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Promoting Independence of People with Intellectual Disabilities: A Focus Group Study Perspectives from People with Intellectual Disabilities, Legal Representatives, and Support Staff

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Abstract

People with intellectual disabilities (ID) commonly struggle with managing their affairs, while they consider it important to be independent. This study aimed to gain insight into the perspectives of people with ID, legal representatives, and support staff on promoting independence in this population. Two focus groups were conducted with people with ID (n = 7), two with legal representatives (n = 13), and three with support staff (n = 17). Topics included the meaning of independence, the current level and needs of people with ID regarding their independence, and what they perceived as barriers and requirements when wanting to promote independence in this group. Possible outcomes of a greater independence of people with ID were also discussed. Verbatim transcripts were analyzed qualitatively with a general inductive approach. According to the respondents, people with ID require support from others, but most want to be more independent. Various barriers are experienced when trying to promote independence. These concern barriers at the level of support staff (e.g., lack of time), family (e.g., taking over tasks), and of the persons with ID themselves (e.g., emotional difficulties). When promoting independence in this population, more support and time seem necessary, as well as a clear, step-by-step tailored approach and good communication between all parties involved. Last, several advantages (e.g., greater self-worth) and risks (e.g., overestimation by others, greater exposure to hazards) were proposed that could result from a greater independence of people with ID. As this study showed that people with ID generally want to become more independent. This stresses the need for the development of interventions, which could benefit from the findings from this study.

Keywords: focus group, independence, intellectual disabilities, self-management, self-reliance

Background

Most people with intellectual disabilities (ID) struggle with managing their affairs independently (Ramdoss et al., 2012; Sigafoos et al., 2005) and are therefore often at least somewhat dependent on the support from family and care staff (Hale, Trip, Whitehead, & Conder, 2011; Vilaseca et al., 2017). The struggles of people with ID can range from difficulties with personal care and household activities, to trouble with community participation and employment (Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011; Ramdoss et al., 2012; Smith, Shepley, Alexander, & Ayres, 2015). However, being independent is valued by people with ID (Kuijken, Naaldenberg, Nijhuis-van der Sanden, & Van Schrojenstein-Lantman de Valk, 2016) and a greater level of independence has been related to increased feelings of happiness and satisfaction (Haigh et al., 2013) and higher quality of life (Dollar, Fredrick, Alberto, & Luke, 2012; Sigafoos et al., 2005).

The United Nations (2006) have declared that people with ID should be enabled to live as independently as possible. Several countries are urging all their citizens to do as much as possible themselves. For example, in the Netherlands a recent shift has taken place from a "welfare state," in which the government is primarily responsible for citizens' well-being, to a "participation society," where people first have to take more care of themselves and their network, before they can turn toward

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governmentally provided care. In relation to this, the Dutch mental health care system has experienced many changes, cuts, and savings over the past couple of years, and support staff experience increasing difficulties to meet the care needs of their clients (Hermsen, Embregts, Hendriks, & Frielink, 2014). This all stresses the importance of fostering independence in people with ID.

Independence, just as self-reliance,[1] is a term that involves the abilities to take actions to manage one's affairs and to provide for oneself. This entails relying on one's own efforts, resources, judgment, and abilities, without requiring support from others (Sandjojo et al., in press). Both independence and self-reliance can be regarded as a part of self-management, which refers to a variety of activities related to deliberately changing or maintaining behaviors to achieve self-selected outcomes (Browder & Shapiro, 1985). Self-management thus also includes self-determination, which has been described as the volitional actions that enable one to act as the primary causal agent in one's life, thereby having personal control over one's choices and actions (e.g., Sexton, O'Donovan, Mulryan, McCallion, & McCarron, 2016; Shogren et al., 2015; Wehmeyer, Kelchner, & Richards, 1996). Independence can be seen as a continuum, with total dependence at one end and complete independence at the other extreme (Aldridge, 2010). No one is completely independent in all areas, which also goes for people with ID. However, one can aim at guiding people with ID toward the most optimal level of independence that is attainable for an individual.

Little research has focused on how to promote the overall level of independence in people with ID. Previous studies mostly focused on teaching specific skills, such as setting the table (Cannella-Malone et al., 2006), extinguishing a fire (Mechling, Gast, & Gustafson, 2009), withdrawing cash (Davies, Stock, & Wehmeyer, 2003), and grocery shopping (Bouck, Satsangi, & Bartlett, 2017). Many of these previous studies had small sample sizes, no control group, and widely varying goals, designs, and outcome measures (Dannenberg, Mengoni, Gates, & Durand, 2016; Ramdoss et al., 2012; Storey, 2007). This makes it difficult to draw firm conclusions about which intervention elements are critical for effectiveness. Nevertheless, Storey (2007) concludes from his review that interventions need to be tailored to the individuals' specific needs and context. This finding is supported by several qualitative studies on self-management of illness and health in people with ID (Hale et al., 2011; Kuijken et al., 2016; Young, Naji, & Kroll, 2012). Several ways of tailoring to people with ID are suggested: providing information visually, using easy-to-understand language, and ensuring sufficient time and repetition. It is also claimed that the promotion of self-management needs to be embedded in an ongoing, lifelong form of education and support (Hale et al., 2011). Lastly, it is suggested that it is also important to involve relatives and professional careers who support people with ID in their self-management process (Hale et al., 2011; Young et al., 2012).

