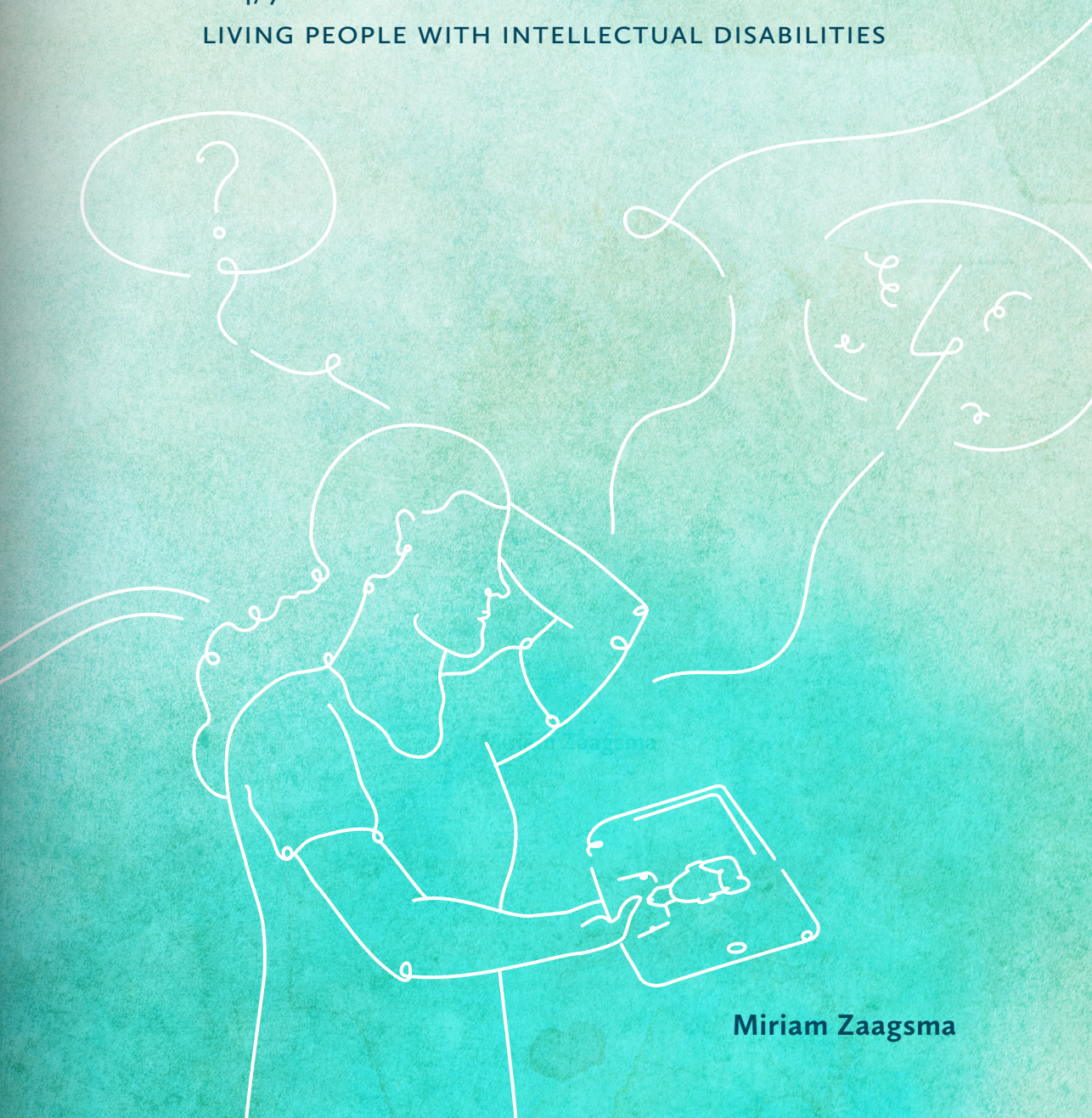
The added value of on-demand remote support

EXPERIENCES WITH DIGICONTACT:
24/7 AVAILABLE SUPPORT FOR INDEPENDENTLY LIVING PEOPLE WITH INTELLECTUAL DISABILITIES



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Experiences with DigiContact: 24/7 available support for independently living people with intellectual disabilities

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Pick up your feet
You've got to move to the trick of the beat
There is no elite
Just take your place in the driver's seat

(Roberts, 1978[1])

1 Roberts, P. (1978). Driver's seat [Song recorded by Sniff 'n' the Tears]. On *Fickle Heart*. Atlantic Records

CONTENTS

CHAPTER 1

General introduction

Service organizations for people with intellectual disabilities are expected to contribute to the creation of conditions and opportunities that enable people to participate in their communities and lead rich and fulfilling lives. In recent years, various changes in the field of intellectual disability policies and practices encourage these organizations to search for new ways to organize and deliver their services. In this search they often look at the possibilities of technology for shaping their service offer. An example is the initiative of the Dutch service organization Philadelphia Care Foundation to set up and implement the remote support service DigiContact as part of its service portfolio for people with intellectual disabilities who live in their own homes in society and need professional support for day-to-day living. DigiContact offers 24/7 on-demand support that is delivered remotely through video conferencing calls or regular phone calls with support workers. For new support services it is essential to know what they can (and cannot) contribute to the lives of the people they assist. This thesis aims to evaluate the potential added value of including DigiContact in a broader offer of services for independently living people with intellectual disabilities.

This introductory chapter consists of three sections. In the first section, the context of this thesis is outlined by describing changes in the field of intellectual disability policies and practices that encourage service organizations to look at the possibilities of technology in their search for new ways to support people. The second section focuses on the DigiContact service and the people whom it supports. In the third section, information regarding this thesis is provided, including its aim, research questions, methodological considerations, as well as an outline of its further content.

CONTEXT

A changed view on the construct of intellectual disability

Over the recent decades, the belief that people with intellectual disabilities should have the same opportunities in life as people without disabilities has grown, as reflected in the adoption and increased ratification of the United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006). This was set in motion by changes in the societal and scientific views on the construct of intellectual disability. Up until roughly the 1970s, intellectual disability was predominantly regarded as a deficit within a person that made that person incapable of taking on 'normal' social responsibilities. This started to change under the influence of the normalization principle, which maintains that the best practice is to normalize the environments, daily routines and social roles of people with intellectual disabilities (Nirje, 1969; Wolfensberger, 1972). Further change was fuelled by the disability studies academic discipline, which emerged in the 1980s as a product of the disability civil rights and emancipatory movement (Barton & Oliver, 1997; Ferguson & Nusbaum, 2012). This discipline supported the assumption that an experience of disability arises due to societal mechanisms leading to the exclusion of people with impairments (e.g., Oliver, 1996; Rioux, 1997) and contributed to a mounting awareness of society's role in the experience of (intellectual) disability and the importance of taking away barriers that hinder the full participation of people with impairments.

In contemporary policies and practices, a socio-ecological perspective on intellectual disability (i.e., a disability arises from the interaction between a person and the environment) generally prevails. A good example is the definition of intellectual disability as proposed by the American Association on Intellectual and Developmental Disabilities (AAIDD)[2]: a state of limited functioning that results from personal competencies not living up to the demands of environments in which a person is expected to function (Schalock et al., 2021). Support is a key element for enhancing functioning and enabling people with intellectual disabilities to pursue a life of good quality (Thompson et al., 2009). Supports can take on different forms and come from a variety of sources, including services from specialized organizations.

2 The AAIDD is a membership organization for professionals and organizations with a strong influence on intellectual disability research, policies and practices internationally (see also: www.aaidd.org).

Changing values in support: towards the promotion of social inclusion and self-determination

As a result of the changed view on intellectual disability, the ideas on how people with such disabilities can be best supported have also shifted. Over time, the focus has shifted towards promoting their social inclusion, self-determination and self-direction (Mansell & Beadle-Brown, 2010; Šiška et al., 2018). The most important strategies have been deinstitutionalisation and the provision of community-based services (Šiška & Beadle-Brown, 2022; Tøssebro, 2016). However, as being merely present in the community has proven to be insufficient to foster meaningful inclusion and a sense of belonging (e.g., Amado et al., 2013; Bredewold et al., 2020; Cummins & Lau, 2003; Overmars-Marx et al., 2014), services have also started to emphasize the building and maintaining of social relationships as well as the participation in community activities (Bigby et al., 2018; Simplican et al., 2015). In addition, services focus increasingly on empowering people by stimulating and enabling them to exercise more choice and control over their own lives, including their support. Person-centered approaches to the planning and delivery of supports and services form the basis for ensuring that support is aligned with the specific needs, wishes and ambitions of individuals (Claes et al., 2010; Ratti et al., 2016; Taylor & Taylor, 2013).

The values of social inclusion, self-determination and self-direction are amongst the foundations of the construct of quality of life. Quality of life refers to a state of well-being that is experienced when a person's basic needs are met and (s)he has the opportunity to pursue and achieve goals in major life settings (Brown & Brown, 2005; Brown & Schippers, 2018; Goode, 1994). It has become a leading concept within intellectual disability policies and practices that is to improve the fit between what people need (in terms of support) and society's expectations in order to improve their opportunities for striving for rich and fulfilling lives (Goméz et al., 2021). With regard to the provision of services, quality of life is increasingly employed as a framework for quality assurance and improvement (Lombardi et al., 2019; Schalock et al., 2018).

The provision of services under pressure

In the recent years, the delivery of services for people with (intellectual) disabilities in many Western countries has come under increasing pressure due to a significant growth in the associated costs. Several developments seem to play a role in this growth. First, the transition from the institutional model of service delivery (in which services are bundled and organized on a large scale) towards a community-based and personalized model is accompanied by increasing costs. Although it is expected that small-scale forms of living and working in society will save costs in the longer term, as people will increasingly take on valued roles within society (Davys & Tickle, 2008),

more investment is needed initially to make this happen (May et al., 2019). Second, as the life expectancy of the general population has increased as a result of medical and social advances, the number of people relying on long-term care and support services (for an extended period) has grown, which causes costs to rise further (Eggink et al., 2016; Mosca et al., 2017; Spasova et al., 2018). People with intellectual disabilities also have an enhanced life expectancy, resulting in a need for more intensive or complex (and sometimes more expensive) forms of care and support (Hermans & Evenhuis, 2014; Thalen et al., 2022). Third, previously there was relatively little focus on clinical diagnosis in people with intellectual disabilities, and over time more importance has been placed on improving their mental health (Didden et al., 2016; Došen, 1993; Einfeld et al., 2011). Fourth, there are indications that societies have changed in a way that causes the demand for specialized intellectual disability services to grow (Woittiez et al., 2018). For example, societies have become in some respects more complex and chaotic and families are less able and willing to provide care for their loved ones (Emerson & Hatton, 2008; Snell et al., 2009; Woittiez et al., 2018).

A substantial increase in care costs is not always considered desirable and feasible. Especially in countries where national governments are neo-liberally oriented, investing in the provision of services for people with disabilities is not always prioritized when also facing other major challenges, such as international tensions and security concerns, climate change and economic setbacks (Power & Hall, 2017). This often results in restricted care budgets that cannot expand in line with the growing costs. In an attempt to safeguard the accessibility of services for people who really need them, various governments have initiated reforms in their national long-term care systems (Hauben et al., 2012; Ranci & Pavolini, 2015; Spasova et al., 2018). This was also the case in the Netherlands, where the long-term care system has undergone a major reformation over the past fifteen years.

Long-term care reforms in the Netherlands

The overall aim of the Dutch long-term care reforms was to reduce costs and enhance quality of care by making it more person-centered (Van Ginneken & Kroneman, 2015). It was envisioned that the reforms would result in a higher quality of life for people with disabilities as more opportunities for participating in community life, exercising control over one's care, and living (for a longer period of time) in one's own home would be created (Kromhout et al., 2018). Maarse and Jeurissen (2016) describe how the reforms were based on four interrelated pillars: a normative reorientation on the concept of care with all citizens needing to take on more personal and social responsibility, an emphasis on non-residential and community-based services, a decentralisation of non-residential care towards municipalities, and significant budget

cuts that were politically sold as being possible due to a more efficient organization of care. These four pillars were applied within an environment in which there was less governmental interference in care. Market principles (with elements of contracting and competition between services and organizations) were introduced to give people the opportunity to make choices between services and to stimulate care providers to deliver better care at lower costs. The biggest landmark of the Dutch long-term care reforms consisted of major legislative changes in the form of four new care acts[3] that came into effect as per January the 1st in 2015 (Van Ginneken & Kroneman, 2015).

One of these care acts was the new Social Support Act [Wet maatschappelijke ondersteuning]. Under this act municipalities were given the responsibility of supporting citizens with disabilities or psychosocial problems who live in their own homes regarding their participation in society (Maarse & Jeurissen, 2016). The starting point in making decisions regarding the use of support was that much of the needed support can be provided by natural (unpaid) support networks. In practice, it is first considered what persons with a need for care and/or support can do for themselves and what their family, friends and volunteers from local community networks can offer. Only when after this assessment there still remains an unmet need for support, paid (professional) services can be deployed. With regard to paid services, general facilities (such as meal services and community centers) are considered first, before resorting to customized care from specialized providers such as service organizations for people with intellectual disabilities.

Although the importance of the reforms and the ideas behind them were generally recognized, the way the reforms were shaped and implemented received much criticism as this was felt to counteract the implementation of values like participation and inclusion. Expenditure cuts led to longer waiting lists and more narrowly defined eligibility criteria, thereby contributing to the exclusion of people with so-called mild needs from a right to care (Grootegoed & Tonkens, 2017; Woittiez et al., 2018). The Social Support Act has been reproached for imposing unrealistically high demands regarding the self-sufficiency of people with disabilities and for overestimating the potential of natural support networks (e.g. Da Roit & De Klerk, 2014; Grootegoed & Tonkens, 2017; Grootegoed & Van Dijk, 2012; Janssen et al., 2016).

3 These acts are: the Long Term Care Act [Wet langdurige zorg], the Health Insurance Act (Zorgverzekeringswet), the Youth Act [Jeugdwet], and the Social Support Act [Wet maatschappelijke ondersteuning]. See for an overview for example van Ginneken and Kroneman (2015).

Service organizations search for new ways to organize and deliver support

All the above mentioned changes encourage service organizations for people with intellectual disabilities to search for new ways to organize and deliver their support. These new ways should above all meet the societal and scientific call for realising personalised and community-based support that promotes the social inclusion of people as well as their level of choice and control over their lives. In addition, it has become essential that these new ways of organising and delivering support make use of monetary resources (care budgets) in a socially responsible way without limiting the opportunities to maintain and further improve the quality of support. In the Netherlands, the long-term care reforms place extra pressure on the need for organizations to set up and shape their support offer, especially for those people who live in their own homes, differently.

As if this situation is not challenging enough for service organizations, there is still another factor that complicates this search; namely a growing shortage of care and support staff (Liu et al., 2017; World Health Organisation, 2022) in combination with the rising demand for long term care (Woittiez et al., 2018). In the Netherlands, the shortage of staff within the intellectual disability care sector is expected to quadruple between 2022 and 2031 (ABF research, 2022). This is largely due to the aging of the general population, as this results in a decline in the number of employable people. However, there may be additional issues at play that make it extra difficult to attract and retain support staff, like relatively low wages, high workplace demands, limited support options and low work status (Bogenschutz et al., 2014; Hussein, 2017; Ineland et al., 2018; Judd et al., 2017; Ryan et al., 2019; Vassos & Nankervis, 2012). This causes service organizations to look for ways to continue the provision of good quality services with fewer available support staff.

