

The Usefulness of Offering 24/7 Online Support Within a Wider Mix of Professional Services for People With Intellectual and Developmental Disabilities Living Independently: A Qualitative, Multiple Case Study

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Abstract

Service organizations for people with intellectual and developmental disabilities (IDD) increasingly use telecare applications to improve their services. This study explored the usefulness of offering the 24/7 online support service DigiContact within a broader mix of professional services for people with IDD living independently. We employed a qualitative multiple case study, in which the cases of nine online support users were reconstructed through semistructured interviews with both support users and their case workers. Thematic analysis showed that online support was used as an addition to regular onsite support to enable a more tailor-made delivery of professional supports. Online support can be valuable for its users by increasing the accessibility of professional support and creating opportunities for more self-direction in support.

Key Words: *intellectual and developmental disabilities; independent living; telecare; support; support needs*

Within a continuously changing field of disability policy and practice it is important for service organizations for people with intellectual and developmental disabilities (IDD) and their families to adapt and transform, as this helps them to enhance or maintain their effectiveness, efficiency, and sustainability (Reinders, 2008; Schalock et al., 2016; Schalock et al., 2018). Several changes drive organizations to reconsider and change the way they provide services. Firstly, the way societies view people with IDD shifts over time. In the recent years, values like inclusion, empowerment, self-determination, and self-direction have become more important, stimulating organizations to give people with IDD an increasingly active role within their policies and practices, to employ an individualized system of supports, and to recognize the importance of using personal outcomes (Schalock & Verdugo, 2013). Secondly, socio-political shifts and challenges, such as diminishing resources and an increasing need for services, drive

organizations towards further transformation (Schalock et al., 2018).

In their search, many organizations look at the possibilities of technology for shaping their portfolio. They are supported by the United Nations Convention on the Rights of People with Disabilities, which stresses the entitlement of all people to affordable assistive technology (Borg et al., 2011). According to Simplican et al., (2017), the concept of assistive technologies is very broad and refers to “any technology that could improve the quality of life for individuals with intellectual disabilities, including information and communication technologies” (p. 2).

Telecare is one subset within assistive technologies that is increasingly being used in the care for and support of people with IDD (Perry et al., 2009). In telecare, electronic information and telecommunication technologies are used to provide support from a distance. Where cameras, sensors, and tags are used to enable monitoring

and surveillance, phones, personal computers, and tablets can facilitate contacts between people with IDD and support staff. Telecare systems are often implemented to save costs and reduce staff burden, but are also employed to enable people with IDD to function more independently and to contribute to their safety (Draper & Sorell, 2013; Niemeijer et al., 2010).

There is a growing body of studies that focus on the use of telecare in the care for and support of people with IDD. Many studies have focused on exploring the experiences with remote monitoring and surveillance (e.g. Friedman & Rizzolo, 2017; Niemeijer et al., 2010; Perry et al., 2012) and delivering specific supports like assessments and practical skills instruction through a video connection (e.g. Bassette et al., 2016; Szeftel et al., 2012). There seem to be only a few initiatives that explored the usefulness of telecare for providing remote support as an alternative or addition to regular, general onsite support services for people with IDD. For example, Taber-Doughty et al. (2010) compared the effectiveness of prompting by onsite support staff with prompting by remote telecare staff on the performance of household tasks. They reported that the tasks were completed more independently but also that the tasks took longer to complete when remote prompting was provided. De Wit et al. (2015) found that an online portal through which independently living people with IDD could contact their onsite support worker in addition to their regular, onsite contacts, increased experienced accessibility of professional supports. Although these studies shed some light on the potential usefulness of telecare in support, the use of 24/7 online support for people with IDD has still received scant attention. This study aims to remedy this situation by reconstructing the use of online support on the basis of information from people with IDD and support staff.

This Study

The current study was part of a broader evaluation project aimed at exploring the value of an online support service named DigiContact for its users. The service aims to support people with intellectual disability in the mild range (IQ 50-69) or the borderline range (IQ 70-85), however, for the sake of simplicity, the term IDD is used in this paper. It is a 24/7 available online support service that uses video conferencing techniques to enable commu-

nication between people with IDD and a team of specially trained support staff. Although having Internet access is necessary to make a video connection, contact can also be realized without the video component through a “normal” telephone connection. People either use their own personal computer, laptop, (mobile) phone, or an iPad they receive on loan from the service organization. Technical support, either from a distance or at home, is available when problems arise. An essential characteristic of the service is that its users, people with IDD, decide if, when, how often and about what they contact the service. DigiContact was developed by the Dutch service provider Philadelphia Care Foundation and implemented in 2014 as part of its broader range of services for independently living people with IDD called *My Network* [Mijn Netwerk] (Vijfhuizen & Volkers, 2016). Other services within My Network are onsite support at home or at a community center, courses and onsite support regarding work. About 1,000 people with IDD received online support at least once in 2018. That same year, on average 1,100 online support contacts a week took place.

