INTEGRATING HEALTH PROMOTION IN EVERYDAY LIFE OF PEOPLE WITH ID - EXTENT TO WHICH CURRENT INITIATIVES TAKE CONTEXT INTO ACCOUNT
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Integrating health promotion in everyday life of people with ID - extent to which current initiatives take context into account
Abstract
Taking the dynamics of everyday life into account is important for health behaviour change. Surveys were conducted to gain insight into available health promoting physical activity and nutrition initiatives in everyday life of people with intellectual disabilities (ID), their characteristics and the attention they give to resources and hindering factors of healthy living for people with ID. The 47 initiatives mostly focused on physical activity and consisted of regularly organized stand-alone activities. Care professionals rather than health professionals were involved. Organizational resources and hindering factors received relatively little attention. Health promotion for people with ID could benefit from incorporating health behaviour into routines of daily living, more attention for organizational resources and collaboration between health and care professionals.

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

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

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

- Which everyday life health promoting initiatives, focusing on physical activity and nutrition, are available to people with ID receiving support from Dutch service providers?
- What are the characteristics of these initiatives, as well as the extent to which these initiatives take into account the context with known resources and hindering factors of healthy living?

Method

Respondents

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

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

**Measures**

A structured questionnaire with pre-defined answers was used to gain information on the initiatives. The questionnaire consisted of two parts (Table 1). Part I was based on general health promotion literature, including criteria for well substantiated and effective interventions
(Centrum Gezond Leven, 2013), and steps in adoption, implementation, sustainability and
evaluation of a program (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). Example
questions of part I are “What is the focus of the initiative?” (answer options: physical
activity/nutrition/both) and “Who executes the activities that are part of the initiative?”
(answer options: family/friend/care professionals providing support in residential settings /
care professionals providing support in day activity settings / personal care professional /
dietician / physiotherapist / remedial therapist / sports instructor / volunteer / other / I don’t
know).

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

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

Insert Table 1 about here

**Procedure**

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

Prior to participation in the telephone survey, respondents were informed about the aim of the study, voluntary participation, estimation of the length of the telephone conversation and anonymity of respondents. Informed consent was obtained verbally (recorded) from all respondents. Only the answers to the structured questions were recorded; personal identifying information of the respondent was not recorded. This study gathered information and opinions of professionals on health promoting initiatives and did not include sensitive, personal data regarding people. Nor did this study influence respondents. This study has been conducted conform the Declaration of Helsinki and did not need ethical approval in The Netherlands as confirmed by the accredited Medical Research Ethics Committee (MREC) (registration number 2018-4977).

Descriptive statistics (SPSS version 20.0) were used to quantitatively describe the answers to the questions of the survey. Answers of the open-ended questions (part I) were quantified based on communalities in the answers. To provide insight into the extent to which
Everyday life ID health promotion

initiatives take into account known resources and hindering factors of healthy living for people with ID, median and mode were calculated for the answers to the questions of part II.

Results

Respondents

In total, 82 employees responded of which 44 (twelve managers/policy makers, fourteen health professionals and eighteen care professionals) were able to provide information on one or more initiatives that met the inclusion criteria. Health professionals who responded were movement teachers (+ two interns), physiotherapists, dieticians, an occupational therapist and a behavioral scientist). These health professionals were active in the initiatives beside their usual professional activities. Figure 1 provides an outline of the response and in- and exclusion of initiatives. Non-response was very low and data collection was extended until all potential respondents were contacted and no new initiatives were mentioned.

Characteristics of the Initiatives

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

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

The majority of the initiatives (n = 37) was offered by the ID service providers themselves, while six were organized by other organizations, such as the municipality. Four initiatives
mentioned collaboration between an ID service provider and another organization in the development and/or implementation of the initiative. Daily care professionals and trainees/volunteers were most often mentioned as executers of the initiatives (in 37 and 18 initiatives respectively), while health professionals (e.g., physiotherapists, sport instructors, movement teachers, dieticians) were mentioned 22 times. Invitations to participate came from daily care professionals (n = 33) through personal contact. Newsletters or emails were also used. For 15 initiatives, mainly physical activities at external venues such as the gym, swimming pool or sports club, the participants needed to pay in order to participate.