Technology as part of a new support strategy

In their search for new ways to organize and deliver services effectively and efficiently, organizations often look at the possibilities of technology for shaping their service portfolio. There are several reasons as to why technology is regarded as a valuable component of a new strategy. First, the use of technology can contribute to the opportunities of people with disabilities to do the things they want to do (e.g., live in their own home, participate in certain activities) without needing (more) help from others, thereby making them more independent (Owuor et al., 2018; Ramsten et al., 2018; Söderström et al., 2019; Wehmeyer et al., 2020). Second, technology is projected to contribute to greater efficiency in care processes and through this may support the work of support staff (Proudfoot et al., 2011; Simplican et al., 2017; Timmer, 2015). Third, the use of technology offers opportunities for gathering and

sharing information (e.g., data from electronic client files, artificial intelligence driven domotics and wearables) that can be used to increase the understanding of complex issues and to predict and prevent problems (Wagner et al., 2019). An example of the latter consists of sensor technology measuring excitation levels, of which data can be used to enable early intervention and to prevent aggressive behavior (Palix et al., 2017). Fourth, technological innovations may help organizations create an offer of services that is different from that of other organizations, which may increase their chances of success within an increasingly market-driven environment. In addition, the use of technology may also make working in disability services more appealing to (some) support workers which may help organizations to attract and retain support staff.

Given the rapid developments in digital technologies and the Internet, organizations specifically look at the possibilities of information and communication technology (ICT), such as mobile apps, sensors and wearable devices, domotics, robotics, serious gaming and video communication software. Initiatives that use ICT to support the health and wellbeing of people are often referred to with the term eHealth (Eysenbach, 2001; Oh et al., 2005; World Health Organisation, 2020). In this respect, eHealth is an umbrella term for a large collection of initiatives. These initiatives can be classified and described in several ways. One way to classify them is on the basis of their purpose, such as peer-to-peer support, self-management, (health) education, the facilitation of communication between care professionals, and a remote provision of care and support services (e.g., Bakker & De Hoog, 2018; Drossaert & Van Gemert-Pijnen, 2010).

This thesis focuses specifically on the topic of support for day-to-day living that is delivered remotely through live and two-way communication contacts between people with intellectual disabilities and support staff. Together with initiatives that use cameras, sensors and tags for monitoring and surveillance, this form of support delivery falls under the overarching term of telecare (e.g. Brewer et al., 2010; Friedman & Rizzolo, 2017; Sorell & Draper, 2012). The use of telecare in intellectual disability services seems to have expanded substantially over the last decade (Friedman & Rizzolo, 2017; Tassé et al., 2020; Wagner et al., 2022), and especially during the last few years when the COVID-19 pandemic pressured organizations to look for ways to continue the delivery of their services during periods of lockdown or social distancing (Doody & Keenan, 2021; Wos et al., 2021).

Despite the increased adoption of remote support initiatives, research on initiatives in which people with intellectual disabilities are supported remotely during live and

two-way communication contacts with support workers seems to be still relatively scarce (Oudshoorn et al., 2020). The studies that have been published on this topic can be divided into two groups. The first group consists of studies that explore the experiences and expectations of people with intellectual disabilities and their support staff regarding remotely provided support. The findings of these studies indicate that remote support can have both benefits and drawbacks. In short, benefits consist of an increased accessibility of support (Brewer et al., 2010; Buono & Città, 2007; Tassé et al., 2020), a more targeted, focused and specific delivery of support (Perry et al., 2009), and an increased sense of independence, autonomy and privacy amongst people with intellectual disabilities as their need for support staff that is physically present in their home decreases (Niemeyer et al., 2010; Tassé et al., 2020; Wennberg & Kjellberg, 2010). Drawbacks consist of concerns regarding safety, ethical issues about privacy and consent, and the risk that remote support will become a full substitute for onsite support (Frielink et al., 2020; Perry et al., 2012; Perry & Beyer, 2012; Tassé et al., 2020). The second group consists of (a few) piloting and feasibility studies that examine the outcomes of remotely provided support for people with intellectual disabilities. The findings of these studies are cautiously positive, as they indicate that the use of remote support may lead to more independence on the completion of specific tasks (Taber-Doughty et al., 2010) while not reducing the satisfaction with the received support, feelings of control and quality of life experienced by people with intellectual disabilities (De Wit et al., 2015).

The research presented in this thesis aligns with the first group of studies, as it focuses on exploring the experiences with remotely provided support. The focus is on a specific remote support service from the Netherlands named DigiContact.

THE DIGICONTACT SERVICE

The development and implementation of DigiContact

The changes in the field of intellectual disability policies and practices, as described in the previous section, drove the Dutch service provider Philadelphia Care Foundation to look for new ways to support people. These ways should be both effective in promoting social inclusion, self-determination and self-direction, as well as efficient in terms of the use of resources. The announcement of the introduction of the new Social Support Act that would come into effect in 2015 functioned as a catalyst to search for new support concepts, specifically for people with intellectual disabilities living in their own homes in society.

As it is part of this organization's overall strategy to invest in the development, evaluation and implementation of technological care innovations (Philadelphia Care Foundation, 2022), the use of technology was considered from the start of this search. Specific attention was given to the possibility of delivering (part of the) support remotely. The organization initiated a practice-based piloting trajectory to gain experience with the possibilities and difficulties of providing support remotely. This trajectory showed promising results (Kuiper, 2013) and resulted in the further development and implementation of a service that was called DigiContact. Vijfhuizen and Volkers (2016) provide a comprehensive overview of the development process from the outset of the piloting trajectory in 2011 up until the start of the service in 2014.

The DigiContact service is implemented as one component of a broader range of community-based services for people with intellectual disabilities living in their own homes called My Network [Mijn Netwerk] (Vijfhuizen & Volkers, 2016). Services within My Network consist of: onsite support at home and/or at work, community centers for meeting other people and/or a support professional, activities in a day care center for adults, educational courses, and remote support of the DigiContact service. From this range, a cohesive and cooperative selection of services is compiled and molded to a person's specific needs, preferences and situation. Which services are combined, and to what extent, depends on a person's support needs and their available natural supports. In practice, remote support from DigiContact is generally combined with onsite support from a support worker who visits the person at home and/or with whom they meet at a community center.

DigiContact offers 24/7 available and on-demand remote support

The DigiContact service offers remote support for day-to-day living which is provided during video conferencing calls and regular phone calls between people with intellectual disabilities and a dedicated team of support workers. The service is located at the main office of Philadelphia Care Foundation, where a separate section of the building has been furnished in 'call-center style', with multiple equipped workstations and cubicles (see Figure 1.1). It is from here that the service's support workers have calls with the persons who have been connected to the service on account of their need for support.[4] These persons are further referred to with the term 'support users'.[5]

4 In response to the COVID-19 pandemic, the service's support staff were offered the possibility to also set up a workstation at home and work from there.

5 An exception is *Chapter 5* of this thesis, as there the term 'service users' is used.

Support from the DigiContact service is 24/7 available. Contacts with the service can be both planned (scheduled in advance) and unplanned (not scheduled in advance). The possibility to have unplanned contacts with DigiContact implies that support can be deployed on demand by support users: they can call in whenever and as often as they feel they need it. They are also not restricted by their location, as they can contact the service from anywhere as long as they have access to a device they can use to call in. In practice, many support users have both planned and unplanned contacts with the service: they have a recurring appointment to call in, and besides that, they call in whenever they feel they need contact with a professional. The initiative to call in generally lies with the support users. However, a different choice is made when this suits a support user's specific needs (e.g., a daily wake-up call to help him or her get to work on time) or when taking the initiative to call in is too difficult or stressful. In such cases, the support workers call the support user.

Support users can use online devices (such as a personal computer, tablet and smartphone) to realize a video conferencing call with the service (see Figure 1.2), or an (offline) telephone to realize an audio-only call. Technical support is available in the form of technicians who assist either from a distance or at home with setting up the connection at home or when problems arise. Many support users own a device which they can use to contact the service. When this is not the case, it is sometimes possible to receive a tablet on loan. Contacting the service is relatively easy: in order to realise a video call, a support user merely activates an installed program or app (with an easy to use interface, needing a 'one click or touch' only) to be automatically connected with one of the support workers.

DigiContact invested in a system that enables eye contact between support users and support workers during video calls. Without this system, it is not possible for people during video calls to look straight at each other and make eye contact at the same time. This is due to the camera being positioned above (or next to) the screen on which the video image is displayed. The DigiContact service uses a system in which a specially coated (half-mirrored) glass panel is positioned at a certain angle in front of the support workers' screen and thereby places the camera optically in the middle of the video image. This enables support workers to look at the person on the screen and to make eye contact during their video contacts.

Figure 1.1 Photo of a DigiContact support professional at work ©Philadelphia Care Foundation

Figure 1.2 Photo of a support user in a video call with DigiContact ©Philadelphia Care Foundation

Support users are not supported by a fixed DigiContact support worker. Every time they call in, they talk to the support worker who picks up their call. This can be any member of the team that consists of about 25 support workers, and this can be a different support worker each time. They do not know in advance whom this will be and they cannot choose whom they will speak to.

The support workers work in rotating 6 to 8 hour shifts to enable the service's 24/7 availability. They are especially recruited to provide remote support (e.g., on their computer skills and affinity with technology). Newly hired support workers receive on-the-job training which is organized through successive periods of observing colleagues, supervised working and a buddy system in which they are linked to more senior colleagues with whom they meet up regularly to discuss their work.

DigiContact support users

The DigiContact service was developed for people with intellectual disabilities who live in their own homes in society (either alone or together with a partner, family or friends) and who have been found eligible for access to specialized non-residential services under the Social Support Act (Vijfhuizen & Volkers, 2016). Since the start of the service in 2014, Philadelphia Care Foundation has decided that the service can also be used by other support user groups such as people with intellectual disabilities living in supported accommodation settings and people with dementia, psychosocial problems or mental health problems. However, this thesis focuses on the original group of DigiContact support users only: people with intellectual disabilities who live in their own homes. This living situation is further referred to using the term 'living independently'.[6] In November 2021, around 2750 people with intellectual disabilities living independently were connected to the DigiContact service and could therefore contact the service for support.

It is difficult to describe the group of (potential) DigiContact support users, as it concerns a heterogeneous collection of persons who, despite sharing the commonality of their living situation, all have a unique set of strengths, limitations, preferences, ambitions and support needs. Many of them have a diagnosis of (or are expected to have) mild intellectual disability. A mild intellectual disability refers to a state of functioning that is characterized by both (relatively mild) limitations in intellectual

6 In this thesis 'living independently' is used to refer to a situation in which people live in their own (privately owned or rented) homes in society, and not in a supported accommodation setting. Beware of confusion with the use of the term Independent Living in reference to the philosophy or movement which strives for equal opportunities, self-determination, and self-respect of people with disabilities so that they can live their lives according to their own preferences and choices.

functioning (full scale IQ standard score of 50-55 to 70-75) and limitations in adaptive behaviour (Schalock et al., 2021). Adaptive behaviour consists of the collection of complex and comprehensive (socio-culturally dependent) skills of conceptual, social and practical nature that have been learned and are performed by people in their everyday lives (Schalock et al., 2021; Tassé et al., 2012). There are also people who strictly speaking do not meet the criterion of limitations in intellectual functioning as their IQ score is somewhat higher (IQ range 70-75 to 85), but who do have (at some point in their lives) such significant limitations in their daily functioning, such that they need similar types of support. In the Netherlands, the term mild intellectual disability is also used in reference to this group, and these people can also have access to specialized support for people with intellectual disabilities (Moonen, 2017; Woittiez et al., 2019).

There are different factors which may contribute to people with mild intellectual disabilities having less opportunities for developing the capabilities that are needed to live up to the expectations and demands posed by society (Snell et al., 2009). Research has for example shown that they have an increased risk of having a marginal position in society which results in socio-economic disadvantages in terms of work, income, housing and education (Emerson et al., 2010; Hassiotis et al., 2008), and in having less access to social capital and support (Dusseljee et al., 2011; Hassiotis et al., 2008; Nouwens et al., 2016). It has also been found that they are more likely than people without intellectual disabilities to have grown up in an unsafe environment with obstacles that threaten their development such as poverty, neglect and abuse (Didden et al., 2016; Vervoort-Schel et al., 2018), and to experience adverse (traumatic) experiences during their adult life (Codina et al., 2020; Wigham & Emerson, 2015). On top of having less opportunities for developing the capabilities that are needed to participate fully in society, people with mild intellectual disabilities have an increased risk of additional difficulties such as mental health problems and behavioural problems (Dekker & Koot, 2003; Emerson et al., 2011; Nouwens et al., 2016; Van Nieuwenhuijzen et al., 2006; VanDerNagel et al., 2017).

There are two misconceptions regarding the need for support of people with mild intellectual disabilities that are quite common. The first misconception is that people with mild intellectual disabilities have relatively mild support needs. This is by no means always true, since the need for support does not arise from the (for these people mild) limitations in intellectual functioning only, but also from (a combination of) other personal and contextual factors. For example, people with mild intellectual disabilities may have significant limitations in adaptive functioning, which means they still have a relatively high need for support (Snell et al., 2009). The

second misconception is that people with mild intellectual disabilities are regularly approached as a single group with comparable support needs. However, the opposite has proven to be true, as there are in fact large differences in both personal and environmental characteristics and also much variation in support needs (Moonen, 2017; Nouwens et al., 2017; Snell et al., 2009; Soenen et al., 2009). It is in this respect important to look for new and differentiated support opportunities for people with mild intellectual disabilities and to explore whether and how new initiatives like DigiContact can contribute to the support of individuals.

THIS THESIS

A research project with a disabilities studies perspective

From the start of the DigiContact service in 2014, Philadelphia Care Foundation felt the need to monitor and evaluate the service in order to be able to make adjustments to improve the usefulness and quality of its support. This required a better understanding of what DigiContact support can (and cannot) contribute to the lives of people with intellectual disabilities living independently. The decision was made to invest in a research project that ran from 2015 to 2022. During this period five separate studies were performed (Table 1.1). Regular meetings were held (once or twice a year) between the research team and representatives of the service organization to share results from these studies and to align research plans with developments in practice. This thesis reports on the studies that were performed as part of this project.

In order to set up and carry out the research project, Philadelphia Care Foundation sought collaboration with the Disability Studies in the Netherlands foundation and the disability studies chair at the Amsterdam University Medical Center (Department of Ethics, Law and Humanities, Amsterdam Public Health Research Institute, location VU University Medical Center).[7] The motivation to adopt a disability studies perspective was two-fold. First, as an academic discipline disability studies aspires to contribute to a fully inclusive society in which people with impairments can realize a good quality of life with opportunities for exercising choice and control over their lives. Given the community-based approach of the DigiContact service and the fact that support users are in control of their own use of support (i.e., they are the ones who decide if, when, where and about what they contact the service), it is important

7 Since 01-01-2021 this chair is continued at the University of Humanistic Studies, Utrecht, the Netherlands.

to examine whether a support service like DigiContact may be a useful instrument to help realize a more inclusive society.