To tailor interventions effectively, insight is needed into the preferences, and resources of people with ID, and their individual, interpersonal, and environmental barriers (Bartholomew, Parcel, Kok, Gottlieb, & Fernández, 2011; Kuijken et al., 2016). Although the abovementioned studies (Hale et al., 2011; Kuijken et al., 2016; Storey, 2007; Young et al., 2012) provide some important clues, when it comes to promoting the overall level of independence of people with ID still too little is known about these issues. To create a better understanding of how to promote independence in people with ID, perspectives need to be obtained from those whom it concerns the most, which are people with ID (Hale et al., 2011; Young et al., 2012) and those who support them (Totsika, Toogood, Hastings, & Nash, 2008), that is, their legal representatives and support staff. The first aim of our study was to explore what these three groups of respondents regarded as "independence" and what they considered to be the current level and needs of people with ID regarding this domain. Second, the aim was to gain insight into which barriers respondents experienced when wanting to promote independence and what they perceived as requirements for increasing the level of independence among people with ID. Lastly, we aimed to examine what respondents thought could be possible advantageous and disadvantageous outcomes of people with ID having a greater level of independence.

Method

This study was the first to obtain the perspectives of people with ID, their legal representatives, and support staff on various topics that concern the promotion of independence in people with ID. These three different viewpoints of the most relevant stakeholders were included to create a broad perspective on the theme of "independence." Perspectives were collected by conducting focus groups, which were held separately for the three different groups of respondents to ensure everyone felt free to speak their minds, without having to worry what respondents from the other groups might think.

Ethical Issues

The Medical Ethics Committee of the Leiden University Medical Center evaluated the study protocol and declared that neither formal medical ethical approval, nor written informed consent was required (registration number P15.037, P15.300, P16.268).

Recruitment of Participants

Three different participant groups were approached: people with ID, and legal representatives and support staff of people with ID. All participants were recruited at Raamwerk, a care organisation for people with ID in Noordwijkerhout, the Netherlands. The participants with ID were living in one of the community-based

[1]**Endnotes**

We used only one Dutch term ("zelfredzaamheid") in our focus groups, which translates into both independence and self-reliance. In this article, we will use the term independence, whereas the term self-reliance could be used as well.

residential facilities of Raamwerk, received day care at Raamwerk, or both. They were previously diagnosed with an ID, based on the criteria from the fourth edition of the Diagnostic and Statistical Manual of mental disorders (American Psychiatric Association, 2000).

For the recruitment of people with ID, support staff helped to select adults who had sufficient language abilities and who did not have severe behavioral or emotional problems that would make participation too demanding for them. Fourteen people with ID were eligible, who were all informed about the study by their personal tutor. Nine agreed to participate. If they had a legal representative, this person was informed and asked for verbal informed consent as well by phone. Representatives were also sent an information letter in which the purpose and the procedure of the focus group were explained again. Participants with ID received a similar, but more accessible letter with shorter sentences containing easy-to-understand information. Textual information was supported by pictograms and in addition, photos were displayed to introduce the moderator and the primary researcher who would attend the focus group. Providing accessible information was previously reported as a good practice method for inclusive research with people with ID (Frankena, Naaldenberg, Cardol, Linehan, & Lantman-de Valk, 2015). For the focus groups with legal representatives and support staff, we contacted all people who were representing or supporting a person with ID who participated in an earlier study (Sandjojo et al., in press). Legal representatives were approached by phone and support-staff were informed during team meetings. Both staff from group homes as well as from day care services were approached and asked to participate on a voluntary basis, which they were allowed to do during work hours.

Participants

Although nine people with ID agreed to participate, one was unable to attend due to illness and another person forgot the appointment. Thus in total, seven people with ID participated. One participant lived in a group home and the other six lived semi-independently in their own apartment with ambulatory support. Information about their level of ID was obtained from their electronic client records. Two participants had borderline ID and the other five had mild ID.

The 13 participating legal representatives supported adults with ID. Almost all were relatives of the person they were representing, except for one professional mentor who was appointed by the court. Based on the electronic client records it was found that one participant represented a person with a borderline ID, nine represented persons with mild ID, two represented persons with moderate ID, and one represented a person with moderate to severe ID. Four legal representatives were relatives of participants with ID who also took part in this study.

The 17 participating support staff members all worked with adults with ID, either in group homes or in day care services that were intended for people with borderline to moderate ID, with the majority of clients being previously diagnosed with mild ID. Eleven staff members supported someone with ID who also participated in this study. All staff members worked several days per week with people with ID. Their years of work experience with people with ID varied from 5 to 33 years (M = 15.13; SD = 9.28).

