

INTEGRATING HEALTH PROMOTION IN EVERYDAY LIFE OF PEOPLE WITH ID -
EXTENT TO WHICH CURRENT INITIATIVES TAKE CONTEXT INTO ACCOUNT
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Acknowledgements

This manuscript was orally presented at the 15th IASSIDD World Congress *Global, Partnerships: Enhancing Research, Policy and Practice*, Melbourne, 15-19 August 2016.

This study was funded by academic collaborative 'Stronger on your own feet' in which the Radboud university medical center collaborates with nine service providers for people with ID. The authors have no conflicts of interest to declare. The authors are very grateful to all respondents for their help in obtaining an overview of available health promoting initiatives.

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

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6

7 **Abstract**

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

18

19 **Keywords**

20 Intellectual disabilities; health education and promotion; health behaviour change; everyday
21 life perspective.

22

23 **Introduction**

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

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

48 the public policy level, including health policies and insurance systems (Sundblom et al.,
49 2015).

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

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

65

66 Method

67

68 Respondents

69 **Setting.** This study was performed within the setting of service providers providing
70 ambulatory support (intermittent support based on a needs assessment given to people who
71 live (semi-)independently), day support (weekly support provided during scheduled daytime
72 hours, including recreational or (un)paid labor activities) and 24-hour support in small-scale

73 accommodations to people with ID in the Netherlands. Recent national government
74 regulations lead to increasingly more people with ID living (semi-)independently in the
75 community. In the Netherlands, people with ID – varying from mild to profound – are mainly
76 supported by daily care professionals who are trained in social work and/or assistant nursing.
77 Tasks include assisting people with ID in personal, daily, social and health care (Heutmekers
78 et al., 2016).

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

91

92 *Insert Figure 1 about here*

93

94 **Measures**

95 A structured questionnaire with pre-defined answers was used to gain information on the
96 initiatives. The questionnaire consisted of two parts (Table 1). Part I was based on general
97 health promotion literature, including criteria for well substantiated and effective interventions

98 (Centrum Gezond Leven, 2013), and steps in adoption, implementation, sustainability and
99 evaluation of a program (Bartholomew, Parcel, Kok, Gottlieb, & Fernandez, 2011). Example
100 questions of part I are “*What is the focus of the initiative?*” (answer options: physical
101 activity/nutrition/both) and “*Who executes the activities that are part of the initiative?*”
102 (answer options: family/friend/care professionals providing support in residential settings /
103 care professionals providing support in day activity settings / personal care professional /
104 dietician / physiotherapist / remedial therapist / sports instructor / volunteer / other / I don’t
105 know).

106 Part II was based on literature describing the resources and hindering factors of healthy
107 living for people with ID (Bergstrom et al., 2014; Brooker et al., 2015; Caton et al., 2012;
108 Kuijken et al., 2016; Sundblom et al., 2015) and the socio-ecological model (Rimer & Glanz,
109 2005). The public policy level of the socio-ecological model was not included in this study,
110 since the focus of this study was if and how service providers for people with ID provide
111 health promoting initiatives. This could have been by working together with public initiatives.
112 Public policy is a more overarching level, in which the facilitating or hindering factors
113 influence the instigation of initiatives rather than the execution of provided initiatives within
114 service providers.

115 The questions of part II were measured on a 6-point summated rating scale, 0 being
116 *strongly disagree* and 5 *strongly agree* (Jamieson 2004). An even scale was chosen to avoid
117 neutral responses and an ‘I don’t know’ option was included to avoid guessing. Example
118 questions of part II are “*To what extent does the initiative take into account physical*
119 *disabilities of participants of the initiative?*” and “*Do the executers of the initiative have*
120 *enough knowledge and skills to execute the initiative?*”. A pilot survey was conducted among
121 three employees of the service providers to check for possible misinterpretation of the

122 questions. As this resulted in only small amendments, it was decided to include the rich
123 information of this pilot in the analyses.

124

125 *Insert Table 1 about here*

126

127 **Procedure**

128 Telephone surveys among employees were used to collect data between March and June
129 2015. During each telephone conversation the researcher (..) entered the answers to the survey
130 questions into an online survey application (Lime-Survey). In the main time the conversation
131 was audio recorded for future reference and validation of the survey answers, after which the
132 audiotapes were destroyed. To increase validity, clarification was allowed and available
133 documentation of initiatives was cross-checked with survey answers.

