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## eHealth in support for daily functioning of people with intellectual disability: Views of service users, relatives, and professionals on both its advantages and disadvantages and its facilitating and impeding factors

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### ABSTRACT

**Background:** The use of eHealth in support for daily functioning of service users with intellectual disability (ID) is a rather unexplored domain. Therefore, the current study identified the a) level of familiarity, b) advantages/disadvantages, and c) facilitating/impeding factors for the use of eHealth in support for daily functioning of people with ID according to service users, relatives, and professionals.

**Method:** Four focus groups and one semi-structured qualitative interview were conducted.

**Results:** Participants were familiar with numerous eHealth applications. Benefits were related to service users (e.g., increased independency) and relatives/professionals (e.g., providing more efficient support). Adequate informing and involving all stakeholders and centrally positioning the needs and possibilities of service users were reported as important facilitators. Contrary, impeding factors were malfunctioning Internet, expenses of eHealth, and lack of proper IT-support.

**Conclusions:** The results provide imperative information for future eHealth implementations and to direct its use more specifically to people with ID.

### KEYWORDS

Intellectual disability; eHealth; advantages; disadvantages; facilitating and impeding factors

Worldwide, health services and information delivered or enhanced through the Internet and related technologies, also known as eHealth (Eysenbach, 2001), are frequently used. For example, according to the 2015 World Health Organization (WHO) global survey on eHealth, 74% of the 160 WHO member countries included eHealth as part of the universal health coverage and up to 62.5% have a national eHealth strategy or policy. Likewise, the number of studies focusing on effects of eHealth interventions also increased considerably in recent years, suggesting that its effectiveness is promising in a wide range of settings, such as preventing obesity, treating smoking dependence, preventing HIV risk behaviours, and improving mental health (e.g., Hutchesson et al., 2015; Oosterveen, Tzelepis, Ashton, & Hutchesson, 2017; Schnall, Travers, Rojas, & Carballo-Diéguez, 2014; Spijkerman, Pots, & Bohlmeijer, 2016). However, high-quality evidence on health as well as economic benefits of eHealth interventions are still lacking despite the increasing number of publications (e.g., Ekeland, Bowes, & Flottorp, 2010).

In line with general health care, eHealth within the field of intellectual disability (ID) is also more frequently used nowadays, yet specific estimations of how

widespread eHealth is across service settings for people with ID are unknown. Within the ID field, eHealth is primarily used in two domains: therapy and treatments settings (e.g., Cooney, Jackman, Coyle, & O'Reilly, 2017; Vereenooghe, Gega, & Langdon, 2017) and support for daily functioning (e.g., Boot, Owuor, Dinsmore, & MacLachlan, 2018; de Wit, Dozeman, Ruwaard, Alblas, & Riper, 2015; Perry, Beyer, & Holm, 2009; Taber-Doughty, Shurr, Brewer, & Kubik, 2010). Regarding the latter, it is important to emphasise that people with ID living in supported community settings often need support with tasks related to daily functioning in order to meet their personal needs (Thompson et al., 2009). Usually this support is provided through onsite support staff (Stancliffe & Lakin, 2007), yet eHealth can have several potential benefits as an alternative (Taber-Doughty et al., 2010; Zaagsma, Volkers, Schippers, Wilschut, & Van Hove, 2019). That is, support for daily functioning delivered through eHealth can be more focused, targeted and specific because it is offered as needs arise rather than regardless of immediate needs (Perry et al., 2009). In addition, it allows service users to make desired choices and decisions, for example about when and what support is desired (Schalken, 2013). Hence, support

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delivered through eHealth can make service users less dependent on the available time and willingness of their support staff and relatives (Wennberg & Kjellberg, 2010).

Despite the progressive use of eHealth in support for daily functioning of people with ID, few studies focused on its feasibility or effectiveness. de Wit et al. (2015) examined the feasibility of a web-based program facilitating professional support for service users with chronic conditions, including 10 people with mild ID, in their daily functioning. Their results showed that the use of this web-based program was accepted by both the professionals and the service users. Moreover, the online support did not reduce service users' satisfaction with the received support, empowerment, and quality of life compared to face-to-face support as usual. In addition, in a pilot study, Taber-Doughty et al. (2010) compared remote telecare support with face-to-face support as usual on independent performance of four adults with moderate-to-mild ID in completing household tasks. Results indicated that service users who were supported by telecare had a higher degree of independent performance compared to face-to-face support as usual. Hence, these initial results are promising and may justify further research on the effectiveness of the use of eHealth in support for daily functioning for service users with ID.