Data Collection

As this study was conducted in collaboration with Raamwerk, data collection took place at this location. Two focus groups were held separately for people with ID, two for legal representatives, and three for support staff. Participants were distributed based on their availability and with the group size in mind (Krueger & Casey, 2015). All focus groups lasted about two hours. They were chaired by an independent moderator with ample experience in the field of ID who was not acquainted with the participants (JH or TJ). The primary researcher (JS) observed all meetings, but did not actively participate. Prior to all focus groups, participants were informed that the discussion would be audio-recorded and that the data would be handled anonymously and confidentially. Verbal informed consent was obtained from all participants. No incentive was given for participation. Each focus group started with an introduction round. The moderator then continued with a semistructured discussion with open-ended questions and participants were encouraged to actively share their own opinions and to respectfully respond to each other. The focus group topics were selected by a group of experts, including researchers and employees of Raamwerk, during several earlier discussions. Topics were chosen based on questions we would like to have answered that would aid the design of interventions that promote independence in people with ID. The discussion topics included the definition of independence, the current level and needs of people with ID regarding their independence, experienced barriers and requirements when promoting independence in this population, and possible advantageous and disadvantageous outcomes of a greater independence. More details about the discussed topics can be found in Appendix A.

The focus groups with participants with ID were slightly adapted, based on good practice methods for inclusive research (Frankena et al., 2015). Accessible language was used and questions were printed in a booklet, in which also pictograms, illustrations, and photos were used to visually represent the questions. For example, a pictogram of a tape recorder was used to explain that the focus group would be recorded and an image of a wall that blocked someone's way was used to illustrate the topic of barriers. This adapted method was first piloted with two people with ID, who did not take part in the focus groups. This pilot indicated that no further adaptations were necessary. During the focus group discussions with participants with ID, responses were written on a flipchart and were repeated and summarized from time to time.

Data Analysis

All focus groups were transcribed verbatim. Data analysis was facilitated by ATLAS.ti 7.5.6 software. The separate

topics of the focus group discussions served as a framework for the analysis (Appendix B). Two coders (JS together with AvR or MG) independently listened to the recordings, while reading and coding the transcripts. For everything that was said, coders evaluated to which topic this was related, what the essence of the quote was, and what code would fit best. For example, the quote "I think that when you're more independent, you feel more confident about yourself" related to the topic of "advantages," concerned the theme "feelings," and was assigned the code "self-confidence." After coding all the focus groups, discrepancies between codes were discussed until consensus was reached. The discussion entailed that both coders gave arguments as to why they assigned a certain code. In case disagreement remained, a senior researcher (WG) was asked to participate in the discussion and to make a final decision. The definitive codes of all focus groups were analyzed with a general inductive approach (Thomas, 2006) where main themes were inductively derived from the data by looking at how extensively they were discussed. For some themes, subthemes emerged. For example, the quote "We have the feeling support staff have too few opportunities to support us" belonged to the main theme of "barriers at the level of support staff," and more specifically to the subtheme "lack of time." To compare the results from the three different groups of participants, we analyzed what the extensively reported (sub)themes were for each of the groups and whether these differed from those reported by the other groups. To ensure the robustness of our analysis, we also crosschecked for each (sub)theme that emerged by which group of participants this was put forward.

Results

Participants

The characteristics of the composition of the seven focus groups are presented in Table 1.

TABLE 1
Characteristics of the focus groups

	Group size, *n* (*n male*)	**Age in years, range (*M; SD*)**
People with ID no. 1	4 (*3*)	26.6–64.1 (*40.4; 16.9*)
People with ID no. 2	3 (*3*)	27.9–29.9 (*29.1; 1.1*)
Legal representatives no. 1	8 (*4*)	51.1–85.1 (*66.0; 10.8*)
Legal representatives no. 2	5 (*3*)	51.7–64.8 (*57.4; 5.1*)
Support staff group homes no. 1	4 (*0*)	24.2–53.1 (*37.1; 12.4*)
Support staff group homes no. 2	8 (*2*)	24.1–51.4 (*37.7; 11.5*)
Support staff day care	5 (*3*)	25.4–50.2 (*34.0; 10.5*)

Results of the Focus Groups

The results are discussed per topic and for the entire sample as a whole, as there were few differences between the perspectives of the three different groups of respondents. The emerged themes that were most extensively discussed by all three groups of respondents are described first. Wherever applicable, it is specified when only one or two groups of respondents put forward a particular theme. The topics that were addressed concerned the conceptualization of the term independence, the current level of independence of people with ID, the needs of people with ID regarding their independence, the experienced barriers and the requirements when wanting to promote independence in this population, and the advantageous and disadvantageous outcomes of people with ID having a greater level of independence. The derived themes and subthemes can be found in Appendix B. In Appendix C, several illustrative quotes are listed per topic.