Second, conform the original adage of the movement of people with disabilities 'Nothing about us without us' (Charlton, 1998), the disability studies perspective is that, in trying to do justice to principles like social inclusion, empowerment and choice and control, people with impairments should be actively involved in all activities that concern them and this includes research. This is not only about being consulted (as participant or respondent) within research on topics that are relevant to their lives, but also about being actively involved in conducting research and being able to influence research agendas and processes. It has been found that actively involving people with intellectual disabilities in research can have a beneficial impact on all people involved (e.g., Frankena et al., 2018; Stack & McDonald, 2018) and on the quality and relevance of research (e.g., Chalachanova & Gjermestad, 2021; Frankena et al., 2015; Puyalto et al., 2016). Regarding the latter, researchers with experiential knowledge (in this case on life with an intellectual disability) can enrich research processes and findings by bringing in personal and collective experiences and by reflecting on findings from their experiential knowledge (Embregts et al., 2021; Woelders et al., 2015). When people with intellectual disabilities are active partners in research, often the term inclusive research is used (e.g., Nind, 2014; Walmsley et al., 2018). Philadelphia Care Foundation was convinced of the importance and value of an inclusive approach to research, and aspired to adopt this within the project on DigiContact (see under heading 'Methodological considerations' for how this was done).

Aim and research questions

As the DigiContact service was implemented as one component of a wider range of supports and services, the specific aim of the research project (and this thesis) was to gather knowledge regarding the added value of including DigiContact in a broader offer of services for people with intellectual disabilities who live independently in society. In order to gather such knowledge, the personal experiences of the people who are closely involved in the DigiContact support process were explored: those who are supported by the service (support users), professionals who work at the service and provide support (support workers), and professionals who provide onsite support and work together with the service (case workers[8]). The main focus was on

8 A case worker is a senior support professional who does not only provide onsite support, but also coordinates services around support users and functions as a contact person for professionals and natural care givers.

support user experiences, as they are the people with first-hand experiences with what DigiContact can (and cannot) contribute to their lives and/or their support.

During the course of the research project this aim was translated into three main research questions[9], around which five separate studies were designed and conducted (Table 1.1):

1. *What does DigiContact support entail?*
   Two studies were performed to gain insight into what the support provided by the DigiContact service entails. In one of these studies, the type of issues that are addressed during the contacts between support workers and support users were explored (study 1). The other study explored what DigiContact support workers do to assist support users and how they do this (i.e., their support practice, study 5).

2. *What is the role of DigiContact support within the context of a broader offer of available supports?*
   To better understand the role of DigiContact support within the context of a broader availability of supports, two studies were performed. One of these studies explored the use of DigiContact support in relation to the use of other services and supports (study 2). The other study specifically examined how the use of DigiContact support evolved during the first months of the COVID-19 pandemic in the Netherlands: a period during which preventive measures adopted to reduce the risk of infection had a restrictive impact on the (onsite) delivery of supports and services (study 3).

3. *What are the experiences of support users and professionals with DigiContact support?*
   Although the experiences of both support users and workers were the most prominent source of information when seeking for answers to both research questions 1 and 2, we also wanted to focus further on the experiences of both parties. In order to gain a better understanding of what it is like to be supported by the DigiContact service, a study was performed which explored how support users experience its support and how they give meaning to their experiences (study 4). To understand what it is like to work at the service as a remote support

9 As an emergent approach to research was adopted (see 'Methodological considerations'), the research questions were not defined in advance.

professional, in another study it was explored what DigiContact support workers experience as distinctive aspects of their job (study 5[10]).

The experiences of people with intellectual disabilities play a central role in this thesis. Not only were these experiences a main source of information in four of the performed studies (studies 1, 2, 4, and 5), but they also formed an integral part of the research process across all studies as an inclusive approach to research was adopted (see 'Methodological considerations'). This thesis not only pays explicit attention to this approach within the chapters on the performed studies, but also in a separate chapter in which the involved researchers (the PhD candidate and the researcher with intellectual disabilities) reflect on their experiences with conducting research together (last row in Table 1.1).

Methodological considerations

As the underlying purpose of the research project was quite broad, namely the monitoring and evaluation of DigiContact in terms of its usefulness and quality, the performed studies had an explorative nature. Decisions regarding research methodology were based on the specific research question(s) and topic(s) of each individual study. In line with the explorative character of the studies, mostly qualitative methods were used for data collection and analysis (Green & Thorogood, 2014; Ritchie et al., 2014). In two studies quantitative methods were (also) used (studies 1 and 3). Details on the used methods can be found in the respective chapters of this thesis.

Apart from being explorative, there are two additional aspects that characterise the adopted research approach. First, the research approach was emergent. This was reflected in that only the general aim of the project was defined at the start of the project, while further specifications (e.g., number of studies, topics, research questions, used methods) were left open (Creswell & Plano Clark, 2017; Pailthorpe, 2017). The course and design of the project was tailored to and guided by the situation in practice. This enabled the project to move flexibly with (changes in) the situation in practice and to respond to new questions that arose from the findings of previous studies.

10 Study 5 provided insights on both what DigiContact support entails (research question 1) and what it is like to work at DigiContact as a remote support worker (research question 3).

Table 1.1 Overview of performed studies (in chronological order of completion)

Study	Research question	Topic	Used method(s)	Publication details	Chapter
1	What does DigiContact support entail?	The type of issues for which DigiContact support is used	• Interviews with support users • Registration by support workers	2019: *Journal of Policy and Practice in Intellectual Disabilities*. https://doi.org/10.1111/jppi.12275d	2
2	What is the role of DigiContact support within the context of a broader mix of available supports and services?	The use of DigiContact support in relation to other available supports and services	• Interviews with support users and case workers	2020: *Inclusion*. https://doi.org/10.1352/2326-6988-8.2.138	4
3	How does the use of DigiContact support evolve during the first weeks of the COVID-19 pandemic?	The use of DigiContact support during the first weeks of the COVID-19 pandemic	• Quantitative data on support contacts from the administrative system of PCF	2020: *Journal of Intellectual Disability Research*. https://doi.org/10.1111/jir.12770	5
4	What are the experiences with DigiContact support?	The experiences with what it is like to be supported by the DigiContact service	• Interviews with support users	2021: *Disability and Society*. https://doi.org/10.1080/09687599.2021.1932756	6
5[a]	What does DigiContact support entail?	The support practice of DigiContact support workers	• Desk research (documents) • Analysis on transcripts of interviews with support users[b] and case workers[c]	2022: *British Journal of Learning Disabilities*. https://doi.org/10.1111/bld.12488	3
	What are the experiences with DigiContact support?	The experiences with what it is like to work as a remote support professional at the DigiContact service	• Interviews with support workers	2022: *Journal of Applied Research in Intellectual Disabilities*. https://doi.org/10.1111/jar.13001	7
1-5[d]	What are our experiences regarding how inclusive research can be organized, and what are the possible benefits for researchers and the quality of research?	A reflection on our own experiences with adopting an inclusive research approach	• Interviews with researchers • Logbooks	2022: *Social Sciences*. https://doi.org/10.3390/socsci11050186	8

Note.
[a] Study 5 explores both the support practice and the experiences of DigiContact support workers. The findings are reported in two separate chapters (3 and 7).
[b] Support users from studies 1, 2, and 4
[c] Case workers from study 2
[d] This chapter does not report on a separate study, but contains a reflection on the inclusive approach to research that was adopted across the performed studies

Second, as discussed before (under the heading 'A research project with a disabilities studies perspective'), an inclusive approach to research was adopted. This was shaped in the form of a collaboration between the PhD candidate (academic researcher) and a researcher with intellectual disabilities. It was expected that the experiential knowledge of the researcher with intellectual disabilities would enrich both the research processes within the studies as well as the findings (Frankena et al., 2015; Woelders et al., 2015). During the research project, the PhD candidate had successive collaborations with two researchers with intellectual disabilities. The first collaboration ended after several months because the role of researcher did not match this person's talents and ambitions, and the level of support (s)he needed to be able to participate in research activities exceeded what the organization and the PhD researcher were able to provide. The second collaboration started just after the data collection for study 2 was completed, and continued for almost four years (until the end of the project). This was a collaboration with a researcher with intellectual disabilities who lived in a supported accommodation setting but prepared himself for a transfer towards independent living with support. This duo worked together during all phases of the research process: they thought about and decided on new research plans (for new studies), interviewed participants, analysed qualitative data, wrote texts about our findings, and held presentations on our collaboration on (inter) national meetings and congresses.

Outline

This thesis consists of nine chapters, of which this general introduction (*chapter 1*) is the first and the general discussion (*chapter 9*) is the last. The chapters in between report on the performed studies and are divided into three parts.

Part I consists of two chapters that provide insight into the support that is provided by the DigiContact service (research question 1). *Chapter 2* describes a mixed methods study in which the type of support needs that are addressed during the support contacts with the service are explored (study 1). *Chapter 3* reports on a qualitative, multiple methods study that examines the support activities of the service's support workers: what they do during their contacts with support users to assist them and how they do this (study 5).

Part II consists of two chapters that provide insight into the role of DigiContact support within the context of a broader mix of available supports and services (research question 2). *Chapter 4* describes a qualitative multiple-case study that explored the use of DigiContact support in relation to other services and supports (study 2). *Chapter 5* reports on a quantitative study in which administrative data

on the service's support contacts are analyzed to explore the use of DigiContact support during the first weeks of the COVID-19 pandemic when lock down measures made onsite support services less available (study 3).

Part III consists of three chapters that zoom in on the experiences with DigiContact by including some very specific personal perspectives on the support (research question 3) and on the adopted inclusive research approach. Two chapters provide insight into the experiences with DigiContact support. *Chapter 6* reports on a qualitative study in which a phenomenological hermeneutic method was used to explore in detail how a small group of DigiContact support users experience the support and give meaning to their experiences (study 4). *Chapter 7* describes the findings of a regarding what it is like for professionals to work at the DigiContact service as a remote support worker (study 5). In *chapter 8* an auto-biographical approach was followed consisting of a reflection on the researchers' personal experiences with working together on the research project on DigiContact (study 6).

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PART I

DigiContact support

CHAPTER 2

The support needs in 24/7 remote support

Zaagsma, M., Volkers, K. M., Schippers, A. P., Wilschut, J. A., & Van Hove, G. (2019). An exploratory study of the support needs in 24/7 online support for people with mild intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 16*(1), 78–87. https://doi.org/10.1111/jppi.12275

ABSTRACT

Service organizations for people with intellectual disabilities increasingly look for technological applications to improve their services. DigiContact is an online support service developed by Philadelphia Care Foundation in the Netherlands which enables independently living people with ID to contact specially trained support workers 24/7. The purpose of this study was to explore the support needs for which people with intellectual disabilities use online support. We first conducted interviews with 21 individuals with intellectual disabilities who use the online support service. Transcriptions of the interviews were analyzed using inductive thematic analysis. Second, online support workers registered items regarding the support needs when in contact with support users. These data were analyzed to assess which and how often the support needs were present. Online support is used for a broad variety of issues. Four themes emerged during analysis of the interviews: mental health, social contacts (conflicts with others as well as lack of contacts), practical issues, and physical health. Analysis of the support workers' data showed that making a connection with someone and talking about worries and stress were the two most frequent support needs. Most support needs did not differ across the time of day or across the week. The results suggest that 24/7 online support is a useful way of providing services to independently living people with intellectual disabilities. Unlimited access to support has multiple advantages. It appears to have a signaling and a preventive function with regard to emotional and behavioral problems.

INTRODUCTION

Many service organizations for people with intellectual disabilities face social and political challenges that cause them to transform their services as well as the way they are structured (Schalock & Verdugo, 2013). For example, organizations may have to deal with reduced resources while at the same time the demand for services increases. Another important trend is the shift toward individualized supports, the emphasis on selfdetermination and self-direction of persons with intellectual disabilities and a need for evidence-based practices (Schalock & Verdugo, 2013). Amidst such changes, technological innovations provide organizations with opportunities to either develop new support services or to organize and deliver existing services in a different way, potentially more effectively or efficiently. DigiContact is such a new support initiative: a 24/7 available online support service for independently living people with intellectual disabilities. The monitoring and evaluation of new support initiatives is important, as it enables making informed, evidence-based decisions about the value of these services to the lives of people with intellectual disabilities. This study is the first step of a broader evaluation of DigiContact. We aim to gain insight into the online support by exploring the support needs for which people with intellectual disabilities use DigiContact.

Background

Like in many countries, disability policy and practices in the Netherlands are directed toward realizing inclusion. This is reflected in recent reforms of the national long-term care system and the ratification of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) in 2016. The changes in Dutch long-term care policy and practice are intended to stimulate all people to take on more individual and social responsibility (Da Roit & De Klerk, 2014). The underlying assumption is that various social care services may be provided by family members and social networks, so that individuals become less dependent on formal care.

Besides impacting the lives of many people with intellectual disabilities, these changes also influence people and organizations who offer (in) formal supports. Service organizations find themselves situated in a relatively open market in which quality and efficiency of services become more and more important. The construction of a specific (read: different from colleague organizations) package of support options is seen as quintessential in the identity building of organizations. As a result, organizations feel the need to reconsider their way of organizing their services for independently living people with intellectual disabilities. Some see this as a chance to be innovative and to break away from the usual ways of providing support, which

generally is through onsite support staff (Stancliffe & Lakin, 2007). With the rapid developments in technology and the use of the Internet, many organizations look into the possibilities of technological applications with a view to shaping their portfolio of services. An alternative to onsite support is remote support, provided for example via a system of video conferencing techniques (Schalken, 2013). This has potential benefits for both service organizations and support users. First, support can be more focused and specific as it is provided as needs arise rather than irrespective of immediate need (Perry et al., 2009). Second, support users experience more control as it allows them to make more choices and decisions, for example about when and regarding what support is wanted (Schalken, 2013).

DigiContact is a support service that offers online support using video conferencing techniques. It was developed by Philadelphia Care Foundation, a Dutch service organization, who implemented DigiContact within its range of services for independently living people with intellectual disabilities in 2014 (Vijfhuizen & Volkers, 2016). People with intellectual disabilities, the support users, can contact a team of specially trained support workers 24 hours a day, 7 days a week, either using their own personal computer, laptop, (mobile) phone, or an iPad they receive on loan.[11] A technician is available to assist support users experiencing technical problems, either from a distance or at home. The support users are the ones who decide when and how often they contact the support workers. DigiContact is part of a broader system of supports for people with intellectual disabilities who live independently called My Network [Mijn Netwerk]. Other components of My Network are: onsite support at home or at a community center, courses, supported employment, and activities in a day center. Which components are combined depends on a person's needs, as well as on the informal supports available to them. About 1100 individuals are currently equipped and connected to DigiContact. During the first 6 months of 2016, on average 720 online support contacts per week were realized.