However, before further examining the effectiveness of eHealth in support for daily functioning for service users with ID, it is essential to explore the expectations and perceptions of relevant stakeholders towards eHealth in support for daily functioning, as these factors are vital in the successful use of eHealth (Clifford Simplican, Shivers, Chen, & Leader, 2018; Oudshoorn, Frielink, Nijs, & Embregts, 2020; Ramsten, Martin, Dag, & Marmstål Hammar, 2019; Wennberg & Kjellberg, 2010; Zaagsma et al., 2019). Obviously, the expectations and perceptions of service users themselves are imperative for the actual use of eHealth in support for daily functioning. So far, several studies explored service users' expectations and perception, focusing in particular on a specific eHealth application, such as a cognitive assistive device (Wennberg & Kjellberg, 2010) or an online support service called DigiContact (Zaagsma et al., 2019). Moreover, as support staff are often key agents in the lives of people with ID, their expectations and perceptions of eHealth in support for daily functioning are imperative as well (Clifford Simplican et al., 2018; Ramsten et al., 2019). For example, Clifford Simplican et al. (2018) found that, in general, support staff encouraged the use of eHealth, but they also observed challenges, including the lack of support staff training and ethical concerns towards privacy.

To the best of our knowledge, however, service users' expectations and perceptions towards eHealth in support

for daily functioning in general (i.e., not related to a specific application) have not been studied before. Moreover, in addition to support staff, relatives are key agents in the lives of people with ID as well (Allen, 1999; Clifford Simplican et al., 2018), yet so far no knowledge is available about their expectations and perceptions towards eHealth in support for daily functioning among people with ID. The goal of the current study was therefore to describe, and compare, the expectations and perceptions of service users, relatives, and professionals towards eHealth in support for daily functioning. Hence, the aims of the current study were to identify 1) the level of familiarity, 2) the advantages and disadvantages, and 3) the facilitating and impeding factors for the use of eHealth in support for daily functioning. Understanding these aspects from the perspective of service users, relatives, and professionals may contribute to the successful use of eHealth in support for daily functioning.

## Method

### Research design

To address the current research aims, a qualitative design with focus group method was chosen. Focus groups are group discussions, led by an experienced moderator, where people discuss different aspects of a particular topic in a focused way (Krueger & Casey, 2015). Due to the group processes within a focus group, focus groups might help participants to explore and elucidate their own views (Kitzinger & Barbour, 1999). In addition, participants can be encouraged to express experiences and ideas that might remain unexplored during an interview. To ensure that the account reported is as rich and comprehensive as possible, separate focus groups were conducted with service users, relatives, and professionals. By doing so, the views of the three stakeholders groups could be compared to determine areas of both agreement and disagreement (Guion, Diehl, & McDonald, 2017).

### Participants

After ethical approval was provided by the Ethics Review Board of Tilburg University (EC-2015.04), the study was conducted in an ID service in the southern part of the Netherlands which offered residential homes, 24-hour community residences, ambulant support at clients' own homes, and day care facilities. To recruit service users (people with mild to borderline ID; IQ 50-85) and relatives of people with ID to participate in this study, the authors contacted the coach of the central client council of the ID service. The coach supports the

members of this council, consisting of both service users and relatives, in various manners (e.g., jointly drawing up the agenda, preparing their meetings as well as meetings with, for example, the board of directors, and being present for any assistance possible). After the coach was informed about the study, she selected eight service users and four relatives (three parents, one brother) based on their experiences and knowledge of eHealth. Next, the authors contacted the service users and the relatives (who were not related to each other) by phone and fully informed them about the study; all voluntarily agreed to participate and provided informed consent. The service users (five men), who had a mean age of 35.6 years (range: 24–53), were equally divided over two focus groups (i.e., four service users for each focus group). According to the clinical judgment of the psychologist, all service users had a mild to borderline ID. All received support within a residential care setting. The relatives, all men, had a mean age of 49.0 years (range: 36–69). One father had a son with a mild ID, one father had a son with a severe ID, and one father a daughter with a severe ID; the brother was the relative of a man with a severe ID. All relatives attended one focus group.