Concept of Independence

The first topic concerned what participants understood as "independence." All three groups of respondents expressed that independence is a broad concept, covering various aspects. It encompasses knowledge about how to do things, the abilities to perform actions, and taking care of oneself. Many participants stated that independence means doing things yourself. However, some viewed that being independent also means asking for help if you cannot do something yourself. Several participants with ID also talked about managing one's time and appointments. Legal representatives furthermore considered that independence means drawing boundaries regarding what you want and do not want, and what you can and cannot handle.

Level of Independence

The level of independence of people with ID was reported to be highly variable. Some need help with basic Activities of Daily Living (ADL), whereas others can live independently with only some ambulatory support. It was agreed by all groups of participants that all people with ID need at least some support. However, various skills were described as well, for example concerning household activities, personal hygiene, and grocery shopping. In addition, legal representatives and support staff stated that the level of independence of the people they were supporting was already increasing and that they constantly notice a development in skills. They also felt that there was still a lot of room for growth for people with ID to develop a lot of skills.

Independence-Related Desires

Participants with ID, legal representatives, and support staff agreed that most people with ID have the desire to become

more independent. When asked what they would want to learn, various things were proposed. In general, it was said that people with ID just want to lead the "normal" life of other people their age and that they want to live independently. Several specific needs, such as obtaining a driver's license were also described. Some participants with ID considered in addition that they would like to learn to better deal with their emotions and to obtain a regular employment, where they can work independently. On the contrary, support staff indicated that a few of their clients do not feel the need to become more independent as they like being taken care of.

Barriers and Requirements

Among all participants, a lack of time for support staff was one of the most frequently discussed barriers that hinder people with ID from becoming more independent. If staff members do not have sufficient time, they are more easily inclined to take over tasks from people with ID, because they can do it faster themselves. However, if they have more time they could use this to teach people with ID new skills. Legal representatives put forward another barrier concerning support staff, which is that staffs sometimes lack the knowledge and skills on how to properly guide people with ID. Representatives also expressed that the high turnover of staff is a barrier. Additional barriers mentioned by staff members are fear among staff that things could go wrong if people with ID do more independently and staff having the tendency to take over tasks from clients.

Barriers at the level of the family were also identified, mostly by support staff. Family members can be controlling and also tend to take over things that people with ID could learn to do themselves. At the level of the person with ID, barriers mostly concern difficulties in emotional and cognitive functioning. For example, anxiety, sadness, or a lack of concentration can make it more difficult for someone with ID to become more independent. Lastly, the situation a person with ID is currently in and whether there are already many changes going on might also hamper someone from becoming more independent as such a situation might already be too overwhelming.

Several requirements for promoting the level of independence of people with ID were identified. The necessity of more time and support (staff) was put forward by all three groups of respondents, as this would create more opportunities to guide people with ID towards a greater level of independence. A clear, univocal approach and adequate communication were almost exclusively put forward by legal representatives and support staff. They stated that all staff and family members must be in line with each other on how to support a person with ID in becoming more independent, which requires sufficient communication, also with the person with ID. Moreover, legal representatives and support staff claimed that a tailored, individualized, step-by-step plan is required. This means, among others, adapting to an individual's level of functioning, interests, learning goals, and speed of learning, and taking small steps to reach a personal goal. Staff furthermore needs to possess proper knowledge and skills, for which training would be necessary.

Advantageous and Disadvantageous Outcomes

Being more independent would have several advantages for people with ID. All three groups of respondents mentioned a greater self-confidence, self-worth, and sense of pride as an advantageous outcome, additional to a better mood. Although some participants with ID said not much would change if they would be more independent, others stressed that they would have increased opportunities to make their own decisions. Support staff moreover felt that the type of support that people with ID receive would change if they would be more independent. They explained that staff would have to spend less time on providing practical support and would have more time for personal contact.

Only a few disadvantages of a greater independence were mentioned, mostly by participants with ID, who expressed that they would then be all on their own, leading to loneliness and having to solve everything themselves. Legal representatives and support staff mainly described several risks. If people with ID would be more independent, they might get more freedom to go out into the community by themselves, thereby becoming exposed to all kinds of hazardous situations, such as exposure to drugs. Another risk concerned overestimating people with ID. If a person with ID is more independent, others might assume that this person is capable of even more, as a result of which they might place demands on this person that are too high. Representatives and staff indicated that this could in turn possibly lead to emotional disturbances such as anger and aggression, and even a relapse in functioning.

Discussion

The aim of this study was to obtain insight into the perspectives of people with ID, their legal representatives, and support staff on various topics concerning independence of people with ID. By combining these three perspectives we were able to create a more comprehensive understanding of these topics. In sum, it was found that all people with ID need at least some support, but that most would like to become more independent. Several barriers are experienced when trying to promote their independence. Barriers include that support staff do not have enough time to guide people with ID, might not know how to promote independence, or are afraid things might go wrong if people with ID handle things more independently. Both staff and family members furthermore have a tendency to take over tasks from people with ID, which limits the opportunities for them to learn to do things themselves. To promote independence it was reported that more time and support are required, as well as a clear, individualized, and stepwise approach, and adequate communication between all parties involved. Although, a greater level of independence could have some negative outcomes, such as an increased risk of overestimation and exposure to hazards, several advantages for people with ID were also proposed, such as feeling more confident and proud.