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

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

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

149

150 **Results**

151 **Respondents**

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

160

161 **Characteristics of the Initiatives**

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

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

170 The majority of the initiatives (n = 37) was offered by the ID service providers themselves,
171 while six were organized by other organizations, such as the municipality. Four initiatives

172 mentioned collaboration between an ID service provider and another organization in the
173 development and/or implementation of the initiative.

174 Daily care professionals and trainees/volunteers were most often mentioned as
175 executors of the initiatives (in 37 and 18 initiatives respectively), while health professionals
176 (e.g., physiotherapists, sport instructors, movement teachers, dieticians) were mentioned 22
177 times. Invitations to participate came from daily care professionals (n = 33) through personal
178 contact. Newsletters or emails were also used. For 15 initiatives, mainly physical activities at
179 external venues such as the gym, swimming pool or sports club, the participants needed to pay
180 in order to participate.

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

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

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

196

197 **Attention to Resources and Hindering Factors**

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

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

216

217 *Insert Table 2 about here*

218

219 **Discussion**

220 Most of the 47 identified initiatives were individually oriented and consisted of stand-
221 alone activities organized on a regular basis. This shows a lack of attention for healthy

222 behaviour in the everyday life of people with ID, which is in line with Steenbergen et al.
223 (2017). Taking an everyday life perspective in health promotion and incorporating health
224 behaviour into routines of daily living, while including the social environment of people with
225 ID, may be much more effective (Van Woerkum & Bouwman, 2014).

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

235 Individual factors, such as disabilities and support needs, received much attention in
236 the organization of the initiatives which helps to increase the accessibility (Kuijken et al.,
237 2016). The knowledge on healthy living of people with ID themselves, however, received
238 little attention. People with mild to moderate ID do have knowledge on healthy living, but
239 have trouble translating this knowledge into behaviour and therefore need others to support
240 them (Kuijken et al., 2016). Attention for their knowledge can help to tailor the initiative to
241 their level of knowledge and to support participants adequately to apply this knowledge in
242 everyday life.

243 Organizational resources and hindering factors such as provided time and money
244 received little attention, which impedes profound embedment within organizational structures
245 and routines. The frequent use of trainees and volunteers as executers of initiatives might
246 impede sustainability of the initiatives as well, as they often work temporarily in an

247 **organization.** Next to that, daily care professionals **were often involved, while** support from
248 health professionals in the implementation of initiatives **was lacking.** Though daily care
249 professionals are in a good position to support people with ID **in everyday life,** their
250 knowledge and skills regarding promotion of healthy behaviour are limited (Cardol, Rijken, &
251 van Schrojenstein Lantman-de Valk, 2012; Leser, Pirie, Ferketich, Haverkamp, & Wewers,
252 2018; Sundblom et al., 2015). Health professionals do have the necessary knowledge and
253 skills to activate people and support good dietary habits (Hilgenkamp, 2012; Van Riper &
254 Wallace, 2010). This implies that health professionals should be more involved in health
255 promotion efforts for people with ID (Van Schijndel-Speet, Evenhuis, Van Wijck, Empelen,
256 & Echteld, 2014), however, our study indicates that health professionals are only marginally
257 involved in prevention of health problems by means of health promotion.

258 For people with ID, everyday life in residential and day activity settings often takes
259 place in groups (Ras et al., 2013). More attention to existing norms and values among peers
260 and professionals is therefore important (Van Woerkum & Bouwman 2014). Additional to
261 individually oriented activities, lifestyle interventions at the group level could be more
262 effective, as they benefit from modelling and social support (Heller, Fisher, Marks, & Hsieh,
263 2014; Van Schijndel-Speet, Evenhuis, van Wijck, & Echteld, 2014).

264 Our study is one of the first studies providing insight into the characteristics of current
265 everyday life health promotion for people with ID. Since **the included service providers**
266 **provide different types of support** to people with ID in three different regions of the
267 Netherlands, we think this study included a representative sample of employees in **support** for
268 people with ID and of health promoting initiatives that are offered to people with ID in the
269 Netherlands. It is, however, important to recognize that our findings are based on the
270 organization and use of health promotion initiatives within Dutch service providers. The
271 enthusiasm of the respondents about the initiatives might have led to a positive bias. However,

272 their close involvement in the initiatives ensured rich information. Validity was enhanced by:
273 using telephone surveys to minimise interviewer effects (Phellas, Bloch, & Seale, 2011);
274 allowing clarification (Jones, Baxter, & Khanduja, 2013), and data triangulation by cross
275 checking with available documentation.