In a previous study we explored the support needs for which the online support service DigiContact was used (Zaagsma et al., 2019). We found that online support is used for a broad variety of support needs. Mental health issues and the need to connect with someone (seeing someone and having someone to talk to) were most prominently present in online support contacts. While online support was studied as if it were a stand-alone service, it is instead one component within a broader array of supports around individual support users.

The current study aimed to expand our knowledge on the value (and usefulness) of online support by taking its context of a wider mix of available services and supports into account. To be precise, we explored the experiences of people with IDD living independently and their case workers regarding (1) the position and value of 24/7 online support within a broader mix of supports, and (2) the relative suitability of online support keeping in mind the diversity of support needs. This paper focuses on two questions: How is 24/7 online support used in relation to other available supports for people with IDD living independently? How is 24/7 online support used for different support needs (in comparison with other available services and supports)?

In this article we use the term *support users* for people with IDD who receive professional support and *support workers* for professionals who provide support (online or onsite) to support users. *Case workers* are senior support workers who provide onsite support, usually at the support user's home and sometimes (also) at a community center. Besides providing onsite support, case workers are responsible for coordinating services and function as a contact person for other involved professionals and, for example, family members.

Method

A qualitative multiple case study was conducted, in which we reconstructed the cases of nine support users. Within each case we focused on the sources of support that were available to a support user, making a distinction between natural (informal) sources of support, like family and friends, and professional sources of support. The design was chosen to be able to study the naturally occurring phenomena of the use and experiences with online support, within its context of a wider mix of supports (Crowe et al., 2011; Stake, 1995). Semistructured interviews were held with support users and their case workers to include both perspectives. The research team consisted of four academic researchers and one co-researcher with IDD. As the co-researcher with IDD joined the team when data analysis was about to start, he was therefore not involved in this study's planning, design and data collection.

Sampling and Recruitment

Cases were selected from the population of people who live in their own homes and receive services from the Dutch service Philadelphia Care Foundation. A purposive sampling procedure (Patton, 2005) was employed to obtain a selection of cases representing a wide variety of support needs. Data of the Dutch version of the *Self-Sufficiency Matrix* (SSM-D; Fassaert et al., 2014; Lauriks et al., 2017) was used, as the SSM-D was used by the organization to plan and evaluate individual support plans of independently living support users and data was therefore available. Fassaert et al. (2014) define self-sufficiency as “the ability of individuals to provide for themselves regarding specific life domains (e.g. housing, social support or mental health)” (p. 584). The SSM-D is an instrument for assessing an individual's level of

self-sufficiency with respect to eleven life domains: finances, day-time activities, housing, domestic relations, mental health, physical health, addiction, activities in daily life, social network, community participation, and judiciary (Lauriks et al., 2017). The level of self-sufficiency on each life domain is evaluated as it is in the current situation, including available supports, through a single item and rated on a 5-point scale: ranging from ‘acute problem’ (1) to ‘completely self-sufficient’ (5). The level of self-sufficiency provided us with an indication of the life domains on which a support user needs support.

The sampling procedure consisted of three consecutive steps. We started by selecting support users who had at least one contact with the online support service during the two previous months (January and February 2017) and for whom relatively recent (2016 or 2017) and complete SSM-D scores were available ($n = 304$). Next, we extracted three subgroups from this selection based on SSM-D scores that reflected the variation of the number of life domains on which a person needs support: support users who were self-sufficient on all eleven life domains ($n = 23$), support users who were self-sufficient on most (defined as seven to ten) life domains ($n = 132$), and support users who were self-sufficient on none or a few (defined as zero to four) life domains ($n = 16$). The final step consisted of randomly selecting twelve support users, proportionally distributed over the three subgroups: respectively two, eight, and two support users.

These twelve support users were contacted through their case workers, who are employed by the service organization. Nine support users agreed to participate and gave permission to ask their case worker to participate as well. All nine case workers agreed.

Participants

Eighteen people participated in the study: nine support users and nine case workers (one of each in each case). Table 1 provides an overview of relevant participant characteristics.