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

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

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

Table 2 shows the extent to which the initiatives gave attention to resources and hindering factors of healthy living. The N in Table 2 varies due to respondents choosing the 'I don't know' option. For two factors, financial situation on the individual level and transport options on the physical environment and community level, more than 70% of the respondents chose the 'I don't know' option. These factors were not included in the analysis.

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

Existing norms and values in the living environment (physical environment and community level) also scored relatively low. When differentiating for level of ID of the targeted audience, the more severe the level of ID, the less attention was given to knowledge and preference of the participant.

Discussion

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

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

Individual factors, such as disabilities and support needs, received much attention in the organization of the initiatives which helps to increase the accessibility (Kuijken et al., 2016). The knowledge on healthy living of people with ID themselves, however, received little attention. People with mild to moderate ID do have knowledge on healthy living, but have trouble translating this knowledge into behaviour and therefore need others to support them (Kuijken et al., 2016). Attention for their knowledge can help to tailor the initiative to their level of knowledge and to support participants adequately to apply this knowledge in everyday life.

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

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

Our study is one of the first studies providing insight into the characteristics of current everyday life health promotion for people with ID. Since the included service providers provide different types of support to people with ID in three different regions of the Netherlands, we think this study included a representative sample of employees in support for people with ID and of health promoting initiatives that are offered to people with ID in the Netherlands. It is, however, important to recognize that our findings are based on the organization and use of health promotion initiatives within Dutch service providers. The enthusiasm of the respondents about the initiatives might have led to a positive bias. However,
their close involvement in the initiatives ensured rich information. Validity was enhanced by:

- using telephone surveys to minimise interviewer effects (Phellas, Bloch, & Seale, 2011);
- allowing clarification (Jones, Baxter, & Khanduja, 2013), and data triangulation by cross checking with available documentation.

### Conclusion

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

References


Figure legends:

Figure 1: Flowchart of response and in- and exclusion of initiatives
### Table 1: Overview of themes, question topics and answer options of the questionnaire

<table>
<thead>
<tr>
<th>Theme</th>
<th>Questions on (answer options)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Part I Characteristics of the initiative</strong></td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>• Focus (physical activity/nutrition/both)</td>
</tr>
<tr>
<td></td>
<td>• Name of the initiative (open-ended)</td>
</tr>
<tr>
<td></td>
<td>• Aim (open-ended)</td>
</tr>
<tr>
<td></td>
<td>• Location (open-ended)</td>
</tr>
<tr>
<td></td>
<td>• Activities (open-ended)</td>
</tr>
<tr>
<td>Organizational</td>
<td>• Type of initiative (regular/project)</td>
</tr>
<tr>
<td></td>
<td>• Costs for people with ID to participate (yes/no)</td>
</tr>
<tr>
<td></td>
<td>• People with ID are invited to participate by (care professionals providing support in residential settings / care professionals providing support in day activity settings / personal care professional / dietician / physiotherapist / movement teacher / legal representative / across the organization / without involvement of the organization/other)</td>
</tr>
<tr>
<td></td>
<td>• Initiative is executed by (family/friend/care professionals providing support in residential settings / care professionals providing support in day activity settings / personal care professional / dietician / physiotherapist / remedial therapist / sports instructor / volunteer / other / I don’t know)</td>
</tr>
<tr>
<td></td>
<td>• Involvement of participants in development of the initiative (yes/no/I don’t know)</td>
</tr>
<tr>
<td></td>
<td>• Promotion of the initiative (open-ended)</td>
</tr>
<tr>
<td></td>
<td>• Type of involvement of participants in development of the initiative (open-ended)</td>
</tr>
<tr>
<td>Targeted audience</td>
<td>• Type of targeted audience (individual/group/social environment of people with ID)</td>
</tr>
<tr>
<td></td>
<td>• Level of ID (mild/moderate/severe/profound)</td>
</tr>
<tr>
<td></td>
<td>• Sensory impairments (yes/no/partly/I don’t know)</td>
</tr>
<tr>
<td></td>
<td>• Physical impairments (yes/no/partly/I don’t know)</td>
</tr>
<tr>
<td></td>
<td>• Age (0–12 / 13–18 / 18–40 / 40–60 / 60+ / I don’t know)</td>
</tr>
<tr>
<td></td>
<td>• Residential status (independent / independent with ambulatory support / with family / 24-hours care (with or without treatment))</td>
</tr>
<tr>
<td></td>
<td>• Level of support needed to participate (no/some/tailored support)</td>
</tr>
<tr>
<td>Participation in the initiative</td>
<td>• How often people participate (daily / 1–3 times a week / weekly / 2 times a month / monthly / 1–4 times a year / yearly / once)</td>
</tr>
<tr>
<td></td>
<td>• How long people participate per time (0–15 / 15–30 / 30–45 / 45–60 / 60–90 / &gt;90 minutes)</td>
</tr>
<tr>
<td></td>
<td>• Average number of participants per time (open-ended)</td>
</tr>
<tr>
<td></td>
<td>• Total number of participants (open-ended)</td>
</tr>
<tr>
<td><strong>Part II Extent to which initiatives give attention to factors related to healthy living</strong></td>
<td></td>
</tr>
<tr>
<td>Individual level</td>
<td>• Motivation (0/1/2/3/4/5/I don't know, accounts for all factors below)</td>
</tr>
<tr>
<td></td>
<td>• Preference</td>
</tr>
<tr>
<td></td>
<td>• Knowledge</td>
</tr>
<tr>
<td></td>
<td>• Level of ID</td>
</tr>
<tr>
<td></td>
<td>• Physical disabilities</td>
</tr>
<tr>
<td></td>
<td>• Support needed to participate</td>
</tr>
<tr>
<td></td>
<td>• Financial situation</td>
</tr>
<tr>
<td>Interpersonal level</td>
<td>• Emotional support</td>
</tr>
<tr>
<td></td>
<td>• Instrumental support</td>
</tr>
<tr>
<td></td>
<td>• Informational support</td>
</tr>
</tbody>
</table>
Everyday life ID health promotion