In order to recruit professionals, the authors informed the program manager eHealth of the participating ID service about the study. Next, the manager selected four professionals (2 men) to participate based on their experience with, and knowledge of, both people with ID and eHealth. The authors then contacted the professionals and fully informed them about the study; all voluntarily agreed to participate and provided informed consent. They had a mean age of 42.0 years (range: 33–62) and, on average, had worked within the ID field for 16.8 years (range: 5–34). Because one of them was not able to attend the focus group due to an emergency, the first author had an individual interview with him; the other three professionals participated in a focus group.

### **The interview and materials**

Depending on the preferences of the participants, the focus groups took place at the head office of the participating ID service and at the shared living room of three of the participating service users; the individual interview took place at the office of the professional. Two interviewers were present at each focus group. Whereas one interviewer introduced the topics and posed open-ended questions, the other interviewer kept track of time, raised questions for clarification, made sure that all topics were discussed, and ensured that all participants came in turn. Hence, all topics in the interview guide were put to all participants, though participants were free to raise new topics in their responses.

Each focus group and the individual interview started with a brief introduction of the interviewers and the participants, followed by an explanation of the current study. Next, the participants agreed to audiotape the focus groups and the interview; participants' informed consent was audiotaped. Subsequently, the interviewers posed questions associated with the topics in a semi-structured interview guide developed for the purpose of the current study. That is, participants were first asked: What comes to your mind when you think of defining eHealth in support for daily functioning? In addition, participants were asked to illustrate examples of eHealth applications they knew. Next, by means of a PowerPoint® presentation, the interviewers provided the most-cited definition of eHealth, by Eysenbach (2001)<sup>1</sup>, and outlined a clustering of eHealth applications based on Timmer (2014) to provide input for the participants in the case they were not familiar with the term eHealth. While doing so, the interviewers emphasised that although the eHealth definition of Eysenbach and the clustering of Timmer is broad, this study focuses only on eHealth in support for daily functioning. Then, in the second part of the focus groups and the interview, the participants were asked about advantages and disadvantages of eHealth in support for daily functioning and, in the third and last part of the focus groups and the interview, what facilitating and impeding factors for the use of eHealth in support for daily functioning they faced. Hence, the interview guide consisted of three parts: 1) familiarity with eHealth in support for daily functioning, 2) advantages and disadvantages of eHealth in support for daily functioning, and 3) related facilitating and impeding factors, each operationalised with numerous open-ended questions. The interview guide for professionals and relatives was identical; the open-ended questions within the interview guide for service users were simplified, but the scope of the questions was nevertheless similar. In addition, the eHealth definition provided to the service users was also simplified (i.e., eHealth was defined as the use of the Internet, a computer, or smartphone in support for daily living).

### **Analysis**

A standard content analysis on the basis of a general inductive approach (Thomas, 2006) was conducted. This approach was chosen as the aim of the current study was to gain insight into the level of knowledge regarding eHealth in support for daily functioning and to identify advantages and disadvantages as well as facilitating and impeding factors for the use of eHealth in support for daily functioning, without theories or prior

assumptions directing the exploration. The general inductive approach aims to abbreviate the text data into a brief summary, make clear associations between the research goals and the summary findings, and to present the underlying structure of experiences and perceptions of participants as originated from the text data (Thomas, 2006). In the first step of this general inductive approach, one of the researchers read the verbatim transcriptions in detail to ensure he is acquainted with the content (i.e., in our case, the first author). Next, phrases of clear importance for the study (i.e., in our case, related to one of three topics of this study: 1) familiarity with eHealth in support for daily functioning, 2) advantages and disadvantages of eHealth in support for daily functioning, and 3) related facilitating and impeding factors) were assigned a code based on the data itself. Subsequent, a second level of coding was conducted to identify themes associated with the topics of the interview guide. Finally, the identified themes, subthemes, and codes were discussed by the authors and two other researchers within our research group and adapted when required.

### **Rigour of the methodology**

To improve the quality of the study, a number of trustworthiness and credibility checks were conducted. First, a second coder performed a coding check to ascertain clarity and consistency of the codes. Second, different stakeholders (i.e., service users, relatives, and professionals) were interviewed to ensure that the account reported is as rich and comprehensive as possible. Finally, extensive discussions about the codes and proposed themes and subthemes were held between the authors and two other researchers to ensure that the themes and subthemes took into account a variety of perspectives, and hence, were as rich as possible.

