dagbestedingplek]?

Klik het hokje aan onder de smiley die het beste past.

o Genoeg

o Kan meer

o Moet meer

o Weet ik niet

29. Als je kijkt naar [wat je nodig hebt/wat de persoon die je vertegenwoordigd nodig heeft/ de cliënten nodig hebben] voor gezond leven. Is dat in de buurt van de [woning/dagbestedingplek]?

Klik het hokje aan onder de smiley die het beste past.

o Genoeg

o Kan meer

o Moet meer

o Weet ik niet

Gezond thuis

Plekken voor gezonde activiteiten

Gemak onderweg

Omgeving op maat

Je hebt verteld over hoe plekken helpen bij gezond eten, drinken, bewegen en sporten.

30. Wat is er [op dagbesteding/in de woning] of in de buurt nog nodig voor gezond leven?

Wat zijn jouw dromen,tips of ideeën?

**alleen voor cliënten volgende instructie* In dit vak hieronder kun je iets opschrijven. Misschien kan je begeleider helpen.*

C1. *alleen voor cliënten* **Zijn er nog andere dingen die beter kunnen?**

Begeleiders krijgen ook vragen over geld en plannen van de organisatie. Wil je ook iets kwijt over hoe geld en plannen van de organisatie kunnen helpen bij gezond leven?

Schrijf dat dan hieronder op.

Deel 4: Beleid en budget voor gezond leven

BV9–12 *Alleen voor vertegenwoordigers + begeleiders* **De volgende vragen gaan over financiële middelen.**

	Zeer onvoldoende	Onvoldoende	Matig	Voldoende	Goed	Weet ik niet
Hebben cliënten op deze locatie voldoende geld om vrij te besteden aan beweegactiviteiten, beweegmaterialen, beweeghulpmiddelen en gezonde voeding?	○	○	○	○	○	○
Heeft deze locatie voldoende geld om te besteden aan gezonde voeding en hulpmiddelen voor gezonde voeding (zoals keukenbenodigdheden)?	○	○	○	○	○	○
Heeft deze locatie voldoende geld om te besteden aan beweegactiviteiten, beweegmaterialen beweeghulpmiddelen voor cliënten?	○	○	○	○	○	○
Heb je het gevoel dat de zorgorganisatie voldoende budget en personele capaciteit gereserveerd heeft voor de ondersteuning van cliënten bij gezond leven?	○	○	○	○	○	○

BV13 *Alleen voor vertegenwoordigers + begeleiders* **Wat vind je van de financiële middelen voor gezond leven op deze locatie?**

- ○ Zeer onvoldoende
- ○ Onvoldoende
- ○ Matig
- ○ Voldoende
- ○ Goed
- ○ Weet ik niet

BV9–12 *Alleen voor vertegenwoordigers + begeleiders* **De volgende vragen gaan over het beleid van de organisatie.**

	Zeer onvoldoende	Onvoldoende	Matig	Voldoende	Goed	Weet ik niet
Wat vind je van de aandacht voor gezond leven in het beleid van de organisatie?	○	○	○	○	○	○
Wat vind je van de aandacht voor gezond leven in de communicatie vanuit de organisatie?	○	○	○	○	○	○
In hoeverre wordt er in deze organisatie afgestemd en samengewerkt met gemeentes op het gebied van ruimtelijke ordening en sportaanbieders (bijvoorbeeld d.m.v. een sportloket)?	○	○	○	○	○	○
In hoeverre wordt er in beleid rekening gehouden met wensen van verschillende doelgroepen?	○	○	○	○	○	○
In hoeverre worden cliënten actief betrokken bij het creëren van een gezonde leefomgeving op de locaties?	○	○	○	○	○	○
In hoeverre is er in besprekingen van het ontwikkelplan* van cliënten aandacht voor bewegen en gezonde voeding?	○	○	○	○	○	○
Is er vanuit de organisatie bepaald welke kennis medewerkers en cliënten moeten hebben op het gebied van leefstijl?	○	○	○	○	○	○

	Zeer onvoldoende	Onvoldoende	Matig	Voldoende	Goed	Weet ik niet
In hoeverre krijgen begeleiders kennisoverdracht en coaching van andere medewerkers binnen de organisatie om cliënten te ondersteunen bij gezond leven?	○	○	○	○	○	○
In hoeverre kunnen begeleiders gebruik maken van coaching van externen, cursussen en scholing op het gebied van ondersteuning bij gezond leven?	○	○	○	○	○	○

* Ontwikkelplan heet bij sommige organisaties ook wel zorgplan, individueel begeleidingsplan, ondersteuningsplan of behandelingsplan.

BV23 *Alleen voor vertegenwoordigers + begeleiders* **Je hebt net verteld hoe het er nu voorstaat op deze locatie met beleid en budget voor gezond eten, gezond drinken, voldoende bewegen en sporten?**

Heb je ook nog tips of ideeën? Wat is in beleid nog nodig? En wat voor financiële middelen zijn nog nodig?

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