Overall, independence was regarded as a broad concept by the respondents, involving the knowledge and abilities to take

care of your affairs yourself. This closely resembles our aforementioned definition, in which we stated that independence concerns: "the abilities and actions to manage your own affairs and to provide for yourself, without requiring support from others". In this study however, some respondents also stated that independence includes asking help from others if you cannot handle something yourself.

The level of independence of people with ID was experienced to vary greatly, especially by staff. Although various skills were described, everyone agreed that all people with ID require at least some support from others. This is congruent with previous studies (Hale et al., 2011; Vilaseca et al., 2017). Even though staff reported that a small minority of their clients might not feel the need to become more independent, staff, and legal representatives expressed that most people with ID would have both the desire and the ability to become more independent. This desire was also expressed by participants with ID. Generally, it was said that most people with ID just want to lead a "normal" life, in which they can live, work, and travel independently, just as people without ID. This is in line with previous qualitative studies, in which people with ID stated that doing daily living activities independently is important to them and that they wish for a greater independence in the future, by learning skills such as cooking and travelling (Bond & Hurst, 2010; Haigh et al., 2013; Kuijken et al., 2016).

Obtaining a greater level of independence can be hindered by several barriers in practice. A frequently reported barrier concerned the lack of time for support staff to guide people with ID toward a greater independence. This is congruent with a study by Hermsen et al. (2014), in which support staff also described a shortage of time and difficulties to meet the needs of their clients. However, quantity does not equal quality. It might not always be about a lack of time, staff, or resources, but more about *how* resources are being used, *what* staff members do and *how* they do it (Beadle-Brown et al., 2016). Staff might lack the knowledge and skills to guide people with ID towards more independence, which was expressed as a barrier in our study by legal representatives. Another reported barrier concerned fear among staff, and family members being overprotective. Supporting people with ID concerns walking a fine line in promoting their autonomy, while protecting them from possible risks (Petner-Arrey & Copeland, 2015). Regulations that exist because of these perceived risks and the tendency of staff and family to take over limit the opportunities for people with ID to develop independent skills (Aldridge, 2010; Caton et al., 2012; Power, 2008; Strnadová & Evans, 2015), which may in turn actually foster dependence, as well as passivity and learned helplessness (Sigafoos et al., 2005).

Barriers were said to exist at the level of the persons with ID themselves as well. These mostly concerned difficulties in cognitive and emotional functioning, and in handling more demanding situations. The global intellectual deficits of people with ID (American Psychiatric Association, 2013), as well as emotional difficulties, stress, and stressful situations (Caton et al., 2012) can negatively affect their functioning and make it more difficult for them to become more independent. These emotional difficulties could include fear to do things independently or difficulties with handling the consequences and responsibilities belonging to a newly acquired skill. Especially in an already demanding or stressful situation, people with ID were said to have even more difficulties with handling things independently, as these situations are already too overwhelming for them cope with.

When asked what would be necessary to overcome these barriers and to increase the level of independence of people with ID, several things were proposed. Requirements for promoting independence in people with ID included a clear, univocal approach and adequate communication between all people involved, including the person with ID. If everyone is united on how to guide a person with ID, it is also clear to everyone what to do and what to expect, which could benefit the promotion of independence. Another reported requirement, convergent with previous studies (Hale et al., 2011; Kuijken et al., 2016; Petner-Arrey & Copeland, 2015; Young et al., 2012), is a tailored, individualized approach, next to a step-by-step plan. This can be achieved by adapting to an individual's level, goals, and speed of learning. In addition, respondents from all three groups proposed that more time and support (staff) would be required. This could help staff who now lack time to guide people with ID toward more independence, which was earlier defined as one of the main barriers. Support from others was also expressed as an important factor for self-management in some previous studies (Hale et al., 2011; Young et al., 2012). Although an initial investment in more time and staff might be necessary, in the long term it could actually save time and money, once people with ID have learnt to do more themselves. A final requirement that was considered was that staff must possess the right knowledge and skills for promoting independence in people with ID. This could be achieved through proper training. Such training should not only consist of an in-service classroom training, but also of coaching-on-the-job and verbal feedback (Van Oorsouw, Embregts, Bosman, & Jahoda, 2009).

Lastly, it was explored what the outcomes would be if people with ID would be more independent. Several advantages were listed, amonge which a greater self-confidence, self-worth, sense of pride, and a better mood. In addition, some participants with ID thought of more opportunities to make their own decisions. This individual autonomy, which includes the freedom to make one's own choices, is not only valued by people with ID (Strnadová & Evans, 2015), but is also one of the leading principles of the United Nations' Convention on the Rights of Persons with Disabilities (United Nations, 2006). Almost no disadvantages were identified, apart from the notion that people with ID might become more solitary. Possible risks were however frequently described, mainly by legal representatives and support staff. They were concerned that too high demands would be placed on more independent people with ID (due to overestimation by others) and that they would be more exposed to risky aspects of life and of society. Especially those who are living by themselves or who are afforded more community independence are more vulnerable and susceptible to abuse, theft, and assault (Bond & Hurst, 2010; Fisher, Baird, Currey, & Hodapp, 2016; Wilson, 2016). This

is because they are often unaware of the risks in vulnerable situations or because they are unable to deal with them effectively (Fisher et al., 2016; Wilson, 2016). Therefore, this should be watched closely when promoting independence in people with ID.