For services, it is important that they meet the individual support needs of their users. DigiContact users share the commonality of living independently, but each support user is an individual with a unique set of strengths and limitations. The support users therefore form a heterogeneous group with diverse support needs. Many of them have mild intellectual disabilities or borderline intellectual functioning. The available evidence suggests that many individuals with mild intellectual disabilities or borderline intellectual functioning face serious difficulties across their life courses and

11 To realize a video connection, it is necessary that a support user has Internet access. However, contact can also be realized without the video component through a "normal" telephone connection.

that they are at risk of encountering various circumstances disadvantaging a person, such as social exclusion and poor health (Emerson, 2011; Peltopuro et al., 2014; Snell et al., 2009). They have been found to experience lower levels of psychological well-being, poorer physical health, reduced access to social capital, more problems in personal and social relationships, a lower employment rate, and a lower income than their peers (e.g., Ferrari, 2009; Peltopuro et al., 2014; Seltzer et al., 2005; Stancliffe & Lakin, 2007; Tymchuk et al., 2001; Vaillant & Davis, 2000). Moreover, several studies showed that the prevalence of mental health problems is relatively high among people with mild intellectual disabilities and borderline intellectual functioning (Cooper et al., 2007; Dusseljee et al., 2011; Emerson et al., 2010; Nouwens et al., 2016).

This study

As a first step in evaluating the online support service DigiContact, we set out to explore the support needs for which people with intellectual disabilities use online support. More specifically, we were interested in two questions. First, for which support needs do people with intellectual disabilities use DigiContact? As the people with intellectual disabilities are the ones who have first-hand experiences of using online support, we interviewed DigiContact users and performed a content analysis regarding their views on what the service helps them with. Second, how often are the support needs present in the online support contacts? To this end, online support workers scored the support needs present in their support contacts with people with intellectual disabilities. Finally, we also analyzed these data to find out whether support needs differed between week and weekend days and between the support workers' work shifts during the day.

METHOD

A mixed methods design was used. We followed an inclusive research approach, meaning that people with intellectual disabilities were actively involved in the research process (Walmsley & Johnson, 2003).

Participants

Online support users

Twenty-one individuals with intellectual disabilities who used online DigiContact support were interviewed. Table 2.1 shows an overview of participant characteristics and their use of (online) support. For recruitment, we distributed a flyer about the research during a DigiContact 'open day' meeting for (potential) online support users. The flyer was also posted on the intranet of the service organization. Eleven participants were recruited via the 'open day' meeting. Two participants contacted

the researchers themselves after hearing about the research from a friend. Six participants were invited to join the study by their onsite support worker. The remaining two participants were acquaintances of the researchers.

Online support workers

Eight online support workers volunteered to register support needs within their contacts with DigiContact users to enable assessing the prevalence of support needs. These eight support workers made up 38% of the entire online support team; six of them had experience of at least 1 year and two had joined the team 4 months earlier.

Measures

Interview with online support users

We developed an interview guide consisting of three parts. The first part contained questions about the participants and their use of the online support service. The second part encompassed one question about the support needs for which the participants use the online support service. Questions regarding the evaluation of the online support formed the third part of the interview guide. In general, this order of questioning was maintained, but sometimes we deviated from this to accommodate the participants' train of thought. The main question about the support needs was 'What does DigiContact help you with?' When necessary, this question was elaborated on with 'Can you tell me about a situation when you contacted DigiContact?' Follow-up questions were adapted to the situation while keeping in mind the aim of getting a complete picture of the participants' experiences.

Table 2.1: Characteristics of the interview participants (*N* = 21) and their (online) support use

Characteristics		***n***	
Participants			
Sex	Male	13	
	Female	8	
Age (years)	*Mdn*. (range)	44	(31-61)
Relationship status	Single	11	
	Relationship	10	
Living arrangements	Alone	11	
	With parent(s)	2	
	With partner	8	
Day-time occupation	Full-time job	8	
	Part-time job	8	
	Activity center	3	
	None	2	
Online support			
Duration[a] (months)	*Mdn*. (range)	13	(5-15)
Frequency	Every day	1	
	Once a week/fortnight	16	
	Once every couple of months	3	
	Variable	1	
Nature of contacts	Planned	12	
	Unplanned	4	
	Planned and unplanned	5	
Onsite support worker	At home	12	
	At meeting point	6	
	At home and at meeting point	3	

Note. Number of participants, unless otherwise stated. *Mdn*, median.
[a] Time interval between the date on which the participants started to use the online support service and the interview.

Registration form for scoring support needs

We developed a registration form for online support workers to score support needs within their support contacts. The items of the registration form were based on the support needs mentioned by the interview participants and additional topics raised by five online support workers who provided feedback regarding completeness and user-friendliness of the form. We tested the form for interrater agreement. Four online support workers independently read two cases and scored the items that represented the support needs they felt were present. Each case was a description of a support contact that was invented by the first author and checked by a fifth online support worker for being a realistic description of a contact that may occur. We compared the scores within two pairs of support workers. We used Cohen's kappa (Cohen, 1960) as an index for the agreement between two online support workers and we followed the guidelines of Altman (1991) for interpreting kappa values. Because the first results were disappointing, we concluded that the registration form could be more structured by including more headings that represented the corresponding items better. A couple of items were merged because the distinction between them seemed unclear. After adaptation, the new version of the form was tested again. This time, the two rater pairs reached good agreement ($\kappa = 0.73$ and $\kappa = 0.66$) for the first case. For the second case, the pairs reached very good ($\kappa = 0.85$) and moderate ($\kappa = 0.54$) agreement. This final version of the registration form[12] consisted of 34 items and included the following eight headings: structure of day and week, traveling, looking for information, administration and finances, housekeeping and personal care, social relationships, mental well-being, and physical well-being.

Procedure

Interviews with online support users

During this part of the study, the academic researchers worked together with a co-researcher with intellectual disabilities. By including a peer interviewer, we wanted to increase the accessibility and appropriateness of our data collection and contribute to the richness of our data. The co-researcher was the primary interviewer, while the academic researcher observed and made notes. The co-researcher had received training on interviewing skills, both prior to and during data collection. The interviews lasted between 30 and 60 min. The participants chose the interview location: 19 participants were interviewed at home, two at a community center. When participants consented, the interviews were audio recorded and transcribed verbatim. One participant did not consent and notes were made by hand and written out with as much detail as possible.

12 More information about the registration form is available from the first author.

We included a member check (Nind, 2008). All participants received a short typed version of their interview to check for accuracy. For participants who could not read, we arranged for someone from their social network to help check the report. To ensure comprehensibility, the co-researcher checked the reports before sending them out. Eight participants responded: all of them felt that the report rendered their experiences well. Five of them provided additional information about their lives (e.g., their work situation), which enriched the context descriptions. We enclosed the extra information as separate notes to the transcriptions and included them in the analysis.

Registration of support needs

During a period of 18 days, eight online support workers scored those items on the registration form they felt corresponded to the support needs present in each contact they had with support users. For each support contact, it was possible to score one or more items. The support workers scored items regarding all contacts they had during a work shift on one registration form. This means the data on the presence of support needs were collected at the level of work shifts. We chose not to score items for each support contact separately, as this would increase the work load and time investment of the online support workers considerably. Table 2.2 shows the amount of work shifts during which was registered and the number of support contacts within these shifts.

Quality assurance

To validate our findings, we checked them for recognizability and discussed their interpretation with a selection of experiential and professional experts. We organized two group consultations: one with three online support users who had participated in the interviews and one with eight online support workers. We also consulted a psychologist and an onsite support worker, both with experience in caring for and supporting people with intellectual disabilities living independently in the community. Finally, we talked to four academics with merit and experience in researching the lives of people with intellectual disabilities.

Table 2.2: Overview of collected registration data

		Work shifts	Support contacts		
		n	*n*	*M*	SD
Week	Early (7 a.m.-4 p.m.)	23	330	14.35	5.04
	Late (2 p.m.-11 p.m.)	18	313	17.39	4.49
	Night (11 p.m.-7 a.m.)	8	27	3.37	1.77
Weekend	Early (7 a.m.-4 p.m.)	7	108	15.43	3.36
	Late (2 p.m.-11 p.m.)	4	79	19.75	2.75
	Night (11 p.m.-7 a.m.)	5	11	2.20	1.10
Total		65	868		

Note. M, mean per shift; SD, standard deviation.

Ethical procedure

The Disability Studies in the Netherlands (DSiN) Code of Practice for Researchers 2016–2017 (Disability Studies in the Netherlands, 2017) was followed, as confirmed by the DSiN Ethical Review Committee. Before asking for informed consent, the co-researcher explained the study and the consequences of participation thoroughly to the participants. We obtained written informed consent from all interview participants, which included the statement that study withdrawal was possible at any time, without a need to explain oneself. This informed consent was checked by the co-researcher with intellectual disabilities to ensure comprehensibility. We took care to protect all research participants from any risk of harm. We anonymized personal data and made sure that all research data were securely stored to prevent disclosure of sensitive information.

Data Analysis

Qualitative data

All transcriptions and notes by hand were analyzed using inductive, thematic analysis (Braun & Clarke, 2006). A mix of computerized (MAXQDA version 12) and manual techniques was used to facilitate data analysis. Each transcript was read, re-read, and coded by at least two authors independently. While reading, we coded phrases with a direct or indirect relation to support needs for which the online support service was used. We used descriptive codes like 'planning of public transport use' and 'advice on conflict with partner'. All codes were documented in a code list. Codes and coded text segments were then compared and grouped: first into subcategories and later into main categories. An example of this distinction: the code 'reading and understanding letters or emails' was grouped together with other related codes in the subcategory 'administrational tasks', which was in turn grouped with other

related subcategories in the main category 'practical issues'. Differences in categories between researchers were compared and discussed until consensus was reached (Guba & Lincoln, 1989).

Quantitative data

The scores on the items of the registration form were analyzed using SPSS version 23 for Windows and Microsoft Excel 2010. Descriptive statistics were run to identify the proportion of all items scored within the support contacts. After this, we compared the proportions of the scored items between week and weekend shifts, and between early shifts (7 a.m.– 4 p.m.) and late shifts (2 p.m.– 11 p.m.). We did not include the data on night shifts (11 p.m.– 7 a.m.) in the comparative analysis as the amount of items scored during night shifts was low due to a small number of support contacts. We tested for differences using *z*-tests for the difference in proportion. We reported its corresponding *p*-value and 95% confidence interval.

RESULTS

Interviews with online support users

Our analysis resulted in four main categories reflecting themes within the support needs for which people with ID use online support. These four main categories were mental health, social contacts, practical issues, and physical health. In the following paragraphs, the main categories and their corresponding subcategories are described.

Mental health

Sixteen participants used the online support for issues concerning their mental health. The subcategories were talking about *worries and stress* (*n* = 15), *signaling and prevention of mental health or behavioral problems* (*n* = 6), *dealing with emotions* (*n* = 3), and *dealing with unexpected situations* (*n* = 1). The first subcategory refers to participants wanting to talk about events that cause them stress and frustrations with the aim to free themselves of these feelings and to feel better. One participant illustrated this by saying: "*Well, I want this out of my system so I can feel fine again. This is how I want it, because if I am doing well, so is the wife and vice versa. Good for me.*" (Male, 37 years) The second subcategory refers to participants for whom the online support fulfills a signaling and preventive function. For five participants, regular contact for stress release helps to prevent adverse consequences such as an aggressive outburst:

> *I am always quarrelling at work... I like to dress up every now and then, and ... I behave like a woman, so to speak. Because I am a bit aggressive, really and I try to get rid of all the stress resulting from a difficult youth.* (Male, 61 years)

One participant talks about how frequent contact with the online support service helps him in his combat with alcohol addiction:

> *I use DigiContact more or less every day. It is like an extra authority and I use them to talk to and at the same time they can check on me. In case I relapse. With the support of DigiContact you remain on the straight and narrow.* (Male, 34 years)

Regarding the third subcategory, participants stressed specifically that the online support helped them to understand and deal with intense (negative) emotions such as anger and anxiety by giving advice on how to become calm, how to let go and by providing reassurance when feelings of insecurity prevailed. The fourth subcategory concerned dealing with unexpected situations and the participant whom this concerned talked about contacting the online support service when he panicked after finding himself in an unexpected situation, something he is very susceptible to:

> *Unexpected situations tend to bother me. When you accidentally break something or something else happens, what do you need to do? Imagine, the television goes down, what then is one to do? I tend to panic first, which is what you shouldn't do, you need to stay calm. Once the electricity in the house short-circuited, and I thought to myself what am I going to do now?* (Male, 45 years)

Social contacts

Eleven participants used the online support for issues related to contacts with other people. This theme included three subcategories: *conflicts with other people* (*n* = 7), *connecting with someone* (*n* = 6), and *expanding the social network* (*n* = 1). The first subcategory concerned relationships with other people while the other two regarded the absence or lack of social contacts. As to relationships with other people: seven participants focused on issues or conflicts with their partner, other family, and people at work. Especially people at work (such as a boss or colleagues) were frequently mentioned:

> *I am a member of an interest group and most of the other members are my friends, really, but I do not want to discuss everything with them. Like a quarrel with my boss and how would you respond? I consider that a private issue, but I do discuss it with DigiContact, and what's more they are online 24 hours of the day.* (Male, 47 years)

These participants felt the need to talk about these situations: to understand what triggered the disagreement and how it evolved into such a big conflict, but also to get advice on how to solve it and how to prevent conflict in the future:

> *Well, at some point in the conversation they start offering me advice about how to deal with those problems... Say, I am stressed, because I am having problems with you or with someone else at work, then DigiContact offers me another way to solve the problem. Of course, you can walk away if you are having problems, You can also try to solve those problems. But if they cannot be solved, that's when you think I'd better walk away from them.* (Male, 61 years)

The second and third subcategories concerned the (felt) absence of social contacts. Six participants used the online support service to be able to connect and talk with someone. They felt the need to share their story and experiences with someone, to make small talk or a chat about everyday experiences: "*The fact that you've had a conversation with someone, that you've been in contact just before you go to bed. That does me a world of good.*" (Male, 43 years) One participant felt this need only when his partner was away in the evenings: "*Last time I was at home alone and I felt like a conversation because* [name spouse] *had to spend the night at the hospital and I felt lonely.*" (Male, 61 years) The third subcategory was expressed by one participant, who wanted to expand her network of friends and used the online support as an intermediate in her attempt to find a buddy through a specialized matchmaking service.

Practical issues

Eleven participants mentioned using the online support service for practical issues that arise in their daily life. The five corresponding subcategories were *seeking and finding information* (*n* = 5), *administration and financial tasks* (*n* = 3), *use of public transport* (*n* = 3), *preparing meetings with health or social care professionals* (*n* = 3), and *planning of day or week activities* (*n* = 1). The first subcategory concerned assistance with or advice on how and where to find specific information, for example, about where to buy certain items and how to plan and execute exploring new activities on their personal computer, for example, using or installing specific software. The second subcategory included a focus on administration and finances, including, for example, reading and understanding incoming letters or emails, filling in official forms, and helping them make financial choices. Regarding the third subcategory, participants wanted help to prepare for (public transport) traveling and sought assistance with looking up time tables or locations and making a time planning. The fourth subcategory consisted of preparing meetings or appointments

with health or social care professionals. One participant talked about preparing a visit to a medical specialist together with online support workers:

> *Last time when I had to go to the hospital, they told me to write down the issues I wanted to discuss. I did and I just read out my list of issues, my questions so to speak. And then I check with them what they think of my list: Does it need improvement or are there things that can be left out?* (Female, 36 years)

The fifth and final subcategory was expressed by one participant who talked about making a day-to-day activity schedule once a week together with an online support worker.