### **Results**

The emerged themes related to the three topics of this study are described and illustrated below. That is, first the level of familiarity with eHealth in support for daily functioning of service users, relatives, and professionals will be discussed, followed by advantages and disadvantages of eHealth in support for daily functioning and the facilitating and impeding factors for the use of eHealth in support for daily functioning.

#### **Familiarity with eHealth in support for daily functioning**

When service users, relatives as well as professionals are asked to illustrate examples of eHealth applications they

**Table 1.** An overview over the description of eHealth and eHealth applications.

Theme	Clustering of responses
Description eHealth	Use of computers/technique Remote care Broad term; it covers a lot Manner to have “low-level” contact with others (but not suitable for all)
eHealth applications	eHealth is a different type of contact Informational websites designed for people with ID Social media (e.g., Facebook, YouTube) Domotica/surveillance technology eCommunication in contact with family/professionals Portals Augmentative and Alternative Communication (AAC)-devices Apps on phone/tablet (e.g., using Whatsapp with professionals) Measurements focused on physiological aspects (e.g., heartbeat)

knew, they mentioned a great diversity of eHealth applications (see Table 1), ranging from informational websites designed for people with ID to the use of social media, such as Facebook and YouTube, and the use of domotica/surveillance technology. In addition, participants indicated the use of eCommunication, and e-mail and video calls in particular, in the contact between service users and their family and support staff to be supportive. In the words of a service user:

Sometimes I follow up a conversation with some feedback [from support staff] by e-mail, I might let them know my thoughts about this or that. So for me, sending an e-mail afterwards works well. [Service user 4]

Furthermore, participants mentioned the use of several specific eHealth applications in support for daily functioning, such as online health platforms, Augmentative and Alternative Communication (AAC)-devices, and the use of WhatsApp to communicate with support staff. Professionals also mentioned the use of specific applications aimed at identifying how someone feels or aimed at measuring physiological aspects:

For instance, those bracelets that can monitor stress by measuring physiological signals – it would be great to work with those. Especially for people who have behavioural problems or who have trouble expressing themselves verbally, such as people with lower cognitive levels. It’s a really new technique that we should start researching and start working with soon. [Professional 1]

Moreover, when service users, relatives as well as professionals are asked what comes to their mind when they think of eHealth in support for daily functioning, they indicated that it involves the use of computers and technology, often in combination with remote care (see Table 1). Furthermore, professionals noted that eHealth is a broad term. According to a professional:



It's not just about having a robot chip that can help people who are paralysed. It's also about having an app that can provide explanations as part of psychoeducation. [Professional 1]

In addition, service users, relatives as well as professionals described eHealth in support for daily functioning as an appropriate way to discuss relatively simple or practical matters with other people, for example via WhatsApp or e-mail, but it is deemed less suitable for more personal issues. As one relative put it:

But as I said, it's really the ordinary things that people say to each other. Things like: where are you now? – I'm here. – Are you staying for dinner? But you can't use WhatsApp to ask: Hey Pete, how are you really feeling today? [Relative 4]

Noteworthy, service users and professionals indicated that contact through digital applications, such as WhatsApp, is indeed a form of contact, though not live. A professional described that contact through digital applications can also be valuable and socially:

Contact through WhatsApp cannot replace live contact. However, having contact to friends using WhatsApp is valuable and social to me. The step towards digital contact in a professional support context does not have to be wrong. [Professional 1]

### **Advantages and disadvantages of eHealth in support for daily functioning**

#### **Advantages**

Regarding the advantages of eHealth in support for daily functioning, participants indicated various benefits for service users themselves (see Table 2). First, according to service users and professionals, using eHealth increases the independency of people with ID. In the words of a professional:

Because why am I here, why do I do what I do? In the end I want the service users to be able to stand on their own two feet again. I want them to be able to make something of their lives, independently. And I think that eHealth can help them achieve those goals. [Professional 1]

In addition, service users, professionals, as well as relatives mentioned that most eHealth applications enhance control over one's own life. For example, regarding an online health platform, it is the service user who determines who has access to what information.

