

University of Groningen

Lifestyle Opportunities

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DOI:
[10.33612/diss.206455014](https://doi.org/10.33612/diss.206455014)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2022

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):
Overwijk, A. (2022). *Lifestyle Opportunities: supporting a healthy lifestyle of people with moderate to profound intellectual disabilities*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen. <https://doi.org/10.33612/diss.206455014>

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Chapter 7

Summary and general discussion

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The aim of the research reported in this thesis was to facilitate a healthy lifestyle for people with moderate to profound intellectual disabilities (ID) by improving the lifestyle support provided by direct support professionals (DSPs). This was achieved by identifying their support needs and designing, implementing, and evaluating an educational lifestyle program to improve DSPs' support of people with moderate to profound ID in living a healthy lifestyle.

In this chapter, a summary of the primary findings will be provided followed by a general discussion. Finally, implications for education, practice, policy, and future research will be discussed.

Summary of main findings

When supporting people with moderate to profound ID to live a healthy lifestyle, DSPs require specific knowledge and skills related to physical activity and nutrition. The development of interventions to meet these needs is required because of their important role. Previous research shows that the Theoretical Domains Framework (TDF) is an evidence-based framework that helps in understanding which domains are instrumental to influencing health behaviors¹⁻⁴. It was unclear which specific knowledge and skills DSPs would need according to the TDF. Therefore, in **Chapter 2**, the aim was to identify the needs of DSPs in their support of people with moderate to profound ID to achieve and maintain a healthy lifestyle. DSPs (n=28) were interviewed with a semi-structured protocol based on the TDF^{1,2}. They most frequently mentioned five support needs in the following domains: (1) Environmental Context and Resources, (2) Social/Professional Role and Identity, (3) Social Influences, (4) Skills, and (5) Knowledge. They primarily need support related to the domain 'Environmental Context and Resources' in order to support people with moderate to profound ID in leading a healthy lifestyle. Within this domain, available time, dealing with different seasons, and a healthy lifestyle policy in the organization were specifically mentioned.

In the domain 'Skills', one of the skills to support a healthy lifestyle is motivating people with ID. A way to do so may be by using Behavior Change Techniques (BCTs). However, it is currently unknown whether BCTs are used by DSPs and, if so, which are used. The aim in **Chapter 3** was to determine whether and which BCTs were used by DSPs for supporting healthy lifestyle behavior such as physical activity and nutrition of people with moderate to profound ID. DSPs (n=18) were observed in their daily work using audio-visual recordings. To

code the BCTs that were used, the Coventry Aberdeen London Refined (CALO-RE-NL) taxonomy was employed consisting of 40 different BCTs⁵. Two BCTs for people with moderate to profound ID were added to the taxonomy based on a pilot study. The results of the observations showed that DSPs were using 33 out of 42 BCTs. The most used were: 'feedback on performance', 'instructions on how to perform the behavior', 'doing together', 'rewards on successful behavior', 'reward effort towards behavior', 'DSP changes environment', 'graded tasks', 'prompt practice', and 'model/ demonstrate behavior'. Although a variety of BCTs is used in the support of people with moderate to profound ID when facilitating healthy lifestyle behavior, DSPs rely heavily on these nine most prevalent BCTs. DSPs may require additional skills to use a wider variation of techniques. Furthermore, awareness about the use of BCTs can overcome their support need for motivation skills and support them in becoming more confident in supporting healthy lifestyle behavior.