Physical health

Three participants sought online support about their physical health, with the subcategories being *monitoring of and talking about physical health status* (n = 3) and *reflecting on doctors' advices* (n = 1). The participants used DigiContact as a help-line for monitoring their physical health status, to talk about symptoms they experienced (e.g. pain) and to seek advice on what to do about these symptoms.

> *In case there is something the matter with me, like with my ear when I got so upset I felt lost, did not know what to do next. So I called, you know, and they offered to contact me the next day to check on any improvements with my ear. That is the kind of thing I use them for.* (Female, 31 years)

One participant also called in every time she had visited her general practitioner, to bring support workers up to date and to talk through the advice she had been given to enhance her own understanding.

Registration of Support Needs

The 34 different items were scored 1208 times covering a total of 868 contacts. There were large differences in the frequencies of the items: some items were scored many times, while others were scored only a few times. Fifteen items were scored 20 times or more: together they accounted for 91% of all scores. Table 2.3 presents the scoring frequencies of these 15 items, expressed as the proportion of the total support contacts. Of these 15 items, six related to mental health issues, four items to practical issues, three to physical health issues, and two to issues concerning social contacts. The comparative analyses were also limited to the 15 items that were scored 20 times or more (results in Table 2.3).

Table 2.3: Proportions and differences in proportions (%) of scored items within online support contacts

	All	Week	Weekend					Early	Late	Night				
	(*N*= 868)	(*n*= 670)	(*n*= 198)	Diff.	95% CI		*p*	(*n*= 438)	(*n*= 392)	(*n*= 38)	Diff.[a]	95% CI [a]		*p* [a]
					LL	*UL*						*LL*	*UL*	
Connecting with someone[b]	30.07	29.85	30.81	-0.96	-8.26	6.35	.797	29.22	31.12	28.95	-1.90	-8.16	4.36	.552
Talking about worries & stress[c]	23.73	25.22	18.69	6.54	0.19	12.88	**.044**	21.69	25.51	28.95	-3.82	-9.61	1.97	.196
Reflection day/week planning[d]	13.94	13.43	15.66	-2.22	-7.91	3.46	.443	12.56	16.33	5.26	-3.77	-8.57	1.03	.124
Talking about physical health[e]	9.10	8.66	10.61	-1.95	-6.74	2.84	.425	9.36	8.67	10.53	0.69	-3.21	4.59	.730
Reminder medication intake[e]	8.76	7.76	12.12	-4.36	-9.34	0.62	.086	8.45	8.93	10.53	-0.48	-4.32	3.36	.806
Advice on healthy eating[e]	7.60	6.27	12.12	-5.85	-10.76	-0.95	**.019**	9.59	5.61	5.26	3.98	0.40	7.55	**.029**
Advice on releasing stress[c]	5.88	5.97	5.56	0.41	-3.25	4.08	.824	5.48	6.12	7.89	-0.64	-3.83	2.55	.693
Wake-up call[d]	5.18	6.57	0.51	6.06	3.94	8.18	**.000**	8.22	0.00	23.68	8.22	5.65	10.79	**.000**
Check-up mental health status[c]	4.03	3.88	4.55	-0.66	-3.91	2.58	.688	2.74	5.61	2.63	-2.87	-5.62	-0.13	**.040**
Coaching household chores[d]	3.57	2.69	6.57	-3.88	-7.54	-0.22	**.038**	3.42	4.08	0.00	-0.66	-3.25	1.94	.620
Reminder psychotropics intake[c]	3.34	3.58	2.53	1.06	-1.54	3.66	.425	3.20	2.81	10.53	0.39	-1.93	2.71	.742
Advice conflicts with others[b]	3.11	2.39	5.56	-3.17	-6.56	0.23	.067	1.83	4.85	0.00	-3.02	-5.49	-0.55	**.016**
Understanding/dealing with emotions[c]	3.00	2.99	3.03	-0.05	-2.76	2.67	.974	2.28	4.08	0.00	-1.80	-4.21	0.61	.143
Making day/week planning[d]	2.76	2.54	3.54	-1.00	-3.83	1.84	.490	2.51	3.32	0.00	-0.80	-3.10	1.50	.493
Talking about recent bad experiences[c]	2.42	2.39	2.53	-0.14	-2.61	2.34	.913	2.51	2.55	0.00	-0.04	-2.18	2.10	.971

Note. Only items that were scored 20 times or more were included. Diff. = difference in proportion. CI = confidence interval; *LL* = lower limit; *UL* = upper limit.
[a] Early versus late work shifts. [b] Social contacts theme. [c] Mental health theme. [d] Practical issues theme. [e] Physical health theme.
Significant *p*-values (<.05) are in bold face.

Week vs. weekend shifts

Comparing the proportions of items scored within support contacts during the week with those during the weekend, we found statistically significant differences for four items. The proportion of contacts that concerned *talking about worries and stress* and *wake-up calls* was higher during the week than during the weekend (difference = 6.54, 95% CI [0.19, 12.88], $p = .044$; difference = 6.06, 95% CI [3.94, 8.18], $p = .000$). The proportion of contacts that concerned *advice on healthy eating* and *coaching on household chores* was higher during the weekend than during the week (difference = –5.85, 95% CI [–10.76, –0.95], $p = .019$; difference = –3.88, 95% CI [–7.54, –0.22], $p = .038$).

Early vs. late shifts

Comparing the proportions of scored items within support contacts during early shifts with those during late shifts, we found statistically significant differences for four items. The proportion of contacts that concerned *advice on healthy eating* and *wake-up calls* was higher during early shifts than during late shifts (difference = 3.98, 95% CI [0.40, 7.55], $p = .029$; difference = 8.22, 95% CI [5.65, 10.79], $p = .000$). In contrast, the proportion of contacts that concerned *check-up on mental health status* and *advice on conflicts with other people* was higher during late shifts than during early shifts (difference = –2.87, 95% CI [–5.62, –0.13], $p = .040$; difference = –3.02, 95% CI [–5.49, –0.55], $p = .016$).

DISCUSSION

The aim of this study was to gain insight into the support provided to independently living people with ID via video conferencing technology. We explored support needs for which the online support service DigiContact is used, as this understanding will help in identifying the value of online support for its users. To start with, we wanted to know for which support needs people with intellectual disabilities used online support. Our results show that online support is used for a broad variety of issues, from which four themes emerge: mental health, social contacts, practical issues, and physical health. We will elaborate on these themes after describing the main conclusions. Next, we were interested in how often the support needs were present in online support contacts. We found that their presence differed widely. The two most frequent support needs were connecting with someone (30%) and talking about worries and stress with the aim to free themselves of them (24%). This indicates that the online support plays an especially important part in addressing a need for connecting with another person as well as releasing stress and frustrations and preventing further stress accumulation.

Finally, we wanted to know whether the presence of support needs shifted over time. Our findings show that most issues for which people use online support do not appear to depend on time of day or time of the week. There were some exceptions. For example, healthy eating and household chores were more often focused on during weekends, for which a plausible explanation may be that people tend to have more time for and interest in these issues during their weekends. Another example is that advice on conflicts with other people was relatively often focus of support during late afternoons and evenings. It may be that such conflicts happen during day time and later the support users keep ruminating about them. The findings that people use online support for more or less the same issues irrespective of time of day and time of week and that a few matters are more frequently present during weekends and evenings, suggest that 24/7 access to (formal) support responds to an existing need of some people with ID and may potentially be of great benefit.

The four main categories resulting from our qualitative analysis are well documented, important issues in the lives of people with intellectual disabilities. Our results indicate that mental health is an important theme in online support. This is not surprising, as previous research has shown that people with mild intellectual disabilities or borderline intellectual functioning experience mental health difficulties relatively often compared with people without intellectual disabilities (Douma et al., 2006; Emerson et al., 2010). The finding that the online support service is being used 24/7 as a helpline for mental health issues is therefore encouraging. Round-the-clock availability of support initiatives such as DigiContact may be of substantial value when it comes to supporting people in managing their mental health, for example, by timely signaling worries or feelings of distress and reminding them to take prescribed psychotropic medication.

We also found that the online support service is relatively often contacted about social contacts with other people. Many people with intellectual disabilities experience difficulties in developing and maintaining social relationships, which results in having a limited social network (Van Asselt-Goverts et al., 2015; Verdonschot et al., 2009). We also know that people with intellectual disabilities report relatively high rates of loneliness (Bhaumik et al., 2008; Heinrich & Gullone, 2006) and that feelings of chronic loneliness are associated with a range of adverse life outcomes (Gilmore & Cuskelly, 2014; Lente et al., 2012; Schinka et al., 2012). The online support service may have a preventive role with regard to the start of or increase of loneliness and through this may positively affect mental and physical health problems.

The theme practical issues represents a broad collection of support needs related to for example administrational and financial activities, preparing for meetings and applying structure in one's daily life. People with (mild) intellectual disabilities often experience limitations in for example planning and problem solving skills and many of them are used to rely on others for certain tasks. In addition, we suggest that our finding should be looked at acknowledging that the progressive complexity of society may complicate participation for people with intellectual disabilities (Woittiez et al., 2016).

People with intellectual disabilities also contact DigiContact for issues concerning their physical health. Physical health problems may (partly) reflect psychological or emotional problems, but people with intellectual disabilities are also known to experience poorer health outcomes than people in the general population (Baxter et al., 2006; Van Schrojenstein Lantman-de Valk et al., 2000). Health disparities largely result from barriers in receiving timely, appropriate, and effective primary healthcare (Krahn et al., 2006), of which an important barrier lays within the exchange of patient health information (Mastebroek et al., 2014). In addition to offering an opportunity to talk about and monitoring physical complaints, the online support could play a facilitating role in contacts with healthcare professionals such as general practitioners. We could for example think about offering support in preparing for a visit and in translating a g.p.'s advice into a plan for action.

Limitations

This study has some limitations. First, due to the exploratory nature of the study, some items of the registration form were quite broad. This may have limited us in making distinctions that might have been valuable. Second, the amount of support contacts during the night was low. This made it impossible to include night shifts in our analyses. Third, as described under procedures in our methodology section, items were scored at the level of work shifts. As a result, we could only look at the presence of support needs within the time frames of the work shifts. As these time frames were quite large (early shifts encompassed mornings and early afternoons and the late shifts included late afternoons and evenings), the data did not allow us to 'zoom in' on more specific time frames.

An additional remark should be made. The current analysis and reporting of the different themes in support needs to raise the impression that themes are separate entities within the support needs of people with intellectual disabilities, while in reality these are likely to be intertwined. For example, support needs regarding the

mental health might be related to social isolation and loneliness and physical health problems may also (partly) reflect psychological or emotional problems.

Implications

This explorative study suggests that 24/7 online support is a useful way of providing services. People can contact a support worker at any time and from any place. This contrasts with the old situation, when people had to wait for an onsite support worker to be available and contacts were restricted and scheduled regarding timing and duration. On the individual level (micro), unlimited access to online support has multiple potential advantages. First, it allows and stimulates people with intellectual disabilities to exert more control over their support: they are the ones who decide if, when, how often and about what they contact the service. Second, it might enable the support and facilitation of learning by experience (Kolb, 2015), as people can call in the moment a problem or question is relevant, while being in the real life situation and they have the possibility to repeat as often as necessary. Third, the possibility of talking to a support worker more often and without a need to postpone contact may result in less accumulation of psychological tension and emotional and behavioral problems may be prevented. A practical issue can be quickly addressed and possibly solved, preventing it from having more effect or evolving into a bigger issue. Fourth, some individuals may feel more secure merely realizing that someone is available when needed. On the organization level (meso), an initiative such as DigiContact enlarges the range of services. It enables organizations to differentiate themselves as well as to compose a more individualized support offer. On the system level (macro), it raises the question if and to what extent this initiative can be seen as (part of) an adequate solution to current social and political challenges.

Several implications for future research can be formulated. First, it will be important to focus more on the diversity of the support needs of people who use DigiContact and the corresponding possibilities and limitations of online support. Second, this study does not allow the drawing of conclusions on exactly what an online support service such as DigiContact brings into an overall system of (formal and informal) supports around an individual. In future studies, an integrated approach of the online support should be included and attention should be paid to the use of online support as an addition to or an alternative for onsite support. Third, more attention will need to be paid to the effects of online support on personal, quality of life related outcomes, such as self-determination and empowerment. Fourth, it would be interesting to look at whether online support merely differentiates itself from onsite support in that it is delivered through a video connection or if offering online support requires support workers to work in an intrinsically different way.

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CHAPTER 3

The support practice of professionals providing 24/7 remote support

Zaagsma, M., Koning, M. H. M., Volkers, K. M., Schippers, A. P., & Van Hove, G. (2022). Supporting independently living people with intellectual disabilities: a qualitative study into professional remote support practices. *British Journal of Learning Disabilities*. Advance online publication. https://doi.org/10.1111/bld.12488

ABSTRACT

Background

Professional support for people with intellectual disabilities is increasingly delivered remotely. Understanding what support workers do to support people with intellectual disabilities remotely, and how they do this, is therefore important. The purpose of this study was to gain insight into the remote support practice of the support staff of the Dutch service DigiContact.

Methods

A qualitative study was performed in which we followed an inductive-iterative process and used different sources of information: documents, interviews with people who are supported by DigiContact and their case workers, and interviews with DigiContact support workers.

Findings

Seven themes were constructed and described. Four themes reflected the support activities of DigiContact support workers, and three themes reflected qualities that guide how the support is provided.

Conclusions

A remote support context can bring both challenges and opportunities to the practice of supporting people with intellectual disabilities. The findings can be useful for service organizations who are contemplating the adoption of remote support initiatives for people with intellectual disabilities.

INTRODUCTION

Service organizations for people with intellectual disabilities increasingly deliver support remotely (Friedman & Rizzolo, 2017). Examples consist of the deployment of sensors, cameras and detectors for monitoring people's health and safety, and the use of online devices (e.g., tablets, smartphones and computers) to enable live communication with support professionals (Taber-Doughty et al., 2010; Tassé et al., 2020). The rationale behind the adoption of remote support strategies can be the desire to save costs and/or to increase access to support (Brewer et al., 2010; Friedman & Rizzolo, 2017; Tassé et al., 2020). Another aspect that may play a role is that remote support has been found to contribute to people experiencing more independence, autonomy and privacy because the need for the physical presence of support staff in their homes reduces (Niemeyer et al., 2010; Tassé et al., 2020; Wennberg & Kjellberg, 2010). On top of this, the coronavirus 2019 (COVID-19) pandemic has given an extra impulse to the adoption of remote support, as organizations searched for ways to safeguard the continuity of their service provision during periods of lockdown and social distancing (Doody & Keenan, 2021; Wos et al., 2021).

For the Dutch service organization Philadelphia Care Foundation (PCF), reforms of the national long-term care sector formed the motivation for the development of the remote support service DigiContact and its implementation as part of its service portfolio for independently living people with intellectual disabilities (Vijfhuizen & Volkers, 2016). The reforms were intended to improve the quality of long-term care by making it more person-centred, and to increase the self-direction and social inclusion of people with disabilities (Kromhout et al., 2018; Van Ginneken & Kroneman, 2015). However, as they were accompanied by substantial budget cuts (Maarse & Jeurissen, 2016), the reforms also resulted in tighter eligibility criteria and a higher risk that people with so-called 'mild support needs' were excluded from a right to care (Grootegoed & Tonkens, 2017). In response, service organizations felt the urgency to search for new and innovative support concepts and services that would enable them to continue their service provision to independently living people with a need for professional support. The remote service DigiContact offers 24/7 available and on-demand remote support through video calls (online) and audio-only calls (online and offline) with specially trained support workers. Table 3.1 provides a description of the service using its main characteristics. DigiContact support is mainly used as an addition to onsite support (either at home or a community centre).

