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Lifestyle Opportunities

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Chapter 1

General Introduction

General introduction

An intellectual disability (ID) can be described as limitations both in intellectual and adaptive functioning in the following domains: conceptual, social, and practical adaptive skills. For individuals with ID, the need for support in daily life is dependent on their capacities and development as well as on the level of ID and mobility¹. People with moderate to profound ID require support in several domains, for example, regarding language, motor skills, sensory functioning, and activities for daily living^{1,2}. Additionally, for healthy living, these individuals need support from their environment with regards to a healthy diet and for performing physical activities.

This population generally has low levels of physical activities and often an unhealthy diet^{3,4}. They are more at risk than the general population for an unhealthy lifestyle and the consequences from it⁴⁻⁷. Moreover, they have a higher prevalence for various health problems, for example, constipation and being under- or overweight⁸ which can be aggravated by an unhealthy lifestyle. Improving this for people with moderate to profound ID may consequently have many benefits: it may give them potential health gain⁹, it may also have positive effects on behavior¹⁰, alertness¹¹, and quality of life¹². For example, being more physically active may lead to a decrease of challenging behavior and an increase in quality of life and alertness¹³.

A supportive environment for healthy living

Healthy lifestyle behavior is generally influenced by different factors; on intrapersonal, interpersonal, institutional, community levels; and by public policy from a socio-ecological perspective (see Figure 1)^{14,15}. Similar to the general population, the various levels from the socio-ecological model need to be involved to support healthy lifestyle behavior of people with moderate to profound ID¹⁵. In the Netherlands, these individuals often receive professional support from ID support organizations regarding living and/or work or participate in organized day programming and, therefore, healthy lifestyles should also be an important aim of the support provided on the institutional level. Related to this, professionals working within these ID support organizations play an important role in the lifestyle support for people with moderate to profound ID on the interpersonal level. Social support on this level helps to improve and maintain healthy lifestyle behavior because people with moderate to profound ID need support from people in their environment for almost every aspect of their lives¹⁶. Thus, with respect to a healthy lifestyle of these individuals, the interpersonal level consists, for a major part, of direct support professionals (DSPs). DSPs are crucial in this

respect¹⁶. For example, people with moderate to profound ID depend on the creativity of the DSPs and their input for healthy food choices. For physical activities, they often also need assistance from them. Providing healthy lifestyle support with respect to the autonomy, wishes, and needs of people with moderate to profound ID requires supportive knowledge, skills, and attitudes of these DSPs^{15,17–20}. This thesis focuses therefore on the improvement of the interpersonal support of DSPs regarding the lifestyle support of people with moderate to profound ID.

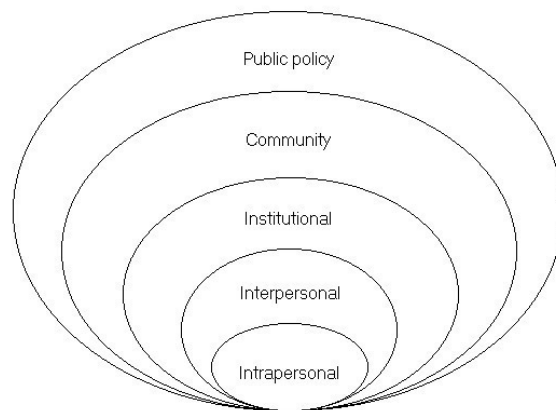


Figure 1 | *Socio-ecological model for health promotion*^{14,15}

Support needs of direct support professionals

DSPs who support people with moderate to profound ID on an interpersonal level require the capability to support a healthy lifestyle which may require DSPs' behavior change in order to optimize the support they provide. In examining and improving their role in the support of healthy lifestyles of persons with moderate to profound ID, we have used the combination of both the Theoretical Domains Framework (TDF) and the COM-B system as a theoretical framework. The TDF is an evidence based framework that is used to gain knowledge about the presence of conditions to support a healthy lifestyle¹⁸. This framework consists of the following 14 domains: (1) Knowledge, (2) Skills, (3) Social/Professional Role and Identity, (4) Beliefs about Capabilities, (5) Optimism, (6) Beliefs about Consequences, (7) Reinforcement, (8) Intentions, (9) Goals, (10) Memory, Attention and Decision Processes, (11) Environmental Context and Resources, (12) Social Influences, (13) Emotion, and (14) Behavioral Regulation¹⁹. The TDF domains can be addressed to influence the behavior of DSPs in their healthy lifestyle support. For changing behavior, it is part of the COM-B system; see Table 1. To implement