The healthy lifestyle support that DSPs provide is a characteristic of their behavior. According to the social-cognitive theory, behavior is influenced by their intention, and their intention is partly determined by attitude⁶. Attitude is defined as the thoughts and feelings of DSPs regarding a healthy lifestyle⁷ for which an instrument for measuring this was previously developed. However, an instrument to measure the attitude of DSPs towards nutrition was lacking. Therefore, the aim in **Chapter 4** was to determine the internal validity of the adapted attitude of DSPs questionnaire for nutrition. The existing Health Enhancing Physical Activity Questionnaire was adapted into the Attitude of DSPs for Health Enhancing Nutrition (ADSP-HENU). The ADSP-HENU was completed by 31 DSPs. The internal validity of the questionnaire was investigated using Cronbach's Alpha and an exploratory non-parametric item response analyses (NIRT). The internal consistency by Cronbach's Alpha for the ADSP-HENU was good (0.87, 95% CI [0.81-0.94]). The NIRT showed monotonicity with wide confidence bounds and strong point polyserial correlations of the items with the underlying nutrition attitude construct. This indicates that each item attributes to the overall attitude that is measured. Despite the small sample size, this study showed that the internal validity of the ADSP-HENU is promising, and it is a short attitude questionnaire for DSPs that can be used in clinical practice for evaluation and therefore to develop, improve, or adapt intervention to DSPs' needs.

Education and training can improve the knowledge and skills of DSPs in their healthy lifestyle support for people with ID, specifically when theory-based programs are used. However, no theory-based education program was available for DSPs. Therefore, in **Chapter 5**, we aimed to develop a theory-based intervention for DSPs to help them support a healthy

lifestyle for people with moderate to profound ID based on the knowledge gained in the previous studies. The Intervention Mapping Protocol was adhered in order to develop a training and education program for DSPs to support a healthy lifestyle for people with moderate to profound ID. This study provided a theory-based program consisting of a training and education section with e-learning and in-person components to achieve this. In the e-learning module, the themes Knowledge and Awareness of physical activity and healthy nutrition for people with moderate to profound ID were addressed. After the e-learning module, three team sessions with the following themes were planned: Social/Professional Role and Identity, Skills (BCTs), and Social Influences, and Environmental Context, and Resources. During the program, structural attention for lifestyle and sustainability were emphasized. The program can be individually adapted to the learning needs of DSPs and the people with ID who they support. In addition, this study provided a protocol for a process and feasibility study to investigate the potential of the program.

For determining the possibilities of the developed program and changes after implementing the interventions, effective implementation is an important prerequisite. However, although knowledge about implementation of interventions aiming at improving physical activity is available, factors influencing the implementation of education programs in ID support organizations are scarce. Therefore, in **Chapter 6**, the aim was to evaluate the preparation, implementation, and preliminary outcomes of a theory-based training and education program for DSPs to learn how to support people with moderate to profound ID in a healthy lifestyle. The program consisting of e-learning, three in-person sessions, and three assignments was implemented. The implementation process was evaluated with a mixed method design and focused on the recruitment, reach, context, dose delivered, dose received, fidelity, acceptability/suitability of the program, factors during implementation, evaluation of data collection process, and changes after the program. Regarding the preparation phase, the amount of time to recruit participants was nine months in duration, and the inclusion criteria were feasible. The program was implemented in four (residential) facilities (DSPs: n=32, people with ID: n=24). The e-learning was completed by 81% of the DSPs, 72-88% attended the in-person sessions, and 34-47% completed the assignments. Overall, the fidelity of the program was good. DSPs recommended the program, although they were either negative or positive about the time investment. Mutual agreement on expectations appeared to be important for its acceptability and suitability. Regarding the outcomes, the goals of the program were achieved, and attitudes of DSPs towards healthy lifestyles were improved three months after implementation of the program. Healthy food

intake of people with ID improved statistically significantly; for physical activity, no statistically significant differences were found to the extent of being active. The program could be sufficiently implemented and, despite some barriers regarding time capacity and mutual expectations, it delivered changes in both DSPs and the lifestyles of persons with moderate to profound ID. The program is therefore a promising intervention for educating DSPs.