- Appraisal support

Organizational level
- Time and money provided by organization
- Communication between employees
- Knowledge and skills of employees
- Information for employees

Physical environment and community level
- Transport options
- Level of stress and safety in environment
- Norms and values
- Facilities

Table 2: The extent to which initiatives give attention to factors related to healthy living, categorized into four levels of the socio-ecological model (n = 47)

<table>
<thead>
<tr>
<th>Level of socio-ecological model</th>
<th>Resource or hindering factor of healthy living</th>
<th>N</th>
<th>Median</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td>Level of ID</td>
<td>43</td>
<td>5.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Physical disabilities</td>
<td>39</td>
<td>5.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Support needed to participate</td>
<td>44</td>
<td>5.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Preference</td>
<td>41</td>
<td>5.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Motivation</td>
<td>41</td>
<td>4.0</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Knowledge</td>
<td>35</td>
<td>3.0</td>
<td>3</td>
</tr>
<tr>
<td>Interpersonal</td>
<td>Emotional support</td>
<td>39</td>
<td>5.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Instrumental support</td>
<td>37</td>
<td>5.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Appraisal support</td>
<td>33</td>
<td>4.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Informational support</td>
<td>36</td>
<td>4.0</td>
<td>5</td>
</tr>
<tr>
<td>Organizational</td>
<td>Knowledge and skills of employees</td>
<td>42</td>
<td>4.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Communication between employees</td>
<td>43</td>
<td>4.0</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Information for employees</td>
<td>44</td>
<td>3.0</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Time and money provided by organization</td>
<td>40</td>
<td>3.0</td>
<td>3</td>
</tr>
<tr>
<td>Physical environment and community level</td>
<td>Level of stress and safety in environment</td>
<td>39</td>
<td>4.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Facilities</td>
<td>42</td>
<td>4.0</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Norms and values</td>
<td>34</td>
<td>3.5</td>
<td>4</td>
</tr>
</tbody>
</table>
Number of participants is different from number of initiatives as some participants could provide information on more than one initiative.

Inclusion criteria were not met for 39* initiatives, due to which 38* respondents could not participate. These initiatives focused on other topics than physical activity and/or nutrition, or were aimed at registration of physical activity instead of implementation of physical activity.

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