Table 3.1: Characteristics of the DigiContact service

Characteristics	Description
24/7 available	Support is available 24 h a day, 7 days a week. The support workers work in rotating 6 - 8 h shifts.
Support is provided remotely	Support is provided through live video calls (online) and audio-only calls (online and offline). Support users either use their own device (e.g., tablet, pc, smartphone, landline phone) to contact the service, or a tablet they receive on loan from the service organization. Technical support is available in the form of technicians who assist either from a distance or at home.
Support can be planned and unplanned	Contacts can be planned and unplanned. Planned contacts are with appointment, usually according to an agreed on time interval. Unplanned contacts are without appointment: support users call in whenever they want or need support (on demand).
No fixed contacts between support workers and support users	Support users cannot choose which support worker they speak to: they talk to the support worker who picks up their call.
Usually combined with onsite support services	The service is implemented as one component of a broader support concept for independently living people with intellectual disabilities (called My Network). In practice, support from the DigiContact service is usually combined with onsite support at home or a community center.

The increased adoption of remote support initiatives such as the DigiContact service underlines the importance of evaluating them, for example, with respect to quality and impact. To understand how a service operates and plans to obtain its intended outcomes, it is essential to take into account the role of its support staff, that is, what their support activities entail and how their support is provided (Rossi et al., 2019; van Yperen et al., 2017). In the case of remote support services, gaining insight into the support practice of its staff might be of particular interest, as not being present at the same location as the person whom one supports may require a specific approach. Besides providing valuable input for evaluation, being able to describe support activities will facilitate the transfer of a service's support practice towards other (new) support staff members (Clement & Bigby, 2011; Douglas & Bigby, 2020) as well as to other organizations. The latter seems especially relevant nowadays, as service organizations display an increased interest in setting up new remote support services, and may profit from the experience gathered by other organizations.

Unfortunately, studies seem to have paid relatively little attention to the role of remote support workers. In general, studies on remote support have focused on exploring the experiences and perceptions of people with intellectual disabilities and/or on onsite support staff (e.g., Frielink et al., 2020; Perry & Beyer, 2012; Tassé et al., 2020), or on evaluating the outcomes of specific initiatives (e.g., De Wit et al., 2015;

Taber-Doughty et al., 2010). To the best of our knowledge, only a few studies have shed some light on the support practice of remote support staff. In a feasibility study on a web-based support programme for people with mild intellectual disabilities or chronic psychiatric disorders, De Wit et al. (2015) asked both programme users and support workers for feedback on the quality of their communication. Their participants indicated that the online support became more directed towards encouraging them to draw on their personal strengths and skills when executing daily tasks, but they did not specify how this was done. In one of our own studies on support user experiences with support from the DigiContact service, we found that the support staff was experienced to adopt a coaching style during their contacts (Zaagsma et al., 2021). Like in the study of De Wit et al. (2015), the participating support users did not elaborate on what the coaching style of supporting entailed.

The limited knowledge of the role and practice of remote support staff underlines the importance of research on this topic. The current study was designed and conducted to describe the support practice of the DigiContact service's support staff. More specifically, the study aimed to explore the support activities of DigiContact support workers by focusing on the following question: What do DigiContact support workers do during their remote contact with independently living people with intellectual disabilities to support them and how do they do this?

METHODS

Study design

A qualitative and descriptive research design was adopted in which we followed an inductive-iterative process (e.g., Kekeya, 2016; Yom, 2014), which consisted of four steps and included three sources of information: (1) key documents on DigiContact, (2) interviews with DigiContact support users and their case workers (senior support workers who provide onsite support and coordinate supports), and (3) interviews with DigiContact support workers. 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, which meant that official approval by the committee was not required. The study was designed, planned and carried out by two researchers: an academically trained researcher (MZ) and a co-researcher with an intellectual disability (MK). Three senior researchers (KV, AS, GvH) advised on methodological issues, were actively involved in data analysis and provided feedback on previous versions of this paper.

Step 1: Desk research

Together with two DigiContact staff members we selected seven documents that were expected to provide initial insights into the provided support: one program description, two informational documents for new support workers, the official job description for the role of remote support worker, two brochures for support users and their families, and a text on the service organization's website. The content of the documents was analyzed through a qualitative content analysis process based on a general inductive approach (Thomas, 2006). Two authors (MZ, KV) selected and coded pieces of texts that provided information regarding the support activities of DigiContact support workers. The codes were clustered into categories and subsequently into themes.

Step 2: Interviews with remote support users

During three previous studies on DigiContact (Zaagsma et al., 2019; Zaagsma, Volkers, Koning et al., 2020; Zaagsma et al., 2021), a total of 55 interviews were carried out with support users and/or their case workers to explore their experiences with DigiContact. Although these interviews were not specifically focused on the support activities of DigiContact support workers, the subject had often come up and we seized the opportunity to include this material in the current analysis. As analyzing all 55 interview transcripts would require a time frame that went beyond our planning, we selected 40 transcripts (Table 3.2) that we considered to be rich in information (criterion: highest number of codes from the original analysis). A new analysis, again following the inductive approach of Thomas (2006), was performed on these transcripts by three authors (transcripts were divided amongst MZ, MK, and KV) to find both information that confirmed the coding scheme from step 1, as well as new information that was added to form a supplementary coding scheme.

Table 3.2: Characteristics of participants

	Step 2, Support users[a] (*N* = 21)	**Step 2, Case workers[b] (*N* = 9)**	**Step 3, Remote support workers (*N* = 10)**
Woman, *n*	7	8	8
Age, *Mdn*. (range)	49 (33-71)		
Years of using online support, *M*(SD)	2.0 (1.4)		
Years of providing online support, *M*(SD)			3.1 (1.9)
Experience with providing onsite support, *n*			8

[a] Participants from previous studies on DigiContact (Zaagsma et al., 2019; 2021; Zaagsma, Volkers, Koning et al., 2020). Included in analysis were 31 transcripts of interviews with 21 support users (most support users were interviewed twice).
[b] Participants from previous study on DigiContact (Zaagsma, Volkers, Koning et al., 2020). Included in analysis were nine transcripts of interviews with nine case workers.

Step 3: Interviews with remote support workers

As a next step, we conducted semi-structured interviews with ten DigiContact support workers. The interviews focused specifically on their support activities during contacts with independently living people with intellectual disabilities.

A combination of purposive and convenience sampling procedures (Patton, 2005) was used for recruitment. The DigiContact support staff team consisted of 25 support workers at the time of planning the interviews (December 2019). Three support workers were excluded a priori, because they had only recently (< six months earlier) joined the team and we felt that this might be too short to be acquainted with every detail of our enquiries. An informational e-mail with an appeal to participate in an interview was sent to the remaining 22 support workers. Seven support workers enlisted themselves in response. To obtain a better representation of the team (with respect to sex, length of time working at DigiContact, and having previous experience with providing onsite support), five more support workers were selected and re-contacted. Three of them agreed to an interview. One support worker did not want to participate, because (s)he felt not experienced enough to reflect on her/his work and the other was not interviewed as we failed to plan an interview due to conflicting agendas. As a result, a total of ten DigiContact support workers were interviewed (Table 3.2).

An interview guide was developed based on the coding scheme from step 2. The guide included four main topics: (1) values and goals, (2) activities and strategies, (3) working in a team and (4) conditions for providing good support. The interviews (held by MZ and MK together) were all audio-recorded with participant approval and transcribed verbatim. We used member validation as a validity check (Green & Thorogood, 2014), in which each participant received a typed summary of their interview to check for accuracy. One participant provided additional input to nuance his/her views regarding the conditions for providing good support.

For analysis, the transcripts were distributed amongst all authors in such a way that each transcript was coded, again inductively, by at least two authors (MZ coded all transcripts). The resulting codes, categories and themes were compared to those in the coding scheme from step 2 by the first author. New codes were added to the scheme, and categories and themes were adjusted where relevant to improve the fit with all data. The new coding scheme was discussed amongst all authors before continuing with the final step.

Step 4: Check on recognisability and relevance

Short descriptions were made of the themes in the coding scheme after step 3. These descriptions were presented to and discussed with two senior DigiContact support professionals in terms of their recognizability and relevance. Although the descriptions were recognized to be an adequate reflection of the provided support, some feedback was given on one of the themes ('Creating a safe and welcoming digital environment') which led to a reformulation of its description.

RESULTS

The analysis of steps 1 to 3 resulted in the construction of seven themes. Four themes, called areas of support, reflect *what* the support activities of DigiContact support workers entail. Contacts vary with respect to how many and which areas of support are present, as well as the relative emphasis placed on each of them. Three themes reflect central qualities that guide *how* DigiContact support workers provide support during their contacts with support users across all areas of support. The areas and qualities of support are interconnected, as depicted in Figure 3.1. The following paragraphs provide a description of the seven themes, as resulting from step 4. Quotes from the interviews with DigiContact support workers are used sparingly by way of illustration.

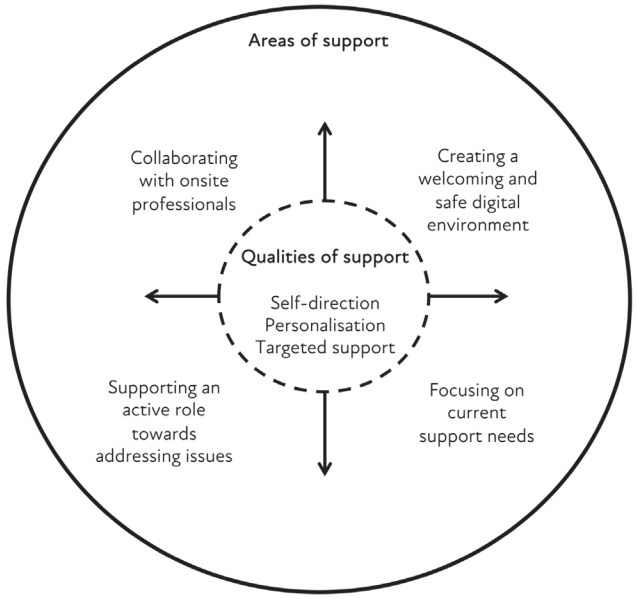

Figure 3.1: Visual representation of the interconnectedness between the areas and qualities of DigiContact support

Areas of support

Creating a welcoming and safe digital environment

During each support contact, the support workers aim to create an environment in which support users feel sufficiently welcome and safe to share and discuss their issues, and can be open and receptive to assistance. It was experienced that creating such an environment is hampered by the absence of fixed contacts between specific support workers and support users. That is, support workers do not have a fixed sub selection of support users under their wings[13], and support users talk to the support worker who happens to answer their call (which can be a different support worker each time they call in).

> *Clients should feel welcome and be invited to discuss their problems.* [...] *It is always a challenge to realize a pleasant atmosphere during conversations, as you are rather anonymous due to being part of a large team, and having plenty of clients. So you miss out on a one-to-one relationship with a client, but even so you need to find a pleasant informal way of conversing.* (Support worker 8)

Despite –and because of- the absence of fixed contacts, the support workers invest time and effort during each contact into making personal contact with support users by using several strategies. First, they adopt an affective attitude characterized by openness, empathy, respect, equality and tranquility. Second, they present themselves as a present and available partner in conversation by giving support users space and time to talk about what is on their mind, by showing sincere interest in their stories, and by providing some level of reciprocity in conversation. Third, they positively reinforce the self-image and self-confidence of support users by complimenting them (e.g., on taking initiative to contact the service) and highlighting positive aspects in their situation. The support workers align their strategies with the specific characteristics and context of each contact. For example, a warm atmosphere is more important when support users call in in tears to talk about an argument with their partner, than when they seek help with drawing up a shopping list.

Sometimes support workers do not succeed in creating a safe environment for (and with) a support user. When they notice that, despite their efforts, a support user does not feel at ease, they consider the possibility of offering the possibility to be connected with a colleague.

13 There are no fixed contacts between specific support workers and support users, which means that the support workers provide support to any support user who calls in during their work shifts.

Focusing on current support needs

In their support contacts, the support workers focus their attention and support on the question(s) and/or issue(s) that are, right there and then, bothering the support users. This is especially the case in unplanned contacts, as there is often a specific issue that caused support users to contact the service. Therefore, in unplanned contacts, the support workers try to get a clear and comprehensive picture of the issue(s) for which support is sought on early in the conversation by listening attentively (with the intent of fully understanding support users), and by reading their support plans and the recent reports on previous support contacts in their electronic client file (ECF). Subsequently, they try to accommodate support users by validating their request for help and letting them know that their support question is understood. In planned contacts, the support workers focus on the support goals as defined in the support users' support plans (in ECF).

> *If someone calls in unplanned, there is usually something that is really bothering the client. So I generally start with an open question like 'How are you doing today?' or 'I see that you do not have an appointment for today, what has made you contact us?' When the call is planned, I usually focus on the support goals that we agreed on. But even then, I do ask whether there are other things to discuss.* (Support worker 10)

Although getting a clear picture of what is bothering a support user may be relatively easy when s/he is able to put thoughts and feelings into words, it can be quite difficult when s/he is not able to do so. In the latter case, support workers try to figure out the 'question behind the story' by asking explorative questions, by intuitively sensing what might be going on and by checking if their assumptions are valid. In this process, not knowing a support user well personally (due to the absence of fixed contacts) was experienced to add to the complexity of identifying the current support needs.

Supporting an active role towards addressing support needs

After clarifying the support users' questions and/or issues, the support workers steer the conversation towards what they need and want in terms of support. While in some cases it is sufficient to provide support users with emotional support in the form of 'a sympathetic ear', in other cases they may (also) need informational and/or practical support. In general, support users are supported towards reaching a point at which they are confident about being able to continue on their own. Several support workers stressed the relatively reactive (ad hoc) character of their support:

> *When you work as an onsite support worker, you may well have two hours to find a solution with someone and you pick up on that theme the next time you meet again. At DigiContact, we do not get that next time. So our support is especially about helping clients with their issues and feelings, so they can deal with them and continue with their day.* (Support worker 7)

Support users are stimulated to take on an active role in thinking about possible answers and solutions. The support workers for example ask them about previous situations in which they encountered similar problems and how they handled them, or about people from their social network who might be able to help. Not being in the same room was experienced to prevent the support workers from taking over tasks and to enable them to guide support users towards using their own skills, knowledge and talents to solve issues.

Although the support workers aim to take over as little as possible, they will do so when a situation calls for it. In the extreme example of a crisis, they take over and arrange what is needed to ensure the support user's safety (e.g., calming them, calling a doctor or emergency service, informing and mobilising family and case worker) and subsequently remain in touch and coordinate actions until this role can be handed over to the case worker. In this respect, the 24/7 availability of DigiContact support was experienced to be of great value, both by support workers and users.