General discussion

Healthy lifestyle in professional education

The training and education program developed in this thesis should be part of the professional education of DSPs because a healthy lifestyle as a topic does not appear to be sufficiently addressed in their professional education. Their professional background is usually educational theory or nursing as a secondary vocational education or at a university of applied sciences. The education consists of a general component for all students and a specific element aimed at a certain specialization. In addition, there are options in the education programs that students can take according to their own interests. In senior secondary vocational education, a healthy lifestyle is often an optional part in the curriculum. Especially for students who are educated to become DSPs, the healthy lifestyle is optional while this topic should be part of the general support they provide given the risks and consequences of an unhealthy lifestyle for people with ID⁸⁻¹¹. Additionally, in the bachelor of social work at a university of applied sciences, the topic of a healthy lifestyle is a minor part in the curriculum, and it does not seem to be addressed with regards to the target group of people with moderate to profound ID. However, a healthy lifestyle is addressed in a few lectures in relation to healthy ageing in general. This seems to be a missed opportunity because professionals lack the knowledge and skills to support this for people with moderate to profound ID¹²⁻¹⁶. Facilitating their healthy lifestyle is important because they generally have low levels of physical activities and often have an unhealthy diet^{8,17}. Moreover, a healthier lifestyle ensures potential health gain¹⁸, positive effects on behavior¹⁹, alertness²⁰, and a better quality of life²¹. Therefore, to support a healthy lifestyle for people with moderate to profound ID, two topics in the professional education of DSPs must be addressed. Firstly, all students need an introduction into the group of people with moderate to profound ID so that students have the opportunity to make an informed choice for the specialization during their education program. Secondly, they need to be educated regarding

the importance of a healthy lifestyle early in their education and how to support this in general and specifically for persons with moderate to profound ID. The need for specialized education also appeared in previous research in the areas of physical, social, and cognitive activity as well as for nutrition and risk factors for the successful ageing of people with ID²².

The use of BCTs should be an important part of healthy lifestyle education in general. They are effective in the support of a healthy lifestyle and are developed for the general population^{23–25}, however, they can also be used in an adapted manner for people with moderate to profound ID (**Chapter 3**). The use of BCTs underlines the need to look at the possibilities of people with moderate to profound ID and their capabilities and thus their support needs. The importance of the use of BCTs is also emphasized in previous lifestyle research that showed that low motivation is a barrier for engagement in physical activities in adults with ID²⁶. Using BCTs is a basic skill for motivating people to change their behavior in general and in supporting individuals with ID. For example, BCTs are also effectively being used by DSPs when challenging behavior such as when aggression or self-injurious behavior is present²⁷. In addition, BCTs can more explicitly be used by DSPs supporting people with ID regarding a healthy lifestyle. As our research showed (**Chapter 3**), DSPs already use BCTs, however, more awareness of if and when to use them may improve their lifestyle support. With BCTs, small steps towards a healthy lifestyle can be made while creating successful experiences and, taken together, these small steps may result in a healthier lifestyle²⁸. One step for persons with moderate to profound ID is, for example, integrating physical activities in daily routines such as helping with simple household chores²⁶. This is very important because they firstly lead to an improvement in health and lifestyle²⁹. Secondly, these types of steps may lead to more participation in daily activities which is also important with regard to quality of life^{30,31}.

Interprofessional collaboration

In addition to the support needs of DSPs, they indicated that they could learn from and be supported by other professionals and from each other in supporting a healthy lifestyle (**Chapter 2**). There should be a learning environment where behavioral scientists, physiotherapists, dieticians, and physicians for people with ID with whom DSPs cooperate should contribute, for example, by sharing knowledge about how physical activities can be supported. Consequently, both aspiring professionals and professionals already working in ID practices can benefit from the new insights gained in this research. Our findings were already communicated to professionals during congresses and papers, but implementing this

knowledge in professional education is necessary. The knowledge gained from learning about and being aware of the potential of DSPs using BCTs regarding physical activity and nutrition could be forwarded to DSPs in the advising role of behavioral scientists and allied health care professionals.

In addition, interprofessional collaboration is needed to learn from each other's expertise in clinical practice in a cooperative learning environment³². Within interprofessional support, behavioral scientists, allied health care professionals, and DSPs should achieve consensus about how to execute BCTs, which BCTs may be most suitable for a specific person, and using the same BCTs in coordination with each other in order to provide clarity and structure to people with ID. This agreement about using BCTs should be adapted in the support plans of people with ID. Using a joint working method based on the perspective of the person with ID, the interprofessional support for these individuals may thus become more effective, coordinated, and improving the support they provide. The interprofessional collaboration can already begin in professional education in which students from different disciplines and education levels collaborate on issues related to a healthy lifestyle, for example, in a minor where students from different disciplines work together on healthy ageing for people with ID³³.