Semistructured Interviews

Two separate interview guides were developed: one for support users and one for case workers. The interview guide for support users covered the topics of getting to know each other, the support user's daily life, support network (professional and

Table 1
Participant Characteristics

	Cases								
	1	2	3	4	5	6	7	8	9
Support user									
Sex	male	female	female	female	male	female	male	female	female
Age (years)	50	51	61	40	36	49	47	64	52
IQ level ^a	MID	BIF	BIF	MID	BIF	MID	BIF	MID	unknown
Relationship status	single	relationship	single	relationship	single	single	single	widow	married
Living arrangements	alone	alone	alone	alone	alone	with siblings	alone	alone	with husband
Urbanization level of residential area	semi-urban	urban	semi-rural	semi-rural	semi-rural	semi-rural	semi-urban	semi-urban	semi-rural
Day-time occupation	full time job	full time job	part time job	part time job	part time job	full time job	full time job	none	activity center
Subgroup based on SSM-D scores ^b	B	B	B	C	B	C	A	B	B
Duration use of ID services (years) ^c	>10	4	>10	>10	1	>10	>10	2	>10
Duration use of online support service (years) ^d	3	2	2	2	1	3	3	2	3
Frequency of online support contacts ^e	3	7	9	4	2	16	5	6	4
Case worker									
Sex	female	female	male	female	female	female	female	female	female

^aMID = Mild Intellectual Disability (IQ range 50-69), BIF = Borderline Intellectual Functioning (IQ range 70-85).

^bSSM-D is the Self-Sufficiency Matrix. A = self-sufficient on all eleven life domains, B = self-sufficient on most (seven to ten) life domains, C = self-sufficient on none or a few (zero to four) life domains.

^cTime interval between the date on which the participants started to receive professional ID services and the first interview.

^dTime interval between the date on which the participants started to use the online support service and the first interview.

^eMean number of online support contacts per month (during period January-June 2017).

natural), online support use and experiences, and the focus of received supports. As this guide was quite comprehensive, the topics were divided over two interviews. The interview guide for case workers contained topics about their support history with the support user, the support user’s support network, the focus of the provided supports and their experiences with online support.

We developed the questions about the lives of support users, their use of online support, and experiences with online support ourselves. Questions about the support network of support users were inspired by the *Manual Maastricht Social Network Analysis for People with Intellectual Disabilities* (MSNA-ID), (MSNA-ID; van Asselt-Goverts et al., 2012), which is an instrument for mapping characteristics of a social network around an individual with IDD. We used components of this instrument for exploring which social network members were felt to be sources of support. For exploring the focus of provided supports, we used the eight life areas plus the two supplemental scales of the Supports Intensity Scale (Thompson et al., 2004): home living, community living, lifelong learning, employment, health and safety, social activities, protection and advocacy, and the two supplemental scales regarding exceptional medical and behavioral support needs.

Procedure

A total of 24 interviews was conducted (see Table 2). The interviews were conducted by the first author and lasted between 30 and 75 minutes. The interview location was chosen by the participants: all support users were interviewed at home and the case workers were interviewed at the support user’s home, their own home or at work. One case worker couldn’t make time available for a face-to-face interview, so it was done by telephone.

If participants consented, the interviews were audiotaped and transcribed verbatim. Audio files were destroyed after analysis had been completed. One support user preferred that audio recordings were not made, so notes were made by hand and written out with as much detail as possible. All data were anonymized and handled and stored with care and respect for privacy. We included member validation as a validity check method (Green & Thorogood, 2014). All participants received a typed summary of their interview in accessible language to check for

Table 2
Conducted Interviews

Cases	Number of interviews		Total
	Support user	Case worker	
1	2	1	3
2	1	1	2
3	2	1	3
4	2	1	3
5	2	1	3
6	2	1	3
7	2	1	3
8 ^a	1	2	2
9 ^a	2	1	2
<i>Total</i>	<i>16</i>	<i>10</i>	<i>24</i>

^aOne interview with a support user was combined with an interview with a case worker.

accuracy. All of them felt that the summary rendered their experiences well. Quotes that are included in the results section, were translated by a professional with an English language proficiency of a native speaker.

The Medical Ethics Review Committee of VU University Medical Center (FWA00017598) confirmed that the Medical Research Involving Human Subjects Act (WMO) did not apply to this study and that official approval by the committee was not required. We followed the Disability Studies in the Netherlands Code of Practice in Research (Disability Studies in the Netherlands, 2017). Written informed consent was obtained from all participants.

Data Analysis

Data were analysed through an inductive thematic content analysis process. The Framework Method (Ritchie & Lewis, 2003) was used as a tool to facilitate data comparisons on a within- as well as across case level. Its defining feature is the use of a matrix for summarizing the data. Instead of being aligned with a specific epistemological approach, the Framework Method can be used within many qualitative approaches (Gale et al., 2013). All authors were involved in the process of data analysis, which corresponded to the procedure as set out by Gale et al. (2013). The data were distributed among members of the research team in such a way that the data belonging to each case were analysed by at least two researchers. The first

author analysed all data and the others each analysed data pertaining to two or three cases.