Yes, and then you can say – you can read it. Or, I give permission to you, for instance, so that it's something that you really have a say over. [Service user 3]

**Table 2.** The advantages and disadvantages of eHealth in support for daily functioning.

Theme	Clustering of responses
Advantages of eHealth	Increased independence of service users Improve care/make care more efficient Increased communication options for service users Service user's social network more informed
Disadvantages of eHealth	eHealth should not be viewed as a substitute for (face-to-face) life contact Social contacts will be different/fewer Dangers of the Internet Text interpretation sometimes difficult

Although all participants experienced this as an advantage, it also raised questions among relatives:

I think that an online health platform can be wonderful. But the question is how to get there? How do you arrange things like who has the authority to do what? [Relative 1]

Hence, relatives stated that it is important to discuss with all stakeholders, including service users and their relatives, who has access to what information and why these persons should have access to that information.

Moreover, relatives and professionals mentioned improved health care and more effective health care as benefits of eHealth in support for daily functioning. According to professionals, the use of surveillance technology is an example of that:

Using surveillance technology will make care more efficient. Fewer staff will be needed during night shifts because the listening equipment, such as a microphone, can pick up any unusual sounds and alert the support staff members on duty straight away. And it will make the care more effective, because support staff working a night shift can never hope to hear every sound but the listening technology does. [Professional 2]

Another example provided by the participants is to fill in an individual support plan on a tablet during a dialogue between support staff and a service user him/herself, so – according to service users, relatives as well as professionals – less time is needed for reporting afterwards and hence, more time remains available for direct contact with the service user.

Moreover, due to eHealth applications such as online health platforms and electronic health records, all stakeholders, including for example general practitioners, are, when granted access, able to read individual support plans and daily reports of support staff. Relatives indicated to find that convenient, not with the aim to control, but in order to keep up to date. As one relative put it:

You can bet that once an online health platform is brought into use, mom and dad will log in regularly just to see how things are going. Not to check up on support staff, but just because they want to see how their son

is doing. And if you can be part of that process, then that's a big plus. [Relative 2]

Finally, service users, relatives as well as professionals pointed out that the use of eHealth in support for daily functioning provides service users with more possibilities to communicate with other people. That is, through eHealth applications such as video calling, they can have rather easily contact with direct support staff who are not in the immediate vicinity, but also with family members. In the words of a service user:

Well I use Skype a lot to talk to my parents. When they're on holiday, I speak to them on Skype when they're online. I can do that using my mobile phone – I can see them, and we can talk. That's how it works. [...] And I also do that with my family in Munich, and with my brother, and my sister-in-law. [Service user 1]

### Disadvantages

Like the advantages of eHealth in support for daily functioning, participants were asked about disadvantages as well (see Table 2). However, instead of disadvantages, they particularly mentioned risks and aspects of raising awareness to the use of eHealth in support for daily functioning. That is, service users, relatives as well as professionals indicated primarily that eHealth should not be viewed as a substitute for face-to-face (live) contact. In the words of a service user:

I wouldn't like it if all face-to-face contact were to disappear. Because when you're using eHealth, you might end up talking about all sorts of things using the computer. And it would take a lot of thought to make that work. But even so, it's still good for just having a bit of a chat once in a while – how are you feeling? Is everything OK? And it would be a shame if we couldn't do that anymore. [Service user 3]

Hence, personal, face-to-face contact remains very important according to service users, relatives as well as professionals. Not only for communication between support staff and services users, but also for communication between support staff and relatives. As one professional put it:

If you start contacting relatives using a monitor, I think you might start to miss the face-to-face contact. You wouldn't be able to read people's body language. And perhaps you just want to hug someone if they're feeling down, or you want to shake hands with them when you arrive – none of that would be possible anymore, and that wouldn't be good. [Professional 2]

Moreover, service users, relatives as well as professionals indicated that by using eHealth-applications, social contacts with other people might change, and its use should

therefore be considered carefully. In the words of a professional:

In the end we are social beings, so you don't want to end up in a situation where you can only talk to a robot. But on the other hand, we shouldn't immediately reject the idea of using eHealth, because we do feel – and I notice this myself when I'm on Facebook or using WhatsApp – that it is another way of having social contact with friends. So I don't want to suggest that someone always has to be visually present in order for you to have social contact. I don't think that's strictly necessary. But it is different. These are things that need to be looked at carefully. [Professional 4]