Competence profiles for DSPs

A more prominent role for physical activity and healthy nutrition and how to integrate this in the daily support would be very helpful in changing the current clinical practice and education, including the required competences that DSPs need to support a healthy lifestyle based on this thesis. For DSPs, the competences and core tasks to support people with ID are described in the competence profiles of the Dutch Association of ID care provider services³⁴⁻³⁶. The general competence profile for DSPs working with individuals with ID describes that the DSP provides information and encourages healthy nutrition and physical activity. However, in the specific competence profile for people with severe or profound intellectual and multiple disabilities and people with severe to profound ID and behavioral problems, encouraging physical activity and healthy nutrition is not a topic^{35,36}. To bridge this gap, BCTs as a competence can be included in the general and specific competence profiles that are used to provide direction for professional education of DSPs. If competences such as using BCTs are integrated in professional education, DSPs have concrete tools to encourage healthy lifestyles in daily practice.

A supportive environment for healthy living

When drafting policies related to a healthy lifestyle, the target group of people with moderate to profound ID need to receive specific attention because of the support they require from their environment to live healthily and their increased risk for developing health problems. This attention towards a healthy lifestyle is needed on national, regional, and organizational levels as well. On the national level, campaigns for a healthy lifestyle led by the government should also be applicable for people with moderate to profound ID. For example, the Ministry of Health, Welfare, and Sport wants to stimulate physical activities in childcare and, therefore, half of the locations are required to have a trained health employee. Similar measures for living and day programming facilities for individuals with ID would be very helpful for supporting a healthy lifestyle for this group as well.

In addition, DSPs operate in a wider context when supporting a healthy lifestyle of people with ID of which, from an ecological perspective, the organization where they work and the community are a part^{37,38}. To improve the healthy lifestyle support from DSPs on an interpersonal level, the environment should be encouraging for healthy lifestyle behavior. To this end, the larger project of which this thesis was a part focused on a healthy environment and on the role of DSPs specifically. To screen the living environment of people with ID, the Discovering Health-promoting Assets in Settings for people with ID (DIHASID) tool can be used³⁹. It provides actionable knowledge about the social, physical, financial, and organizational assets for physical activity and healthy nutrition. DSPs can follow the training and education program developed in this thesis and use the DIHASID tool which accords with the last topic of the education program about the environmental context, resources, and social influences. In an ideal situation, there is cooperation at all levels around the people with ID in order to optimize the support and therewith their well-being. To perform healthy lifestyle support in an optimized environment, people with ID, for example, are supported by their families to live healthily. They are afforded opportunities for physical activities whereby the environment is accessible to go outside, there is a budget to cook healthily or to undertake physical activities such as swimming, and a healthy lifestyle policy is present in the ID support organizations. In such an environment, DSPs are facilitated and motivated to support healthy lifestyle behavior.

Methodological reflection

In most of the research with people with moderate to profound ID, the small sample sizes and heterogeneity of the samples are a methodological challenge^{10,40}. The total population of these individuals in the Netherlands is estimated to include 70.000 people⁴¹. This population is very heterogeneous, varying in the degree of ID, and experience additional problems such as health issues, sensory problems, motor problems, behavioral problems, and support needs. The heterogeneity of people with ID implies a large sample is needed to perform randomized control trials (RCTs) when analyzing the effects of interventions that are implemented but, at the same time, it is challenging to recruit large samples of participants. In addition, due to individual differences, the effects of an intervention may differ between persons. In RCTs, these individual benefits and variations may remain unnoticed⁴² and, therefore, for this heterogeneous group, these types of study designs cannot be justified⁴³. For this population, to examine what works for whom, when, and under which conditions may provide information that is more valuable and meaningful. Therefore, a multiple baseline design may be a strong and feasible alternative for examining effectiveness of interventions when groups are heterogeneous^{44,45}. In such studies, multiple baseline measurements are performed in order to determine if possible effects can be attributed to the intervention whereby participants are their own control group.