While the academic researchers read and reread the transcripts and notes to familiarize themselves with the data, the co-researcher with IDD preferred to listen to audio-recordings of the interviews. As a next step, the researchers read the transcripts and notes (or listened to the audio-recordings) again and applied descriptive codes, independently from one another. Researchers who coded data on the same cases met up to compare and discuss their codes. At first the co-researcher coded data together with the first author, later on he (like the other researchers) applied codes on his own and compared and discussed them with the first author. During a day-long meeting with the whole research team, the nine cases were discussed one by one. Codes were first grouped into (sub)categories and subsequently into categories, which all together formed the analytical framework. To facilitate this process, we used coloured paper for the assignment of different (sub)categories, which turned out to help in making the process and its output accessible for all. After this, the first researcher returned to the data and coded all transcripts and notes one more time as a final check that nothing was missed, using the codes and (sub)categories from the analytical framework. The final framework consisted of two parts: the codes and (sub)categories in the first part were about the use and position of online support within a broader mix of available supports, those in the second part rendered what the provided supports focused on. In the next stage a matrix was constructed to display the data on provided supports by different sources in a highly-structured way, again using colours to mark the (sub)categories. As a last step, during a three hour meeting with the entire research team, this matrix was used to make comparisons within and between cases, in which we identified, discussed and interpreted patterns and exceptions.

Results

The findings are presented in parallel to the two research questions. We first present the findings on how 24/7 online support was used and positioned within a broader mix of services and supports and we continue with findings regarding how online support was used for different support needs. Quotes are used to illustrate findings. Each quote ends with a code between parentheses, as a

reference to its source. This code consists of a prefix (SU = support user, CW = case worker) and a number (case 1-9).

Position and Value of Online Support: Tailoring Professional Supports

In all nine cases, online support was seen and used as an addition to onsite support at home. Support users and case workers agreed that onsite support at home was the most important professional support service. Onsite support was mostly provided by case workers, who had a central and coordinating role within the range of services and functioned as a link between professional services and natural sources of support like family members. Other available professional services, such as online support and support at a community center, were felt to be complementary.

The online support service was used as a tool to provide support whenever and wherever a need arose and facilitated a more tailor-made delivery of professional supports. Three ways of tailoring professional supports through online support were identified: (1) extending the availability of professional support by functioning as a back-up for onsite support, (2) broadening professional support options by being an alternative for onsite support at home, and (3) enhancing flexibility in professional supports by being more easily and quickly adjusted.

Extending Availability of Support

In all cases online support was seen as an extension to onsite support at home. It was contacted when onsite support was not available, for example during evenings, nights, weekends, and part-time days of onsite support workers. Most support users felt that having continuous access to professional support was valuable for them, as the situations in which they need support were often not plannable and postponing contact was not always a good idea. The online support service enabled a more frequent outlet for stress and tension and feelings of uncertainty could be taken away sooner:

It's about taking away the insecurity more quickly. Otherwise, he would end up worrying over things. And he would not phone his parents or his sister when feeling troubled. He'd ruminate over a problem, increasing his own feelings of stress, which may result in him

wetting his bed or hyperventilating and feeling restless. (CW7)

Moreover, merely knowing that a professional can be contacted at all times, gave some support users a reassured feeling:

The fact that it is there, is very nice. If I don't find a solution I can phone them. They are available at all hours. So, if I have a problem, I can phone them and ask them what to do. I find that pleasant, useful and how shall I say it, reassuring. I know I can rely on them. (SU2)

However, not all support users felt that having 24/7 access to online support was useful for them. Two support users felt that their contacts with an onsite support worker were sufficient: "So, Digicontact actually became too much. I already am talking to support workers two times a week. If I then also have to talk with Digicontact, well, then I don't know what to say to Digicontact" (SU5).

A few case workers talked about the online support service also having positive consequences for them. Knowing that their client could contact the service when they are not working, enabled them to disconnect from work without worrying:

So, in that sense, it was quite a relief that we had Digi and that Digi enables us to test the waters of what is going on at home. So it is very pleasant for us that we can keep tabs on the goings on during the weekend. (CW6)

Broadening Supports Options

In about half of the cases (1, 2, 3, 7, 9), online support was also used parallel to onsite support at home and the two services complemented and strengthened each other. Support users also called the online service at times when their onsite support worker was available, because it better suited their needs.

The first thing is Digi. Yes, I think very highly of it. They may be far away, but it is a very good thing to have. Those people listen to me and they have suggestions which I can try out, but the fact that they are listening, can give me such peace that you automatically know what to do. (SU3)

One support user preferred the (literal and figurative) distance of online support workers over

the proximity of an onsite support worker at home.

To be honest, I don't call anybody, not even my brother. I call DigiContact instead and tell them what's up. That I do want. They are different people. They are very nearby and they are far away. Digicontact, you know. (SU2)

In contrast, other support users preferred to talk to their onsite support worker, as they found the trusting relationship they had built over time to be a prerequisite for sharing worries and doubts.

It also depends a bit on whom I get to talk to, because sometimes I do not know them so well and then I am really not, with people I do not know well, I can not always talk really well, let's put it this way. (SU1)

Enhancing Flexibility in Supports

The case workers in five cases (1, 4, 5, 6, 8) felt that online support enabled more flexibility in the intensity of provided professional supports and therefore increased the agility in services. Adapting online support frequency was relatively easy and quickly done, facilitating responsiveness to fluctuations in support needs: "At first I really needed it. But now I am good and I don't really need them that often anymore" (SU4).