This study is the first to combine the views of both people with ID, legal representatives, and support staff on promoting independence. By considering these three perspectives a valuable contribution is offered to the understanding of how independence can be promoted in this population. Nevertheless, this study also has some limitations. The sample was small and only included people affiliated to one care organization. Furthermore, although our aim was to assemble a heterogeneous group of people with ID, mostly men with borderline to mild ID participated who were already relatively independent. Thus, this study did not include the views of people with more severe levels of ID or with difficulties in communication and group interaction. Altogether, this means that our findings cannot be generalized to the entire population of people with ID. This calls for a broader study with a larger sample, involving several care organizations across countries, thereby also including people with more severe levels of ID and with communication and social difficulties. Another suggestion for future research concerns interventions that aim to promote independence in this population. These interventions do not only have to be targeted at people with ID, but could also be directed at support staff and family members. It seems that interventions need to take several barriers and risks into account. Furthermore, adequate communication is required between all parties involved, just as a univocal, tailored, and stepwise approach. As this study showed that most people with ID wish to become more independent and that a greater level of independence could have several advantageous outcomes, this stresses the need for the development and evaluation of these types of interventions, which could benefit from the assorted insights acquired in this study.

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Conflict of interest statement

The authors declare that they have no conflict of interest.

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Appendix

Appendix A: Focus Group Questions

Topic	Question for people with ID	Question for legal representatives and support staff
Concept of independence	What do you think independence means? What is independence?	What do you mean by independence?
Level of independence	How independent are you? What can you do yourself? With what things do you still need help from others?	How independent are the people you are representing/supporting?
Needs	Would you want to become more independent? If so, what would you want to learn?	Would the people you are representing/ supporting want to become more independent? If so, what would they want to learn?
Barriers	Is there something that causes you to not be as independent as you would want? Is there something in the way?	What are current barriers that hinder people with ID from becoming more independent?
Requirements	What is necessary to become more independent? How can you be helped to achieve this? What needs to be done?	What is required in order to increase the level of independence of people with ID?
Advantages	What would be the advantages of more independence? Why would it be a good thing if you can do more yourself?	What would be the advantages of a greater level of independence?
Disadvantages	What would be the disadvantages of more independence? Are there also downsides if you can do more yourself?	What would be the disadvantages of a greater level of independence?

Appendix

Appendix B: Derived Themes and Subthemes from the Focus Groups Per Topic

Topic	Theme	Subtheme
Concept of independence	Abilities and skills	Doing the housekeeping
		Grocery shopping
		Handling money
		Performing actions
		Planning your activities
	Acceptance	Accepting yourself
		Accepting criticism
		Accepting help
	Alone, by yourself	
	Asking for help	
	Behaving yourself	
	Broad concept	
	Different for each person	
	Drawing boundaries	
	Emotion regulation	
	Knowledge	About what you need

(Continues)

Topic	Theme	Subtheme
		About what to do (at work)
		About whom to ask for help
	Living by yourself	
	Making and keeping appointments	
	Social interaction	
	Taking care of yourself	
	Taking initiative	
Level of independence	Abilities and skills	Asking for help
		Cognitive abilities (e.g., telling time)
		Communication
		Cooking
		Coping
		Drawing boundaries
		Emotion regulation
		Filling in leisure time
		Getting dressed
		Grocery shopping
		Handling money
		Housekeeping, work in and around the house
		Living independently
		Making coffee
		Managing medication
		Perseverance
		Personal hygiene
		Planning
		Regular employment
		Social interaction
		Taking care of chickens
		Using public transportation
		Using own transportation (car, bicycle, motor scooter)
		Using the internet
		Waiting one's turn
		Withdrawing cash
	Already increasing	
	Need for support	Social interaction
	Room for growth	
	Variable	
Independence-related desires	Discipline	
	Doing the housekeeping	
	Emotion regulation	
	Making decisions	
	Managing medication	
	No desire	
	Normal life	Having a family
		Living independently
	Outdoor activities	
	Planning	Making appointments
	Reading and writing	
	Regular employment	
	Self-determination	
	Social contact	Listening to others

(Continues)