In addition, factors relating to the dangers posed by the Internet were also reported, primarily by service users. For example, they indicated insecure websites, unreliable contacts, and threats and harassment as risks of social media. Moreover, service users, relatives as well as professionals also indicated that it is sometimes difficult to understand and correctly interpret texts (e.g., in the case of e-mail or WhatsApp). In the words of a relative:

E-mails and WhatsApp messages can sometimes be interpreted in completely the wrong way. That's because there's no tone of voice there. The same words are there, but you don't hear the intonation and you don't see the facial expressions. So it's easy to read a message in the wrong way. [Relative 1]

### Facilitating and impeding factors for the use of eHealth in support for daily functioning

#### Facilitating factors

Regarding the facilitating factors for the use of eHealth in support for daily functioning, service users, relatives as well as professionals indicated that it is important to recognise that there is a distinction between people who are open-minded towards eHealth and people who are not (see Table 3). That is, not everyone want

**Table 3.** The facilitating and impeding factors of eHealth in support for daily functioning.

Theme	Clustering of responses
Facilitating factors	Acceptance that not everyone is willing to work with eHealth Connect to individual's needs and possibilities Involvement of all stakeholders (including relatives) from the start Service users control their own data (related aspects: good security, authorisation, and clear policy regarding privacy) Sharing of (experiential) knowledge A number of preconditions must be met (expenses, time, Internet, devices)
Impeding factors	Privacy concerns No or malfunctioning Internet Expenses No proper IT-support Complexity of eHealth application

or is able to use eHealth applications, for example through lack of interest or aging. In the words of a service user:

I'm 46 years old. For people who are much younger than me, using computers and the Internet often comes naturally, but sometimes it can be harder for people my age or older, because we didn't grow up with this kind of technology. [Service user 4]

Service users, relatives as well as professionals also indicated that it is crucial that the individual needs and possibilities of each service user are the starting point. In addition to general issues such as the use of simple and concrete language, relatives and professionals highlighted that it is important to consider what a service user can manage and what suits his interests. In the words of a professional:

It is important to make a decision beforehand regarding which eHealth applications you want to use, before you invest a lot of time in the wrong applications with the service user. [Professional 3] ... So you need to consider that on a case-by-case basis, to see what suits that particular person. And not what suits a whole group, or what suits a whole region. [Professional 2]

Service users, relatives as well as professionals also indicated that a vital facilitating factor for the use of eHealth in support for daily functioning is to involve all stakeholders, for example by explaining what is going to happen (e.g., *within the ID service, we will start using online video calling*), and especially why this is going to happen (e.g., *using online video calling has proven to be more effective in supporting service user's independency*). In this way, fear of the unknown can be reduced according to service users, relatives as well as professionals. Also, informing and questioning all stakeholders is important. According to a relative:

There's a lot more to it than just saying, hey guys, here's this eHealth application and we think it could be really useful. You really need to assess the situation for each individual client and see how to arrange authorisations and what each person is permitted to do, and what not. We, as relatives, are a very important party in this, but also the professionals. [Relative 3]

Furthermore, according to service users, relatives as well as professionals it is essential that service users themselves should control their own data. In this respect, optimum security, authorisation, and good policies were important issues for participants that requires attention. Also, professionals indicated that it is not necessary to reinvent the wheel. According to a professional:

As soon as you've found the right app, you should share this with others. You need to avoid having lots of small islands where some people discover this and others

discover that, but nobody knows what other people are discovering. [Professional 4]

Finally, service users, relatives as well as professionals pointed out several key preconditions to facilitate the use of eHealth in support for daily functioning: adequate time and sufficient expenses, a good Internet connection, availability of required equipment, and a good cooperation with and access to IT support for all stakeholders.

### Impeding factors

Regarding the impeding factors for the use of eHealth in support for daily functioning, service users, relatives as well as professionals indicated concerns of privacy. They pointed out that it is important to discuss these concerns with all stakeholders. In the words of a professional:

When you start measuring or filming, certain privacy aspects are attached to it. I'm not sure whether I would like it if someone knows how I feel all the time through, for example, a bracelet. This is a good example of ethical issues that should be addressed properly. [Professional 1]

Moreover, service users, relatives as well as professionals frequently mentioned a malfunctioning Internet, and in some cases even the absence of Internet. The expenses of eHealth applications were seen as another impeding factor for the service users and professionals, which is related to both the costs for an Internet connection and the costs of the required equipment. Furthermore, a lack of proper IT support for professionals, service users, and relatives was also considered to be an impeding factor. Finally, professionals indicated that certain eHealth applications are rather complex, for example due to the difficult language or the operationalisation of the application. As a consequence, the time investment to delve into a specific eHealth application can be substantial. In the words of a professional:

The fact that not everyone wants to work with eHealth is not just because they "don't want to". It takes a lot of time to get the hang of it if you've never worked with something like this before, and it all has to be done on top of all your regular work. [Professional 3]

### Discussion

In this study, eight services users with mild to borderline ID, four relatives, and four professionals participated in four focus groups and one semi-structured qualitative interview to identify 1) the level of familiarity, 2) the advantages and disadvantages, and 3) facilitating and impeding factors for the use of eHealth in support for



daily functioning. In order to do so, a general inductive approach was used to cluster the responses of the participants.

With regard to the level of familiarity regarding eHealth in support for daily functioning, the image of eHealth of the participants in the present study was in line with Eysenbach's definition (2001): health services and information delivered or enhanced through the Internet and related technologies, aiming to improve care and make it more efficient. In addition, the examples of eHealth applications provided by the participants also fit the clustering of eHealth applications of Timmer (2014) focusing on the function and the technique of eHealth applications: online information, social media, self-tests, eCommunication including video communication, domotica and ambient technology, online treatment interventions including serious games, online self-help course, online healthcare portals, monitor applications including remote care, and other technologies such as the use of robots and applications on smartphones and tablets. In other words, in general, the participants in the current ID study were familiar with eHealth. This might be due to the fact that participants were early adopters of eHealth within the participating ID service. It should be noted, however, that both service users, relatives, and professionals gave some examples that were not (directly) related to eHealth in support for daily functioning, such as playing an online game with friends, reading the news on a smartphone, and sending WhatsApp messages to friends. In this respect, service users noted that the term eHealth is rather complex. Therefore, before widely deploying eHealth, it is important to pay attention to what eHealth is and how it could best be described in order to be clear for all stakeholders.

Regarding the advantages and disadvantages of eHealth in support for daily functioning, participants indicated benefits directly related to service users (e.g., increased independency and more opportunities for communication) and benefits which were more related to relatives and professionals (e.g., providing more efficient support and being able to stay in contact with the service user remotely). These benefits are consistent with previous ID research (e.g., Clifford Simplican et al., 2018; Gutiérrez & Martorell, 2011), indicating that engaging in social contacts and more control over one's own life are important benefits of eHealth. Although participants in the current study suggested that the use of eHealth in support for daily functioning of people with ID may result in more time for face-to-face contact with the service user, they also mentioned this was not always the case. As pointed out by Vereenooghe et al. (2017), an important value of face-to-face

contact with professionals is that they are able to address social care needs of service users, which cannot be replaced by a computer. Interestingly, although mentioned in the study of Vereenooghe et al. (2017), none of the participants in the current study noticed that a combination of the two (i.e., face-to-face support and online support) might also be a possibility (Timmer, 2014). It would be recommendable for future research to pay specific attention to blended support as well, as it remains unclear whether participants were unfamiliar with the term or also with the concept of blended support. If the latter is the case, it would be interesting to introduce this concept and investigate the views of service users, relatives, and professionals towards this concept, as it might combine the advantages of both worlds.

Furthermore, participants of the current study mentioned various facilitating and impeding factors for the use of eHealth in support for daily functioning: a lack of equipment, a lack proper IT support, and a lack of time to delve into a specific eHealth application were considered to be impeding factors for the use of eHealth in support for daily functioning. Similar to Palmer, Wehmeyer, Davies, and Stock (2012), Clifford Simplican et al. (2018) and Nieboer, van Hoof, van Hout, Aarts, and Wouters (2014), the participants of the current study suggested that accessibility of all stakeholders to the used eHealth applications, appropriate training into how to use these applications, and the availability of a help desk would be essential. Regarding the facilitating factors, participants mentioned adequate informing and involving of all stakeholders, centrally positioning the individual needs and possibilities of each service user, and accepting that not everyone wants to, or is able to, work with eHealth because of a lack of interest or age as important aspects. Based on their study in the general population, Ossebaard and Idzardi (2013) highlighted the aversion of older people against modern technology and a lack of technical understanding too, as well as the importance of protecting the privacy of the service user. The issue of privacy and confidentiality when using eHealth in support for daily functioning was also stressed by Clifford Simplican et al. (2018) and by the participants of the current study, that is, privacy issues can be an impeding factor that should be discussed with all stakeholders. In this respect, Chalghoumi et al. (2017) reported that privacy breaches are a key risk for people with ID, who, in general, do not understand how their personal information is used. Although the General Data Protection Regulation (EU 2016/679), a regulation in European Union (EU) law on data protection and privacy for all individuals within the EU, was enforced in May 2018, it is a rather complex law for people with ID to understand, let alone that they know