In two cases the support users had lost a close relative, without whom living independently was no longer feasible. They were currently on a waiting list for supported accommodation and online support helped to bridge time by upgrading the intensity of available supports:

She really needs our availability, she asks for it, too. You can see it in how she continuously contacts DigiContact, and us, and anybody. Unfortunately, we cannot offer her what she needs. You could invest 10 hours, but she will still be like a young girl in need of her mother: someone who tells her like, now we are going to do this and then we will do that. That is what she wants and asks for. And that is why we arranged a contact each day. (CW6)

In two other cases (1, 5) online support was used to anticipate on changes in available natural supports. The case workers found it important that support users get used to online support now,

to facilitate it taking on a possible bigger role when needed. For example, one case worker talked about a future in which a support user's parents can no longer give support:

And I think we need to point this out again and again, like: assuming the situation occurs, you can call DigiContact more often, also without an appointment. It will be one of those things that need to come up automatically. However, we need to remind him time and again. (CW1)

Suitability of Online Support for Different Support Needs

Fifteen subcategories that reflected the focus of provided supports were identified and clustered into five categories: mental health, interpersonal relations, metacognitive strategies, social contacts and practical issues. In each of the nine cases support was focused on issues belonging to these five categories. Cases differed with respect to the relative importance of the supports from the different categories (for example, mental health related supports were felt to be more important in some cases than in others), but as these differences fall outside the scope of this paper, they are not included in the description of the findings. However, the relative importance of the five categories on the level of the cases as one group, is reflected in the order in which the categories are presented: from most to least important. Table 3 gives an overview of the sources that provided support on each (sub)category within the cases. In each case support was provided by a combination of natural and professional sources. Whereas onsite support at home focused on all fifteen (sub)categories, the online support service focused on eleven sub-categories. The number of (sub)categories on which online support was provided varied between cases from one to six.

Focus on Mental Health

The first category consisted of supports focusing on mental health related issues. Support users were supported to manage their emotional state of mind with the aim of maintaining a certain balance. In all cases, mental health related supports were provided by a combination of natural and professional sources. The support worker at home and family members were the main sources of support. This category consisted

of three sub-categories: influencing the emotional balance, signaling of emotional and behavioral problems and referral to a specialized mental health care professional.

In all nine cases, support aimed at influencing the emotional balance. In seven of these cases (1, 2, 3, 6, 7, 8, 9), the online support service contributed by talking with support users about what was bothering them, offering them emotional support through understanding and reassurance and giving practical advice on how to continue. "Once I feel at a loss with myself, I call Digi. In fact, I called them this afternoon. I had a terrible morning and they give me advice and make notes and that helps to empty my mind" (SU3).

In four cases, support aimed at signaling emotional and behavioral problems. In two of these cases (3, 9), the online service was involved.

Yes, she is really troubled by emotional things in her life. She finds it hard to talk about them, and equally hard to find solutions. She gets stuck at a certain point. That is when she needs help in order to get a grip on the problems and to help her through them. That is what I do, what [name husband] does, what her mother does and what Digicontact does. (CW9)

In one case mental health related supports also consisted of referring the support user to a specialized mental health care professional, but the online support service did not play a role in the referral process.

Focus on Interpersonal Relations

The second category consisted of supports that focused on the interactions and relationships with other people. Supports were provided by a combination of natural and professional sources, with the onsite support worker at home having a prominent role. This category consisted of three sub-categories: coaching on assertiveness, preventing and resolving conflicts with others and stimulating insights into social situations.

In seven cases support aimed to enhance the support user's ability to be more assertive and to stand up for themselves. In three of these cases (4, 6, 7), the online support service was involved as it coached support users on how to use strategies to make one's wishes and needs adequately known to others:

Table 3
Overview of the Focus of Provided Support

	Natural support			Professional support		
	Family	Friends and acquaintances	Support at home	Support at community center	Online support	
Mental health						
Influencing emotional balance	1 2 3 4 5 6 7 8 9	3 5 6 7	1 2 3 4 5 6 7 8 9 1	1 2 3	6 7 8 9	
Signalling of emotional problems	4 8 9		3 8 9	3	3	8
Referring to mental health professionals			3			
Interpersonal relations						
Stimulating insights into social situations	1	7	1	4 5 6		
Coaching on assertiveness	1 2	8	1 2 3 4	6 7 8	4 6 7	
Preventing and resolving conflicts with others	1 4		2 3 4	6 8 9	3 4	4 6
Social connection						
Having someone as company	1 2 3 4 5 6 7 8 9 1 2 3 4 5 6 7 9 1 2 3	9 1 2 3 4 5 6 7 9 1 2 3	5 6 7 8 9 1 3	5 7 1	3 6 8	
Stimulating activities with others	1 2 4 5 6 7 8 9 1 2 3 4 5 6 7 9 1 2 3	9 1 2 3 4 5 6 7 9 1 2 3	5 6 7 8 9	5 7	3 6 8	
Metacognitive strategies						
Facilitating choice and decision making	1 2 4 5 6 7 8 9		1 3 4	6 7 8 9	3 7	
Facilitating goal determination and planning	1		1 2 3 4 5 6	9 1		
Applying and maintaining structure in daily life	1 6 8		1 3 5 6	8 9 1	1 3 5 6	
Practical issues						
Maintaining and promoting physical health	1 4 6 7 8		1 2 3 4 5 6	8 9	5 7 1	
Administration and finances	1 2 6 7 8 9	3	1 2 4 5 6	9 1	2	
Running the household	1 2 4 5 6 7 9	3	7 9 1	3 4 5	1 4	9
Mobility		9 3	1			

Note. The numbers 1 to 9 refer to the nine cases (e.g., 1 refers to case 1).

I love my mother very much, I try to explain her that. I say, yes, but I want to make my own choices. I try to explain that, but it is difficult. I think, never mind, and I stop. That is tough. If it is difficult, I can always call DigiContact for advice. (SU4)

In eight cases, support focused on preventing or resolving conflicts with other people. In two of them (4, 6), the online service played an active role by signaling conflicts and coaching for prevention and solving conflicts:

Then they can give me advice. Because I often think that people are angry, even when they are not. I cannot deal with angry people. I get angry too or I walk away. I cry a lot, recently, and they support me, try to make me stronger. I really hate quarreling. (SU4)

In five cases support was more generally aimed at enhancing insights into and understanding of social situations. The online support service was not involved in this subcategory.

Focus on Metacognitive Strategies

The third category consisted of supports that focused on using metacognitive strategies (reflective thinking strategies and cognitive problem-solving skills). This support was provided by a combination of natural and professional sources of support, with the onsite support worker at home playing a prominent role. This category consisted of three sub-categories: facilitating choice and decision making, facilitating goal determination and planning and applying and maintaining structure in daily life.

In all nine cases, support aimed to help making choices and making decisions. In two of these cases (3, 7) online support played a role by giving advice or helping to get an overview of possible options.

Yes, the choice is mine. But I do ask others what is the best thing to do. Mainly my mum and my sister. And sometimes my support worker. Especially when I am in a difficult situation, I will discuss it with DigiContact. We think together and they make suggestions. And often I can work with it. (SU7)

In seven cases support was aimed at applying and maintaining structure in daily life. The online

service was involved in four of them (1, 3, 5, 6) by helping to keep up a certain structure in daily rhythm and activities.

So, once he is without supervision or stimulation from us, you can see him lose control. So he still needs that supervision and stimulation from outside, and we need to keep him on track. And once he is on track, all seems well, and you may start wondering whether he still needs us. I still think he still needs Digicontact for support. They take his list of tasks and they check what he has done. Did you eat, what did you eat? Did you do all your tasks? So in that sense, that extra check up on him, keeping him on the straight and narrow, can be quite handy. (CW1)

In seven cases support aimed at facilitating goal determination and making plans. Online support was not involved in this subcategory in any of these cases.

Focus on Social Contacts

The fourth category consisted of supports with a focus on being connected to other people and aimed at having (enough) social contacts. Again, a combination of natural and professional sources of support was present: in all cases supports were broadly provided by family members, friends and acquaintances and the onsite support worker at home. This category consisted of two sub-categories: being a social contact or company and expanding leisure activities with other people.

In all nine cases, the people who provided support were at the same time seen as a social contact. In four of these cases (1, 3, 6, 8), the online support service was used to be able to see and talk to someone, especially at times when other people were less accessible (e.g. weekends, evenings and nights):

I think it does do something extra for her, because the Sunday can be a very long day. The children are not always there. I think the bonus is that she has had a conversation after she's been on her own for a while. (CW8)

In all cases support was aimed at stimulating activities with other people. In three of these cases (3, 6, 8) the online support service was involved, for example by helping to find information online

about possible activities and by motivating to keep in touch with people when feeling depressed: “And they also give advice, like do visit your religious community” (SU3).

Focus on Practical Issues

The fifth and final category consisted of supports that focused on practical issues to help with the execution of tasks in daily life. These supports were provided by a combination of natural and professional sources of support, with the onsite support worker at home and family members as main sources. This category consisted of four subcategories: maintaining and promoting physical health, administration and finances, running a household and mobility.

Although in all cases support aimed at promoting physical health, in just one case (1) the online support service was involved by stimulating healthy eating, by checking meal plans, and encouraging, and brainstorming about easy to make, healthy meal options: “Uh, DigiContact usually asks about my week and whether I am eating healthy foods, that too” (SU1).