276

277 **Conclusion**

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

288

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388 **Figure legends:**

389 **Figure 1: Flowchart of response and in- and exclusion of initiatives**

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392 **Table 1: Overview of themes, question topics and answer options of the questionnaire**

Theme	Questions on (answer options)
<i>Part I Characteristics of the initiative</i>	
General	<ul style="list-style-type: none"> • Focus (physical activity/nutrition/both) • Name of the initiative (open-ended) • Aim (open-ended) • Location (open-ended) • Activities (open-ended)
Organizational	<ul style="list-style-type: none"> • Type of initiative (regular/project) • Costs for people with ID to participate (yes/no) • 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) • 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) • Involvement of participants in development of the initiative (yes/no/I don't know) • Promotion of the initiative (open-ended) • Type of involvement of participants in development of the initiative (open-ended)
Targeted audience	<ul style="list-style-type: none"> • Type of targeted audience (individual/group/social environment of people with ID) • Level of ID (mild/moderate/severe/profound) • Sensory impairments (yes/no/partly/I don't know) • Physical impairments (yes/no/partly/I don't know) • Age (0–12 / 13–18 / 18–40 / 40–60 / 60+ / I don't know) • Residential status (independent / independent with ambulatory support / with family / 24-hours care (with or without treatment)) • Level of support needed to participate (no/some/tailored support)
Participation in the initiative	<ul style="list-style-type: none"> • How often people participate (daily / 1–3 times a week / weekly / 2 times a month / monthly / 1–4 times a year / yearly / once) • How long people participate per time (0–15 / 15–30 / 30–45 / 45–60 / 60–90 / >90 minutes) • Average number of participants per time (open-ended) • Total number of participants (open-ended)
<i>Part II Extent to which initiatives give attention to factors related to healthy living</i>	
Individual level	<ul style="list-style-type: none"> • Motivation (0/1/2/3/4/5/I don't know, accounts for all factors below) • Preference • Knowledge • Level of ID • Physical disabilities • Support needed to participate • Financial situation
Interpersonal level	<ul style="list-style-type: none"> • Emotional support • Instrumental support • Informational support

- Appraisal support

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

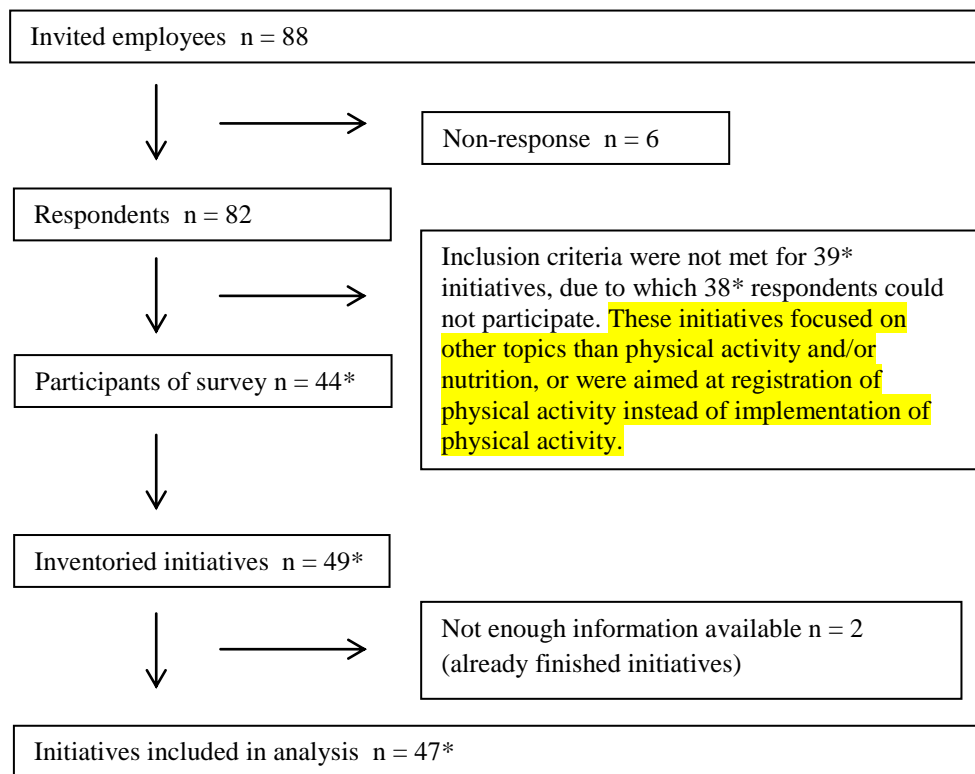
- Physical environment and community level**
- Transport options
 - Level of stress and safety in environment
 - Norms and values
 - Facilities

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

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

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