Topic	Theme	Subtheme
	Travelling/transportation	Driver's licence
Barriers	Current situation	
	Disagreement between staff and family members	
	External influences	Changes in the environment
		Group dynamics
	Family	Difficulties letting go
		Overprotective
		Taking over
	Lack of resources	Facilities
		Financial resources
	Limited transfer to daily life	
	Management team	
	More complex society	
	Person with ID	Age
		Autism spectrum disorder
		Busy schedule
		Cognitive disabilities
		Difficulties handling emotions
		Difficulties handling pressure
		Focus on hobbies
		Laziness
		Limited insight
		Limited motivation
		Limited self-confidence
		Losing patience
		(Performance) anxiety
		Personal history
		Social–emotional developmental level
	Restrictions of freedom	
	Support staff	Different ways of providing support
		Fear
		High turnover
		"Institutionalising" clients
		Lack of knowledge and skills
		Lack of time
		Own norms and values
		Taking over
		Working "on autopilot"
	Taking too far steps	
Requirements	Attainable goal	
	Clear, univocal support	
	Communication	Being clear
		With family members
		With the person with ID
	Encouragement	Compliments
	Experiencing success	
	Family	Involvement
		Shared responsibility
	Patience	
	Perseverance	

(Continues)

Topic	Theme	Subtheme
	Person with ID	Insight
		Less focus on hobbies
		Less worrying
		Self-confidence
		Training
	Plan	Step-by-step plan
	Resources	Facilities
		Financial resources
	Setting the right example	
	Support staff	Advice and training
		Attitude
		Exchanging experiences
		Flexibility
		More staff
		One-on-one support
		Skills
	Tailoring to the individual	
	Taking risks	
	Time	
	Understanding the person with ID	Taking the person with ID's perspective
Advantages	Attaining goals	
	Health	
	Less behavioral problems	More mature behaviour
	Living independently	
	Making your own decisions	
	Mood	Happiness
		Less frustration
		Satisfaction
	Motivation	Wanting to learn more
	Participation in society	
	Peaceful life	
	Pride, self-worth	
	Self-confidence	
	Social interaction	Having a partner/family
	Taking care of yourself	
	Type of support	Less support needed
		Time for other types of support
	Work	
Disadvantages	Less support	Being on your own
		Loneliness
	Feeling unsafe	
	Mood	Tension
	No disadvantages	
	Risk	Difficulties defending oneself
		Drug abuse
		Emotional disturbance
		Psychosis
		Relapse in functioning
		Too high demands

Appendix

Appendix C: Illustrative Quotes from the Focus Groups

Topic	Theme (*Subtheme*)	Reported by[a]	Quote
Concept of independence	Broad concept	PID#1	Independence is something general. Something very broad. Living, working, leisure, learning.
		LR#12	That you can take care of yourself, mentally, physically, and socially.
		SM#1	That someone knows what to do to be able to do something.
	Asking for help	PID#4	Independence also means asking for help when cleaning the bathroom … That you ask for support yourself.
		LR#10	… that they [people with ID] know themselves, "This is beyond my limits, so I need to ask for help."
Level of independence	Highly variable	PID#4	There are all kinds of different degrees … One person can do this, but not that.
		SM#7	Some [people with ID] really won't manage. They can't even dress or undress themselves. Another person only partly needs help, how to make a shopping list, but that person is able to go to the store himself. Whereas for another [person], you need to accompany him to the store.
	Need for support	PID#6	In general, it all just goes really well, but I do need help with everything.
		SM#12	They [people with ID] can actually do a lot themselves, but everything is created by us to such an extent that they are able do it. As soon as we would withdraw, everything would relapse.
	Abilities and skills	PID#7	Washing, ironing, my household, cooking, grocery shopping … Even, um, that's going somewhat okay, I do still need some help with money.
	Room for growth	LR#10	She is very teachable, so you could teach her a lot.
		SM#4	A while ago we got a question from someone who wanted to manage his own medication … We started training and now it goes really well. So in fact, you're always working on teaching things … and that promotes independence.
Independence-related desires	"Normal" life	PID#6	My hobby, my work, and living. Those are the three things I would just like to do independently.
		SM#6	They want their own house, a family, to get married, possibly children … They actually want everything I have in my life ... because that's just how it's supposed to be.
	No needs	SM#2	There are a couple, but then I'm talking about clients who have been pampered a lot at home, who are fine with sitting comfortably, while things are being arranged [for them].
Barriers	Support staff		
	Lack of time	PID#4	There's not enough time. And too little staff, and therefore, too little time. As a result of which, they can't guide us enough.
		LR#7	Independence also has to do with having time for it. They are cutting back [on staff] more and more.
		SM#4	I would like to have a whole day to think about what I would want to achieve with a client, but I don't have time for that.