In all cases support on administration and finances was present, but online support was again involved in only one case (2) and consisted of helping to understand difficult letters: “I will tell them when I have mail. I ask them what I should do. And then they tell me” (SU2).

In eight cases, support aimed at running the household. In three of them (1, 4, 9) the online support service played an active role by checking if chores had been completed, remembering to do remaining chores, making a plan together for completing tasks and functioning as a helpline for unexpected situations:

It is nice to know they are there when something unexpected occurs, that they can help you. Like when I was wondering what to do about a blocked toilet, what should I do? I called them and then it was solved. They can advise you. (SU4)

In four cases support was aimed at the mobility of the support user, for example by helping to prepare public transport plans or driving the support user to his or her destination. However, the online service was not involved in this subcategory.

Discussion

The cases of nine online support users were reconstructed to enhance our understanding of the usefulness of 24/7 online support as part of a broader mix of available supports and services for independently living people with IDD. The participating support users were high-functioning individuals with IDD who had reached a basic level of comfort in using the online support service, resulting from an active learning process when they started using the service and from having access to technical assistance when necessary.

The first question we aimed to answer concerned how 24/7 online support is used in relation to other available services and supports. We found that online support is used as an addition to regular onsite support (i.e. a support worker visiting the support user at home) to facilitate tailor-made professional supports. First of all, the round-the-clock availability of online support enables people to seek support whenever and wherever a need or question arises. They do not have to postpone contact when onsite support staff is not available. In addition, offering online support creates an extra support option, that some support users (sometimes) prefer over regular onsite support. Finally, online support can move with and adapt to fluctuations in support needs more easily compared to regular onsite support services. Adding online support to a broader mix of services therefore improves flexibility and agility of professional services.

The second question concerned how 24/7 online support is used for different support needs. In a previous study we found that support users as a group used online support for a broad range of support needs (Zaagsma et al., 2019). The current findings show that, an individual support user uses online support for a relatively small selection of support needs compared to regular onsite support. Whereas onsite support at the support user’s home focuses on the complete range of support needs of individual support users, online support mostly focuses on mental health related issues and provides support users with an extra social contact (i.e. someone to see and talk to). Many support users use online support as a readily available outlet when feeling bad, which helps them to balance and steer their emotional state of mind and prevent from bigger emotional outbursts. Online support is less often used for practical

support, relationships with other people (like coaching on social skills) and the use of metacognitive strategies such as planning and decision making. A possible explanation for this finding - that online support is mostly used for mental health related issues-, is that these issues have a relatively high sense of urgency, as postponing contact will extend emotional tension. Other issues, like how to make a certain decision, may be experienced as less urgent and support users may therefore tend to wait for onsite support.

Online Support as an Addition, Not Substitute

The findings that onsite support continues to be the principal service and that online support forms an addition that is mainly used for mental health related issues, indicate that (at least for the included cases and in this phase) online support contributes to a more tailor-made delivery of professional supports but cannot be considered to be a substitute for all onsite support contacts. This may have multiple reasons, of which we would like to discuss two in particular. First, a difference between onsite and online support lies in the nature of the relationship between support user and support professional. Onsite support is often provided by one or a few onsite support professionals during a longer period of time and it is quite common that a relatively close and personal bond is formed between a support user and his or her onsite support worker (Bigby, 2008; van Asselt-Goverts et al., 2013). Support users do not have a fixed online support worker; each time they contact the online support service, they talk to the professional who is on duty. Therefore, it is not likely that such a bond is formed with online support workers. As a result, support users may strongly prefer to discuss issues with their onsite support worker. However, we also found that some support users actually prefer to talk to someone who is less involved and can help them better because they have an outsider view.

Second, for many years, onsite support on a regulated time interval at home has been the standard model of service delivery for people with IDD living independently. As a result, support users and onsite support staff have gotten used to this way of receiving and providing support; such as support users learning to postpone their questions and concerns until their onsite support worker is available. Including the online support

service into the mix of professional services brings about shifts in roles, tasks, and responsibilities for support users and professionals alike. These shifts can be experienced as challenging by both parties. The role of onsite support workers becomes more about coordinating and managing different supports and less about directly supporting. Support users have more opportunities to take on responsibility and ownership of their own support, but may struggle with changes in their relationship with support staff. As a result, people may feel hesitant towards adopting a different way of providing or receiving support.