healthy lifestyle behavior support of DSPs and thus improve their behavior, the COM-B system explains the nature of behavior with three components: Capability, Opportunity, and Motivation. In this system, Capability is defined as the person’s psychological and physical capacity to perform an activity; Opportunities are external factors outside the individual that influence the performed behavior; and Motivation is the process that energizes and directs a person’s behavior¹⁹.

Table 1 | *Behavior Change Wheel’s COM-B system in relation to the Theoretical Domains Framework determinants*^{18,19}

COM-B		TDF domain
Capability	Psychological	Knowledge Skills Memory, Attention and Decision processes Behavioral regulation
	Physical	Skills
	Social	Social Influences
Opportunity	Physical	Environmental Context and Resources
	Reflective	Social/Professional Role and Identity Beliefs about Capabilities Optimism Beliefs about Consequences Intentions Goals
Motivation	Automatic	Social/Professional Role and Identity Optimism Reinforcement Emotion

According to the TDF, DSPs require knowledge and skills to support people with moderate to profound ID to live healthy. However, DSPs do not seem to be sufficiently equipped to provide healthy lifestyle support^{21,22}. It is important to optimize knowledge and skills of DSPs because insufficiency in these areas are impeding the support to physical activity²³, as well as healthy nutrition²⁴⁻²⁶. To support DSPs, in-depth knowledge about their specific support needs is essential for optimizing their support towards healthy lifestyle behavior for these individuals. Insights into the support needs of DSPs can help ID support organizations to support their staff in following healthy lifestyle policies and guidelines. However, until now, it is not clear which specific knowledge and skills they need.

Behavioral change techniques

With regards to the Capability Domain of the COM-B, one major skill to support a healthy lifestyle is motivating people with ID. To do so and achieve concrete behavior change for people with ID themselves, behavior change techniques (BCTs) can be used by DSPs^{17,27}. BCTs are, for example, someone can 'provide instruction on how to perform the behavior' and explain or demonstrate how to use gym equipment or 'set graded tasks' by breaking target behavior into smaller tasks that are easier to perform¹⁷. BCTs can be used to motivate and stimulate people with ID for healthy lifestyle behavior by DSPs as they have a major influence on this for people with moderate to profound ID. Concrete BCTs that can be used in daily practice are covered in the Coventry Aberdeen London Refined Taxonomy (CALO-RE-NL, a Dutch translation of the original taxonomy). Previous research shows that BCTs can be used in lifestyle interventions and are considered suitable for people with mild ID^{27,28}. Knowledge about the use of BCTs may also be beneficial for supporting DSPs in their work during facilitating healthy lifestyle behavior in persons with moderate to profound ID because BCTs show promising results in persons with mild ID²⁹. However, their use to support healthy living of people with moderate to profound ID has not yet been examined. It is unclear if BCTs are being used to support people with moderate to profound ID and, if so, which techniques are being used and how. Therefore, their current use for this population should be evaluated.