Collaborating with onsite professionals

For the grand majority of support users, DigiContact support is an addition to onsite support provided by their case worker (and sometimes also by other support workers). In this case, DigiContact support workers form a collaboration with their onsite colleagues, with the purpose of working together and aligning their support. In their contacts with support users, careful attention is paid to signaling issues that would benefit from being addressed by an onsite support worker, in which case support users are referred accordingly, and a note is made in their ECF. When a potential problem is signaled, the support workers (DigiContact and onsite) contact each other directly to enable a quick intervention which might prevent problems from getting worse:

> *Once we suspect that someone is not doing well, we contact the regular onsite worker who will then pay a visit to this client. It is also possible that the onsite worker calls us, for instance when the weekend is approaching and he or she will be off duty. They may say something like: 'I will not be there over the weekend, but* [name client] *is having trouble with this and that, and it may be important*

for you to know this, should this client phone in. Could you phone her once or twice additionally?' (Support worker 3)

As described before, DigiContact can function as a first contact for support users in the case of a crisis, and its support workers undertake the first necessary steps before informing the onsite support worker, who then takes over.

The collaboration with onsite support workers is anchored in the overall support process. At intakes and evaluation sessions, the support user, his/her case worker and one of the DigiContact support workers all participate. An ECF system that is accessible to all parties is used to record the support plan and reports on support contacts.

Qualities of support

Self-direction of support users

The support activities of DigiContact support staff are guided by the principle that support users are in control of their support. Not only do they control the timing and frequency of their support contacts by making decisions on when and how often they need support, they are also given a steering role regarding the content of the support (i.e., what their support focuses on ('Focusing on current support needs') and what they need to move forward in terms of possible answers and solutions ('Supporting an active role in addressing support needs'): *"You always put the clients in charge. You hear them out and you provide the support that is desired."* (Support worker 8)

The self-direction of support users is most evident in unplanned contacts, as the opportunity to deploy online support without having an appointment enables them to make on-the-spot decisions regarding if and what kind of support is needed. In planned contacts, support user control is exerted more indirectly, as decisions regarding timing, frequency and content of contacts are made during intakes and periodic evaluations, together with their case worker and a DigiContact support worker.

Personalisation

DigiContact support workers aim to adjust their support as much as possible to the personal needs and preferences of support users. This was experienced to be a challenging process, because they provide support to a very large and diverse group

of support users[14] and they do not know each of them well, due to the absence of fixed contacts. Having access to up-to-date information on each support user (i.e., support goals and plans, points of attention in the interaction, and reports on support contacts with onsite support workers) is therefore of essential importance. Ideally, the support workers prepare themselves by reading this information in advance. When this is not possible, for example in case of an unplanned contact or when there is not enough time to prepare, the support workers read this information during their contact with the support user:

The first thing we look up are the instructions concerning how to relate to this client. It regularly happens that we have a call with someone whom we only speak to once every three months or so. In that case I obviously do not know immediately who this client is, and how I can best relate to him or her. We really want these instructions to be up to date and well organized. (Support worker 2)

Besides having access to information on support users, it is important for the support workers to rely on their intuition, to try out approaches and to evaluate them together with the support users.

Targeted support

For each support contact, DigiContact support workers take out as much time as needed, but also as little as possible by keeping their conversations to the point and directed towards the four areas of support (as described under 'Areas of support'):

We want conversations to be about what is the matter. Once the problems have been discussed and, in some cases, the solutions established, we should end the conversation. We do not talk for the sake of talking, but we support and guide. (Support worker 9)

The remote context of DigiContact was experienced to make it easier to keep conversations to the point, as the absence of fixed contacts and the physical distance between support workers and support users frees up time that would otherwise be used for things like 'catching up and drinking coffee'.

14 At the time of the interviews with support workers (January 2020), about 1500 support users were connected to the service.

DISCUSSION

Despite the fact that remote professional support for people with intellectual disabilities is becoming increasingly prevalent, there is still limited knowledge of the role of remote support workers. This paper contributes to the body of such knowledge by exploring the support practice of the remote support service DigiContact. The findings show that the support activities of DigiContact workers focus on strengthening the capabilities of independently living people with intellectual disabilities regarding coping and problem-solving and on giving them (more) control over their support and the way they confront the difficulties they encounter in their everyday lives. In addition, they aim to create the conditions that enable and facilitate the support process: a welcoming and safe digital environment and a close collaboration with onsite support staff.

The findings indicate that a remote support context can bring both challenges and opportunities to the practice of supporting independently living people with intellectual disabilities. With regard to challenges, the findings show that that DigiContact support workers feel the need to pay extra attention to the creation of a safe and welcoming environment in which people feel invited and sufficiently safe to discuss problems. As people are not supported by fixed remote support workers (i.e. every time they contact the service, they speak with a support worker who happens to pick up their call; this can be a different support worker every time), they do not know the remote support workers well (and vice versa) and are therefore not able to build up a bond of trust over time. Not knowing the people who one supports well underlines the key importance of support workers having access to up-to-date information on each support user and taking the time to read this and prepare. Although giving support users space and time to talk is part of the support workers' strategy to make people feel at ease, this seems to interfere with the aim to keep conversations to the point. Finding the right balance between keeping conversations to the point and making people feel safe and welcome seems complicated (especially as this balance might be different for every person). Creating a safe and welcoming environment brings to mind the term safe space, which is often used in referral to a physical place (e.g., in schools, universities, workplaces) where people can meet and discuss their experiences without facing prejudice, judgement, conflict and critique (e.g., Flensner & von der Lippe, 2019; Harless, 2018). In reference to working with people with intellectual disabilities, the importance of creating a safe space has been stressed with regard to different contexts, such as inclusive research collaborations (Puyalto et al., 2014; Schwartz & Durkin, 2020) and inclusive training settings (Sergeant et al., 2021). Despite the efforts of the DigiContact support

workers to make personal contact with each support user and to create a friendly, open, respectful and positive atmosphere, in a previous study we found that support users can still perceive their contacts with the service as relatively impersonal and that this can inhibit them to open up and discuss certain issues (Zaagsma et al., 2021).

With regard to opportunities, the findings indicate that providing support from a distance may compel support workers to take a step back and give support users room to do things their way. DigiContact support workers encourage and guide support users from a distance to tap into their own skills, knowledge, experiences and motivations as much as possible when confronting their problems, and they try to provide the tools and support that they need to take on an active role towards struggles and difficulties. Their support is not about pushing people into dealing with problems alone or independently, but about partnering up with them and giving support and guidance so that they can act as a causal agent in their own lives (Wehmeyer et al., 2017). This finding corresponds to the concept of relational autonomy, which centres around the conviction that agency and autonomy emerge through the support and enablement of other people (Björnsdóttir et al., 2015; Davy, 2019). Another parallel can be drawn between the support activities of DigiContact support workers and Freire's concept of 'conscientisation', which refers to a process of raising critical awareness of one's social reality through reflection and action that often leads to personal and social transformation (Freire, 1970). DigiContact support may have an empowering impact on people with intellectual disabilities through enhancing their understanding of the difficulties that they encounter and their own potential with regard to addressing them. This may in turn lead to a growth in (self) confidence regarding one's competence to confront issues (Zaagsma et al., 2021).

Besides indicating that a remote support context can bring both challenges and opportunities to the practice of supporting independently living people with intellectual disabilities, the findings also underline the importance of remote support workers collaborating closely with onsite support workers to provide good support. DigiContact support workers were found to coordinate and align support plans and activities with their onsite colleagues, and to work closely together in supporting support users. This resonates with the concept of collaborative teaming, which is used in inclusive education literature to depict the collaboration between professionals (e.g., special needs and general educators) who share the goal of supporting students with disabilities in inclusive classrooms (King-Sears et al., 2015; Snell & Janney, 2000). In care settings, a frequently used term for situations in which onsite and remote (online) services are combined is blended care (Wentzel et al., 2016). Several authors have stressed the potential value of blended care for the daily functioning of people

with intellectual disabilities (Frielink et al., 2020; Timmer, 2014; Vereenooghe et al., 2017). However, studies on its use in the field of intellectual disability services have so far been relatively limited and primarily focused on initiatives in therapy and educational settings (e.g., Bell et al., 2016; Cooney et al., 2017; Hronis et al., 2019; Zavaraki & Schneider, 2019). The fact that DigiContact support is generally used in combination with onsite support at home (Zaagsma, Volkers, Koning et al., 2020) is an example of how blended care can be realized in support settings.

Limitations

This study focused on the support practice of one specific remote support initiative: the DigiContact service. The findings can therefore not be generalized to other initiatives or remote support services in general. Caution is also warranted regarding the transferability of the findings towards other support user groups than people with intellectual disabilities living independently. Although it may not be likely that DigiContact support workers will adopt an entirely different approach when supporting groups like people with intellectual disabilities in supported accommodation settings, it is possible that some differentiation will occur. Another limitation lies in the use of semi-structured interviews as the main method of data collection. The use of interviews implies that we explored beliefs and perceptions regarding the DigiContact support practice, and these may not be a direct reflection of actual behavior and actions (Green & Thorogood, 2014). Observational data on the interactions between DigiContact support staff and support users are needed to investigate this.

Implications for practice and research

Although the DigiContact support practice may not be easily transferrable beyond the context of this service, it may function as an example for organizations in the field of intellectual disability services who look into the possibility of organizing remote support and how to shape the role of the involved support workers. Previous studies have shown that a service like DigiContact should not be seen nor used as a 'miracle service' in times of social care reforms, as it is not equally suitable for all people with intellectual disabilities and it cannot replace all onsite support (Zaagsma, Volkers, Koning et al., 2020; Zaagsma et al., 2021). Nevertheless, the current findings indicate that DigiContact is not an efficiency measure of which the quality of support cannot be guaranteed and/or receives little attention. Instead, they suggest that DigiContact can play a valuable role in the support of people with intellectual disabilities, especially when deployed as an addition to and in close collaboration with onsite support services. It may for example offer people the opportunity to exert (more) control over their own professional support and give them room to learn

and develop in the area of coping and problem solving. DigiContact may also increase the chances of relatively high-functioning and independently living people with intellectual disabilities maintaining access to specialized support services in the face of budget cuts and tightened eligibility criteria (Zaagsma et al., 2021). Furthermore, the COVID-19 pandemic has underlined the usefulness of having remote support to fall back upon when onsite support provision is hampered (European Association of Service providers for Persons with Disabilities, 2020; Zaagsma, Volkers, Swart et al., 2020).

Regarding future research, the insights into the support activities of DigiContact support staff contribute to an enhanced understanding of how the service operates and plans to obtain its intended outcomes. Thereby, they provide input for future evaluation efforts (Rossi et al., 2019; Van Yperen et al., 2017). It would for example be valuable to explore whether, and to what extent, DigiContact support has an empowering impact by promoting the (relational) autonomy, self-direction and (self-) confidence of people with intellectual disabilities. In addition, to gain insight into potential differences between remote and onsite support activities, it would be interesting to perform an observational study in which remote and onsite support interactions are compared.

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PART II

The role of DigiContact support

CHAPTER 4

The usefulness of 24/7 remote support within a wider mix of services

Zaagsma, M., Volkers, K. M., Koning, M. H. M., Van Hove, G., & Schippers, A. P. (2020). 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. *Inclusion*, *8*(2), 138–154. https://doi.org/10.1352/232-6988-8.2.138

ABSTRACT

Service organizations for people with intellectual and developmental disabilities 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 intellectual and developmental disabilities living independently. We employed a qualitative multiple case study, in which the cases of nine online support users were reconstructed through semi-structured 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.

INTRODUCTION

Within a continuously changing field of disability policy and practice it is important for service organizations for people with intellectual and developmental disabilities 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 intellectual and developmental disabilities 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 intellectual and developmental disabilities 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 intellectual and developmental disabilities (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 intellectual and developmental disabilities and support staff. Telecare systems are often implemented to save costs and reduce staff burden, but are also employed to enable people with intellectual and developmental disabilities 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 intellectual and developmental disabilities. 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 intellectual and developmental disabilities. 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 intellectual and developmental disabilities could contact their onsite support worker in addition to their regular, onsite contacts, increased the 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 intellectual and developmental disabilities 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 intellectual and developmental disabilities 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 intellectual and developmental disabilities is used in this paper. It is a 24/7 available online support service that uses video conferencing techniques to enable communication between people with intellectual and developmental disabilities 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 intellectual and developmental disabilities, 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 intellectual and developmental disabilities 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 1000 people received online support at least once in 2018. That same year, on average 1100 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 intellectual and developmental disabilities 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 intellectual and developmental disabilities 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 individuals with intellectual and developmental disabilities 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.

METHODS

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). Semi-structured 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 intellectual and developmental disabilities. As the co-researcher 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 provider 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 4.1 provides an overview of relevant participant characteristics.

Semi-structured 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 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-VB; van Asselt-Goverts et al., 2012), which is an instrument for mapping characteristics of a social network around an individual with intellectual and developmental disabilities. 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.

Table 4.1: 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

[a] MID = Mild Intellectual Disability (IQ range 50-69), BIF = Borderline Intellectual Functioning (IQ range 70-85).
[b] SSM-D is the Self-Sufficiency Matrix. A = Self-sufficient on all eleven life domains, B = self-sufficient on most (seven to ten) life domain, C = self-sufficient on none or a few (zero to four) life domains.
[c] Time interval between the date on which the participants started to receive professional ID services and the first interview.
[d] Time interval between the date on which the participants started to use the online support service and the first interview.
[e] Mean number of online support contacts per month (during period January – June 2017).

Procedure

A total of 24 interviews were conducted (see Table 4.2). 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 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.

Table 4.2: Conducted interviews

	Number of interviews		
Cases	**Support user**	**Case worker**	**Total**
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
Total	16	10	24

[a] One interview with a support user was combined with an interview with a case worker.

Data analysis

Data were analyzed 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 intellectual and developmental disabilities 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 grouped into (sub)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 parenthesis, 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 cannot 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 4.3 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 subcategories, the

online support service focused on eleven subcategories. The number of subcategories 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.

Table 4.3: 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	3,4,6,7	1,2,3,4,5,6,7,8,9	1	1,2,3,6,7,8,9
Signaling emotional problems	4,8,9		3,8,9		3,8
Referring to mental health professionals			3		
Interpersonal Relationships					
Stimulating insights into social situations	1,7		1,4,5,6		
Couching 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	6,7
Social connection					
Having someone as company	1,2,3,4,5,6,7,8,9	1,2,3,4,5,6,7,9	1,2,3,5,6,7,8,9	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	1,2,3,5,6,7,8,9	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 finance	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	1,3,4,5,9		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).

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 subcategories: *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:

> *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 subcategories: *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 taking 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 subcategories: *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 sub-categories: *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 intellectual and developmental disabilities. The participating support users were high-functioning individuals with intellectual and developmental disabilities 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 intellectual and developmental disabilities 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 relatively strongly on professionals for support. Multiple studies have shown that people with intellectual and developmental disabilities 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, conflicts, and stress. It is recognized that many families and other caregivers are in need of services and support (Amado et al., 2013; Reynolds et al., 2015; Reynolds et al., 2018). Besides being a service for people with intellectual and developmental disabilities, 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 intellectual and developmental disabilities 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 intellectual and developmental disabilities 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 divers 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 intellectual and developmental disabilities (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 independently living people with intellectual and developmental disabilities, 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 intellectual and developmental disabilities 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 intellectual and developmental disabilities adopting a new technological application into their daily lives and benefitting from it. It would be interesting to extent our look into the possibilities of using smart home technologies and their potential to improve the quality of life of people with intellectual and developmental disabilities 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 intellectual and developmental disabilities. 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 intellectual and developmental disabilities.