what rights they have. Therefore, it is important to support people with ID in weighing eHealth use in terms of its risks and benefits. Interestingly, the concerns raised by the participants of the current study about privacy when using eHealth did not seem to apply to the use of surveillance technology, as participants merely expressed positive sentiments about surveillance (i.e., improved and more effective health care). This contradicts previous findings showing that the application and use of surveillance technology in residential care for vulnerable populations raises substantial ethical concerns (Niemeijer et al., 2010). However, these concerns do not necessarily focus on the effects of surveillance technology, but rather on the moral acceptability of those effects. Niemeijer et al. (2010) found in their study this is particularly the case when there is a discrepancy between the interests of the service user and the interests of the health care organisation. Future research should pay more attention to this important yet complex privacy issue in the ID field.

A strength of the current study was that we collected data directly from people with ID rather than via proxy. Although proxy reports can be useful and informative, studies reported perception gaps between people with ID on the one hand and support staff or family members on the other hand (e.g., van Scott & Haverkamp, 2018; van Oorsouw, Theeven, Leenders, Vermeulen, & Embregts, 2019). Especially in the case of people with mild ID, much information can be obtained by asking service users themselves, in particular when it concerns their views or experiences. With this in mind, we encourage researchers to take steps to broaden the involvement of service users in studies that directly concern topics that affect them.

The present results should nevertheless be interpreted in light of the limitations of the study. Firstly, although a qualitative research design with focus group method was chosen, one semi-structured interview was conducted in this study with a professional. It was intended that this professional participated in the focus group with the three other professionals, but due to an emergency he was not able to attend. Given his particular expertise with eHealth in support for daily functioning as clinical psychologist working with people with ID, we have decided to include his views and experiences on the basis of a semi-structured interview. Secondly, all participants of the current study were related to one ID service in the Netherlands. Given that the policy of organisations and their vision towards eHealth influence the views of individuals related to that organisation (Parsons, Daniels, Porter, & Robertson, 2008), it would be recommendable to extend this exploratory study to multiple ID services. Thirdly, the level of ability of the service

users was based on the clinical judgment of the psychologist rather than on actual IQ-scores or scores on the level of adaptive functioning derived from psychometrically sound tests. Fourthly, all relatives in the current study were male. Although this may suggest that eHealth seems to be of more interests to fathers and other male relatives, this suggestion cannot be supported by eHealth literature (e.g., Cho, Park, & Lee, 2014; Wang, Wu, & Wang, 2009). Hence, the preponderance of men in this study is likely to be due to the convenience sample. In addition, in line with research in the general population (e.g., Hardiker & Grant, 2011), age might be an important variable in understanding or familiarity with various eHealth applications as well. To overcome these issues in future research, research on a larger scale is needed with specific attention to the distribution of age and gender. Fifthly, although participants in several cases explicitly stated to what specific eHealth application they were referring to when mentioning an advantage or disadvantage about eHealth, this was not always the case. Therefore, some statements are linked to a specific eHealth application and some statements are rather general. Nevertheless, in all cases participants referred to eHealth applications in support for daily functioning and therefore, providing significant insights for the current study. It would be interesting for future research to explore the views of people with ID, their relatives, and their professionals regarding specific eHealth applications in order to determine areas of agreement as well as areas of disagreement.

Despite these limitations, the current study provides valuable insights into how people with ID, their relatives, and professionals view eHealth in support for daily functioning and what they consider to be advantages and disadvantages of this new manner of providing support and facilitating and impeding factors to support people with ID in their daily functioning. Understanding these aspects may be beneficial for the successful use of eHealth in support for daily functioning and to direct eHealth applications more specifically to people with ID, their relatives, and professionals.

## Note

1. eHealth is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterises not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology. (Eysenbach, 2001, p. 1)

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