The attitude of direct support professionals

Beside the Capabilities and Opportunities to support a healthy lifestyle, Motivation to perform supportive behavior is also needed. In the Motivation part of the COM-B model, Intentions, Goals, Beliefs about Consequences, and Beliefs about Capabilities are reflective aspects¹⁹. Attitude towards behavior is one of the characteristics that determines intention³⁰ and may also contribute as a mediator to Beliefs about Consequences and Beliefs about Capabilities¹⁹. Attitude is defined as the thoughts and feelings of DSPs regarding a healthy lifestyle³¹. In accordance with previous research³¹, a DSP's positive attitude towards supporting a healthy lifestyle is needed for its implementation and support of persons with moderate to profound ID regarding healthy living^{20,32}. In addition, attitude can be influenced by education^{31,33,34}. However, there is a lack of knowledge about the attitude of DSPs towards a healthy lifestyle. Insights into DSPs' attitudes can be used in the teams of DSPs to cooperate in improving attitudes where necessary and thus improve lifestyle support. In previous research, an attitude questionnaire based on the TDF domains was developed to gain insights into attitudes of DSPs towards supporting healthy physical activity³¹. However, a

questionnaire for them to measure nutrition attitude is lacking. For that reason, an attitude questionnaire regarding supporting healthy nutrition needs to be developed and evaluated with regard to internal validity.

Development and implementation of a program to support direct support professionals

Regarding the COM-B system, DSPs experience that they do not have the Capabilities to support a healthy lifestyle^{24,25,35,36}. Education to support this can improve the capabilities of DSPs and also improves their attitudes^{34,37}. For example, training for them in physical activity support will help develop the necessary knowledge and skills and motivation to support physical activities³⁴. To improve DSPs' support, it is necessary to tailor education to their needs³⁸. Previous research also shows that theory-based interventions are most effective³⁹⁻⁴¹. In these, there is an underlying theory that makes it possible to show a connection between the intervention and the outcomes and thus provides knowledge about why something is effective or not. However, there is currently no such theory-based education lifestyle program available that meets the support needs of the DSPs, and thus this should be developed^{27,33}.

After developing a program, its potential must be examined before widespread implementation can occur³⁸. The potential of an intervention can be examined with a process evaluation and a feasibility study^{42,43}. In a process evaluation, the implementation of a program is followed within the context. For example, the fidelity is monitored to check whether the intervention is delivered as intended. In a feasibility study, the implementation, the acceptability and suitability of the program, and preliminary results can be examined⁴³. Based on an evaluation of the implementation and, consequently, possible improvements of the program, a program can be implemented to overcome the support needs of DSPs to ensure that they are capable of supporting a healthy lifestyle within ID support organizations. Implementation of newly developed interventions is a challenge for ID support organizations due to, for example, the lack of time for implementation^{11,31,44} and lack of continuity in staff¹¹. For successful implementation, these processes and identification of facilitators and barriers need to be mapped in order to improve further implementation processes⁴⁵. However, it is currently unknown what facilitators and barriers for implementing educational lifestyle programs for DSPs are, and it is not established what processes play a role during implementation.

Aim of this thesis

The aim of this thesis is to facilitate a healthy lifestyle for people with moderate to profound ID by improving the lifestyle support provided by DSPs. In this thesis, this will be 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. To achieve the aim of this thesis, DSPs will participate by collaborating as partners in each part of this research and by providing input about their support needs.

Content of the thesis

The first step towards the overarching aim of this thesis is to identify the needs of DSPs for supporting people with moderate to profound ID in order to achieve and maintain a healthy lifestyle; this is addressed in **Chapter 2**. In addition, in **Chapter 3**, the objective is to determine whether and which BCTs are used by DSPs for supporting healthy lifestyle behavior for physical activity and nutrition of people with moderate to profound ID. In **Chapter 4**, the goal is to develop an adapted attitude questionnaire for DSPs towards healthy nutrition of these individuals and to determine the internal validity of this questionnaire. The purpose of **Chapter 5** is to develop a training and education program for DSPs and to describe the design of the evaluation. Subsequently, in **Chapter 6**, the aim is to evaluate the preparation, implementation, and preliminary outcomes of a theory-based training and education program for DSPs in order to learn how to support people with moderate to profound ID in a healthy lifestyle. In **Chapter 7**, the primary findings of this thesis and implications for policy, education, practice, and future research will be discussed.

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