(Continues)

Topic	Theme (*Subtheme*)	Reported by[a]	Quote
		SM#10	Literally, time of course also plays a role. No time is no independence … If you don't have time, then often independence is taken over to reach a goal. And that's not always in favour of the client.
	Fear	SM#12	… a lot of fear to let things go. When I come with a client and I say: "I would like to let him work outside of the institution." Then I get all these counter-arguments [from colleagues], because he might ruin the job for the next [client], if it doesn't go well.
	Taking over	SM#17	So many things were done for her in the past that she could've learnt and now still could learn, that she now I think just refuses to do. Because it was done for her all those years.
		SM#7	I am like, "Well, they're finished eating, put your plate on the kitchen counter." Then colleagues are like, "No, support staff takes care of that. We always clear the table." And I am like, "You can pick up your plate, you can walk, you can come to the kitchen counter, so bring it to the counter yourself. Preferably in the dishwasher as well." So as far as this is concerned, there's also a difference between staff members.
	Family	LR#9	You can be impeding or facilitating. For example, you may not want to let go of your control.
	Taking over	SM#3	We have one client, whose aunt is "putting her claws" into everything. And everything we suggest or want to try out with him is immediately rejected: "He can't do that, that won't work." … We're now teaching him to do his laundry himself. And then you discover that his laundry was snatched away by his aunt.
	Person with ID		
	Emotional difficulties	PID#7	My angry moods. I then send people away, whereas I should actually let them in. As in, "Guys, I can't manage it anymore."
		LR#9	My son doesn't start with things, because he's afraid to fail. So that's his barrier.
		LR#12	You could teach her a lot, but deep down she's a little girl.
	Cognitive difficulties	LR#10	…that she's quickly fed up with it, because she has to think about it, concentrate.
	Current situation	PID#1	That so many things are going on, that you can't see the wood for the trees.
		SM#2	Let's say a client is going to change jobs in the meantime. Then with all due respect, we're not going to overload a client with 20 independence-things they could also learn.
Requirements	More time and support	SM#7	Don't expect that something is already picked up within a month. Just give people the time to learn something.
		LR#7	Independence comes down to more time for the client and more money.
		SM#7	Availability. By that I mean, if you want to teach someone to go to the store, you will have to go the store with that person a couple of times, which means you can't be with the rest of the group at that moment ... Then you need to have

(Continues)

Topic	Theme (*Subtheme*)	Reported by[a]	Quote
			an extra staff member to take over the other three clients, so you have time to go with that person.
	Communication and clear approach	SM#7	If you have a plan to reach a goal, then you all have to work in the same way with a client. Because I can't, for example, when doing groceries, say: "Well, I will make a shopping list, if you make sure you have money and a shopping bag." And that someone else comes the next day and says: "I will take care of the bag and you make the list."
		LR#6	The only advice I can think of now is [to] keep communicating with clients' representatives, with support staff, with managers. Keep each other posted and exchange information … so it becomes clear what it should be like and how we can achieve that.
	Tailored, step-by-step plan	SM#13	It's indeed important to look at an individual, at your own client, and to listen well. What are the wishes and interests? Once you have identified that, you can anticipate much better on independence.
		SM#13	We're training, but that goes in very small steps. I mean, you do groceries at a store. First always at one store, then you extend it to two stores, to three stores, until that is routine. You build it up step by step and then you expand.
	Staff training	SM#12	I think that you also need clues as to how you will go about it, how you are going to teach clients to be more independent, by means of the right attitude and tools to teach someone something. Because it's not that easy.
Advantages	Feelings	PID#1	Satisfied. Because then I have achieved what I wanted.
		LR#12	It's much more fun to do groceries by herself, than when someone goes with her. Because then she gets just a little of that self-confidence. As in, "Hey, look at me, I just did some groceries!"
		SM#2	Some [clients] become enormously happy when they do something themselves, they are literally cheering.
	Decision making	PID#7	Personally, an advantage is, I think, that you can just decide for yourself when you're going to do what. If you, so to speak, want to sit on your balcony, but you know staff is coming by to help with vacuuming, mopping, just to name a few, then you're tied to that. And then you're free, you can think, well the floor looks fine, I'll do it next week.
	Received support	SM#7	Once someone is more independent, you have less to do as staff … You're not supporting the ADL … You're teaching things, thinking of a step-by-step plan, you then have more time for that. You can shower Dick in half an hour, or you can sit with Harry half an hour and look at grocery shopping, what do you need, this and that.
Disadvantages		PID#1	If you live independently, you don't have someone you can talk to or who gives you clever advice every day.
	Risks	LR#9	They wanted to make him [a client] more independent, but that went all wrong because they gave him too much freedom. Then he got all confused, because there were too little boundaries.

(Continues)

Topic	Theme (*Subtheme*)	Reported by[a]	Quote
	Exposure to hazards	PID#1	You're exposed to all joys of life. You have to say no more quickly … Drugs, alcohol, cocaine, heroin, all that shit.
		SM#1	If they will do more things themselves, that involves all kinds of other things… In society, things could happen to them.
	Overestimation	SM#14	He is also a client you easily overestimate ... Then he doesn't understand it at all, and then, well, he starts showing undesirable behaviour.
		SM#16	Then you ask too much from him, and then he relapses and then you have to heal those wounds.
		LR#10	We have literally experienced that she then was no longer able to handle, then she becomes aggressive, angry and cranky.
		PID#4	No, that's not good, not for me. I can relapse. If I relapse, then you can't go back that easily. That's also the problem. Because if it's not going well with me at that moment, because it was too big of a step, then try to get back.

[a]PID = Person with ID, LR = Legal representative, SM = Staff member.