Another methodological challenge in the research field of people with ID is the lack of the use of evidence-based theoretical models⁴⁶. Theoretical models that are evidence based may lead to measuring instruments and outcome measures. For example, a questionnaire to assess the attitude of DSPs towards physical activity was developed based on the TDF^{2,7}, and the concept attitude was used as one of the outcome measures in **Chapter 6** of this thesis. The underlying theoretical model of that instrument to assess attitude is a framework that is used to gain knowledge about the presence of conditions to support a healthy lifestyle and was originally developed for the general population². This demonstrates that such theoretical approaches can also be used effectively to evaluate interventions for DSPs who support people with moderate to profound ID.

Finally, awareness of the ethical dilemmas concerning involving participants who are not able to provide written consent for participation themselves is however challenging⁴⁶. Persons with more severe ID are not able to provide informed consent themselves, and therefore, written consent is provided by legal representatives (such as a family member or a curator) on behalf of those individuals. Despite the careful way of asking consent, it is possible that the person concerned shows that he or she does not want to participate. The

well-being of people with moderate to profound ID is paramount in giving informed consent for the participation in research. However, research to gain knowledge and to support these vulnerable persons cannot be conducted without them. In this thesis, next to DSPs, persons with moderate to profound ID also participated in the studies. Though they cannot give consent for the research study themselves, they were able to indicate if they wanted to be audio-visually recorded, for example, with gestures or facial expressions. These expressions need to be considered when doing research with these individuals. For example, data collection can be stopped with an indication from a person who knows the participant well and that he or she seems to be expressing not wanting to be recorded. During a study, the willingness of people with moderate to profound ID to participate in research needs to be monitored which requires specific attention from DSPs and researchers.

Future research

For future research, the effectiveness of BCTs should be investigated for people with moderate to profound ID in order to examine the outcomes of the use of BCTs to improve physical activity and healthy nutrition with an effect study. This could address the question of which of the promising and mostly used BCTs we identified would be effective in promoting healthy nutrition and physical activities. Due to the heterogeneity within the group of people with ID, the effectivity of BCTs may initially be explored with case studies to identify which BCTs work for the individual with ID in their specific context. This knowledge gives insights into the use of BCTs for specific groups of people with ID.

Considering the importance of the levels of the ecological model, an integrated and personalized intervention for healthy lifestyle should be developed focusing on intrapersonal, interpersonal, institutional, community, and public policy levels^{37,38}. Based on the promising results reported in this thesis of the training and education program, this program should be a component of such an integrated intervention aiming at improving healthy lifestyle support on the interpersonal level. Health care professionals should be able to compose a personalized intervention because the target group is heterogeneous in terms of degree of ID and, for example, health and motor problems. It should focus on all of the levels of the environment such as the interpersonal role of DSPs and their attitude as well as characteristics of the residential facility.

Recommendations

Education

- Use the training and education program developed in this thesis to include a focus on healthy lifestyle for people with moderate to profound ID in the professional education of DSPs.

Education and Practice

- Create interprofessional collaboration in both professional education and clinical practice to stimulate a learning community in which knowledge and skills are shared, coordinated, and integrated to support a healthy lifestyle for people with moderate to profound ID.

Practice

- Use the training and education program for DSPs to improve healthy lifestyle support that is available at www.dekrachtengebundeld.nl.
- Use BCTs consciously to motivate people with moderate to profound ID for healthy lifestyle behavior.
- Evaluate the attitude of DSPs with the attitude questionnaire in order to offer and adapt interventions meeting the needs of DSPs and as part of continuous improvement of the quality of lifestyle support.

Policy

- Evaluate the competences for DSPs regarding physical activity and healthy nutrition established by the Dutch Association of ID care provider services.
- Provide continuous and specific attention for people with moderate to profound ID to implement healthy lifestyle behavior and education in daily routines.

Future research

- Examine the effectiveness of BCTs for the support of physical activity and healthy nutrition.
- Develop an integrated and personalized intervention focusing on all levels of the ecological model including the training and education program of this thesis.

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