Continuous Accessibility of Professional Support

Offering 24/7 online support enhances the accessibility of professional supports for a group of people who before had restricted and regulated access to professional support, for example a few hours once or twice a week. This can have several advantages for support users and their onsite support staff. For support users, continuous access to online support can have a preventative impact on functioning and emotional well-being (Zaagsma et al., 2019), as support can be sought whenever and as often as needed. Problems can be solved while they are still relatively small; and stress, worries, and frustrations can be vented more often, which prevents accumulation of tension. Also, simply knowing that professional support is always available, makes some support users feel safe. For onsite support staff, partnering with the online support service can lead to a feeling of shared responsibility and enables them to disconnect from work more easily. This may reduce work related stress and risk of burnout, which can have a positive impact on the quality of their support (Skirrow & Hatton, 2007; Thompon & Rose, 2011).

The value of having 24/7 access to professional supports seems to be especially evident for people with limited social networks, as they depend strongly on professionals for support. Multiple studies have shown that people with IDD have relatively small social networks and that support professionals make up a significant share of these networks (Forrester-Jones et al., 2006; Lippold & Burns, 2009; van Asselt-Goverts et al., 2013; Verdonschot et al., 2009). This was also the case for some support users in this study. At the same time, we saw that people around support

users were not only an important source of support, but at times also of confusion, conflict, and stress. It is recognized that many families and other caregivers are in need of services and support (Amadoet al., 2013; Reynolds et al., 2015; Reynolds et al., 2018). Besides being a service for people with IDD, the online supports service could also be a valuable way of supporting family members, friends, volunteers, and general health professionals. By supporting the support network around a person, the online support service could also indirectly have a positive impact on the lives of support users (Barrio et al., 2016; Brown & Schippers, 2018; Zuna et al., 2015).

Self-Direction in Support

Self-direction regarding support contacts is a central element of the online support service, as support users are the ones who control their online support contacts; they choose if, when, how often, and for what reason they contact the service. Self-direction in support is often associated with positive outcomes for support users (e.g. Harkes et al., 2014; Lakhani et al., 2016), for example with higher levels of support satisfaction (Williams & Porter, 2015). The fact that support users can direct and design their online support contacts also generates possibilities for more personalized support packages with a better fit with individual preferences and needs. This ties in well with the international trends within the field of support for people with IDD of offering more personalized supports and opportunities for self-direction (Schalock & Verdugo, 2013; Wehmeyer & Abery, 2013).

Strengths and Limitations

By using the experiences and perspectives of support users and their case workers, this study demonstrates that the experiential knowledge of people with IDD and professionals who know them well, not only makes up useable information, but is also an invaluable source of information when evaluating new support initiatives. Incorporating both viewpoints (that of support users and case workers), enabled us to avoid giving too much emphasis on a single perspective. However, there are more perspectives that might offer interesting insights. The perspective of a family member or close friend, for example, might give us more detailed information about the role of natural supports.

Although great care was taken in the selection of cases and we feel confident in having captured a diverse sample of cases with respect to support needs, it is important to stress that the nine cases are not representative of the entire group of online support users. Caution should therefore be taken with generalizing the findings.

Implications for Practice and Research

The increasing use of assistive technologies and telecare within care and support practices for people with IDD (Perry et al., 2009) underlines the relevance of this study. Although offering 24/7 online support is a useful and valuable way of providing additional services to people with IDD living independently, there are limitations to what online support can offer compared to regular onsite support. For many support users, who in the past experienced onsite support, face-to-face contacts with a fixed onsite support worker are at this moment irreplaceable. Within a context of social care reforms, nowadays a reality in many countries, a service like DigiContact should not be seen as a cost-saving replacement for onsite services, but rather as a way to give people with IDD a worthy addition to onsite support as a response to austerity measures.

For organizations and professionals active in service planning, it is important to think carefully about why and how online support is embedded within the range of available services and what support users need to be able to benefit optimally from it. At the same time, it is crucial to acknowledge the diversity among support users. Each support user has his or her unique set of support needs, preferences, and experiences, and there is not one mix of services and supports that fits all. Decisions on if and how online support is offered to an individual support user should result from an inclusive process of deliberation and tryout, in which the support user has a central role. It is essential that people get the space, opportunities, and support they need to find their own optimal mix of supports.

This study shows an example of people with IDD adopting a new technological application into their daily lives and benefitting from it. It would be interesting to extend our look into the possibilities of using smart home technologies and their potential to improve the quality of life of people with IDD and their surroundings, for example with regard to safety and energy saving.

This study raises interesting questions for further research. For example, it would be interesting to find out how people who just entered the service delivery system (and are not used to other ways of support delivery, yet) experience online support. In addition, a study on how individual online support users give meaning to their experiences of having round-the-clock access to the online support service could also provide interesting additional insights.

Conclusion

This study provides interesting insights into the value and usefulness of offering 24/7 online support within a broader mix of professional services for (the lives of) independently living people with IDD. Although online support is not seen and used as an equal partner to regular onsite support services, it is considered to be a valuable addition by creating a situation in which support users have continuous and unlimited access to professional supports and can control and direct their own support contacts. The potential value of round-the-clock online support is promising, especially in relation to the mental health of people with IDD.

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