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CHAPTER 5

The use of 24/7 remote support during COVID-19

Zaagsma, M., Volkers, K. M., Swart, E. A. K., Schippers, A. P., & Van Hove, G. (2020). The use of online support by people with intellectual disabilities living independently during COVID-19. *Journal of Intellectual Disability Research*, *64*(10), 750–756. https://doi.org/10.1111/jir.12770

ABSTRACT

Background

During the COVID-19 outbreak, service providers in the Netherlands had to switch towards providing remote support for people with intellectual disabilities living independently. This study aims to provide insight into the use of online support during the outbreak.

Methods

We analysed quantitative data on planned and unplanned contacts between the online support service DigiContact and its service users.

Results

The results indicate that the COVID-19 outbreak and the related containment measures had a strong impact on online support use, specifically on the unplanned use of online support.

Conclusion

Offering online support as a standard component of services for independently living people with intellectual disability enables service providers to be flexible and responsive towards fluctuations in both support needs and onsite support availability during a social crisis such as COVID-19.

BACKGROUND

The global outbreak of the COVID-19 virus and the restrictive measures imposed by governments aimed at containing its spread have a strong impact on the provision of social care and support services for people with disabilities around the world (Armitage & Nellums 2020; European Association of Service Providers for Persons with Disabilities 2020). It seems likely that also people with intellectual disabilities have been (or still are) at risk of experiencing a discontinuation of support to some extent. For example, in the Netherlands, while residential care services for people with intellectual disabilities continued, visits from friends and family were mostly prohibited. Services such as day activity centers and meeting centers, as well as some sheltered workshops, were put on hold for several months (Dutch Association for Healthcare Providers for People with Disabilities 2020; Woittiez et al., 2020). Although at the time of writing this paper (June 2020), restrictive measures are being lifted, it remains to be seen whether relapses will occur causing measures to be reinstated.

While in the Netherlands, considerable (media) attention was paid to the impact of restrictive measures on people in residential services and on their families, the impact on people with intellectual disabilities who live independently has been relatively underexposed. With day activity centres and some sheltered workshops being put on hold, people risked temporarily losing their daytime occupation that not only provided them with structure in their day, but also implied the loss of an important vehicle to community participation and social inclusion (Brooks et al., 2020; Lysaght et al., 2016; Simplican et al., 2015). In addition, service providers had to switch towards offering support as much as possible remotely, for example, through online video calls, to safeguard the health of both support staff and service users (Dutch Association for Healthcare Providers for People with Disabilities 2020; European Association of Service Providers for Persons with Disabilities 2020). For people with intellectual disabilities, such a sudden change may result in an experience of being thrown back to one's own resources, especially when family and friends cannot provide (more) support due to the containment measures (Courtenay & Perera 2020; De Vries et al., 2020).

Although it is still early to evaluate efforts to provide remote support during the COVID-19 outbreak, the specific case of the Dutch online support service DigiContact presents us with the opportunity to get insights into the use of online support by people with intellectual disabilities living independently. DigiContact was developed and implemented in 2014 by the service provider organization Philadelphia

Care Foundation (Vijfhuizen & Volkers 2016). People with intellectual disabilities can contact a team of specially trained support workers 24/7, either planned or unplanned (whenever they feel the need). Contact can be realized through specially developed videoconferencing techniques (using a PC, laptop, tablet or smartphone) or through a regular phone connection. Depending on a person's support needs, online support is usually combined with onsite support. As DigiContact was already operational before the COVID-19 outbreak, the capacity for online contacts could relatively quickly be scaled up by adding resources such as necessary equipment and bringing in onsite support staff, who could no longer provide onsite support, to increase the size of the online support staff team. In addition, a team of nurses was installed that could be consulted through DigiContact for COVID-19-related medical questions.

This study aims to contribute to the knowledge on the usefulness of offering remote, online support to independently living people with intellectual disabilities during a time of crisis, when regular onsite services are not or less available. With this aim, we explored the use of DigiContact support during the first weeks of the COVID-19 pandemic. In this paper, we focus on the following question: how does the (planned and unplanned) use of online support by people with intellectual disabilities living independently evolve during the first weeks of the COVID-19 pandemic in the Netherlands?

METHODS

A retrospective, descriptive research design was employed in which quantitative data on support contacts between DigiContact support staff and independently living people with intellectual disabilities were employed. The Medical Ethics Review Committee of VU University Medical Center (FWA00017598) confirmed that the Dutch Medical Research Involving Human Subjects Act (WMO) did not apply to this study and that official approval by the committee was therefore not required. The privacy officer of the involved service organization reviewed and approved the research plan and procedure.

Before the COVID-19 outbreak, the number of independently living persons with intellectual disabilities connected to DigiContact fluctuated around 700. During the pandemic, 282 additional persons were connected at the initiative of the service provider, to create a safety net for them in the event that many onsite support workers would fall ill and/or regular support (from a distance) could not be continued. Being connected to DigiContact means that several technical and administrative

actions have been completed that enable a person to contact the service. However, being connected does not necessarily imply that someone actually has contacts with the service. Persons who actually have contacts with the service are from now on referred to with the term service users.

We used data on online support contacts from the service provider's administrational systems to explore the use of DigiContact. As our focus was on the use of online support during the first months of the COVID-19 pandemic, we used data on contacts during the first 20 weeks of 2020. To enable a comparison with the use of DigiContact support during a similar period without a pandemic outbreak, we also included data on contacts during the first 20 weeks of 2019. All data were anonymized before being handed over to the first author for analysis: a unique identification code was allocated to each service user, which enabled us to identify contacts belonging to the same service user. The data set included the following information for each support contact: date, start time, a service user identification number (recoded for anonymization) and whether a contact was unplanned or planned.

Analysis was performed using SPSS version 23 for Windows and Microsoft Excel 2016. First, descriptive statistics were run regarding the number of service users and (unplanned and planned) contacts per day during the period with active COVID-19 containment measures (weeks 12–20 of 2020, see Fig. 5.1.) and two reference periods: (1) the weeks prior to the period with active containment measures (weeks 1–11 of 2020) and (2) the first 20 weeks of 2019. To get a more detailed overview of how online support use evolved over time, we also calculated the number of unplanned and planned contacts per day for each week. Second, we compared the amount of unplanned and planned contacts per day per service user during the COVID-19 period and both reference periods. Given the non-normal distribution of the data, non-parametric two-tailed Wilcoxon signed-rank tests were used to test for differences between periods. The significance level was set at 2.5% to adjust for multiple testing, as we had two reference groups. The findings were presented to two senior members of the DigiContact team, and possible interpretations were discussed.

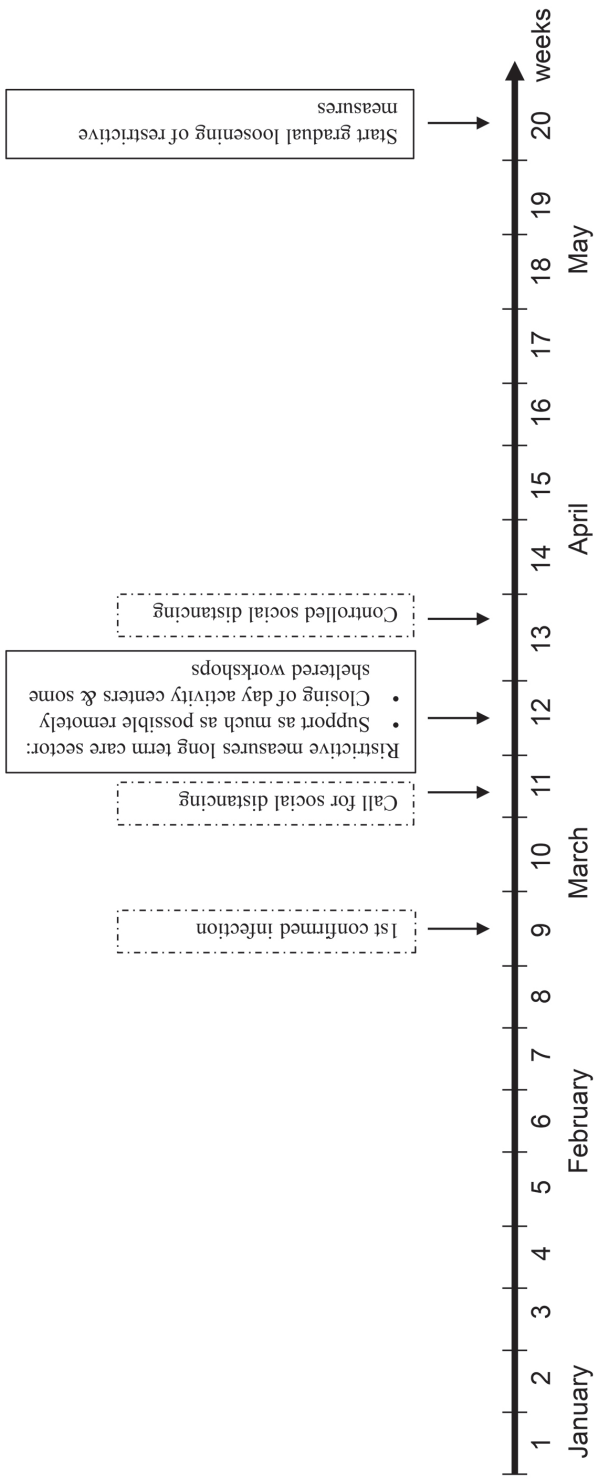

Figure 5.1 Timeline of Dutch COVID-19 containment measures impacting service provision to people with intellectual disability living independently.

RESULTS

A total of 648 service users had at least one contact during the first 20 weeks of 2019 and/or the first 20 weeks of 2020. Of these service users, 32 had been newly connected to DigiContact during (and due to) COVID-19 and therefore only had contacts during the pandemic. Table 5.1 presents the median scores and interquartile range of the number of contacts per day between DigiContact and its users: it indicates that the service dealt with a higher number of contacts per day during COVID-19 than during the two reference periods. Figure 5.2 presents the patterns in the number of contacts per day during the first 20 weeks of 2020 and 2019 and therefore gives a detailed view on how the amount of contacts evolved over the weeks. The 2020 patterns were more or less comparable with those of 2019 up to week 10/11. In weeks 11/12 (2020), the number of unplanned contacts per day considerably increased, and after which, it slowly decreased again from week 13 and reached a level comparable with before COVID-19 in week 16. Although the number of planned contacts per day also increased during COVID-19, this increase was more gradual and continued longer than the unplanned contacts.

Table 5.2 presents the median and interquartile range of the amount of contacts per day per service user, of the group of service users who had already been using the service before the pandemic (N = 616). The amount of unplanned contacts per day per service user was significantly higher during COVID-19 than during the first 11 weeks of 2020 (z =-4.602, p = .000), as well as than during the first 20 weeks of 2019 (z = -5.328, p = .000). Although the amount of planned contacts per day per service user during COVID-19 did not differ significantly from the first 11 weeks of 2020 (z = -1.776, p = .076), it was significantly higher than during the first 20 weeks of 2019 (z = -3.689, p = .000).

Table 5.1: Median scores and interquartile ranges of the amount of support contacts per day, during COVID-19 and two reference periods

Period	Service users	Planned contacts/day		Unplanned contacts/day		All contacts/day
	n	*Mdn* (IQR)		*Mdn* (IQR)		*Mdn* (IQR)
Old service users	616					
COVID-19[a]	466	74.00 (70.00-79.00)		32.00 (24.00-40.00)		106.00 (96.00-116.00)
Ref. 2020[b]	445	63.00 (57.00-70.00)		23.00 (19.00-28.00)		88.00 (78.00-97.00)
Ref. 2019[c]	435	64.00 (57.00-72.00)		22.00 (18.00-26.00)		86.00 (77.00-97.00)
New service users						
COVID-19[a]	32	1.00 (0.00-2.00)		0.00 (0.00-1.00)		2.00 (1.00-3.00)

Service users are people with at least one contact with DigiContact during a specific period. Old service users were already connected before COVID-19 started. New service users were connected during the COVID-19 period.
[a] COVID-19 period: weeks 12–20, 2020; [b] Reference period: weeks 1–11, 2020; [c] Reference period: weeks 1–20, 2019.
IQR, interquartile range.

Table 5.2: Median scores and interquartile ranges for the number of support contacts per day per service user, during COVID-19 and two reference periods

	COVID-19[a]	Ref. 2020[b]		Ref. 2019[c]	
	Mdn (IQR)	*Mdn* (IQR)	COVID-19[a] vs. Ref. 2020[b]	*Mdn* (IQR)	COVID-19[a] vs. Ref. 2019[c]
Unplanned contacts	.016 (.000-.032)	.000 (.000-.027)	*z* = -4.602, *p* = .000	.007 (.000-.022)	*z* = -5.328, *p* = .000
Planned contacts	.048 (.000-.143)	.040 (.000-.133)	*z* = -1.776, *p* = .076	.036 (.000-.128)	*z* = -3.689, *p* = .000
Total contacts	.079 (.000-.144)	.067 (.000-.160)	*z* = -3.626, *p* = .000	.058 (.000-.144)	*z* = -4.832, *p* = .000

Wilcoxon signed rank tests (*N* = 616) were used to test for differences between the number of (unplanned and planned) contacts during COVID-19 period and both reference periods.
[a] COVID-19 period: weeks 12–20, 2020; [b] Reference period: weeks 1–11, 2020; [c] Reference period: weeks 1–20, 2019.
IQR, interquartile range.

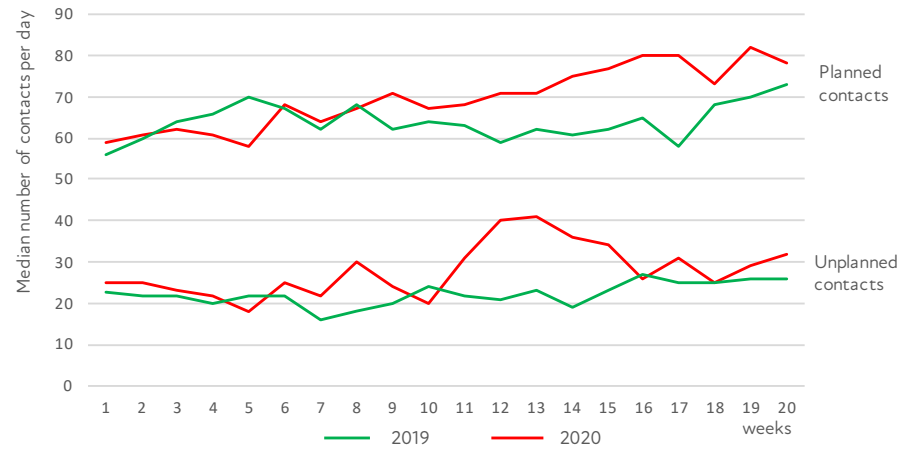

Figure 5.2 The number of planned and unplanned support contacts per day, over the first 20 weeks of 2020 and 2019.

DISCUSSION

The findings show that the use of the online support service DigiContact by independently living people with intellectual disabilities increased during the first weeks of the COVID-19 pandemic, as people had more (unplanned) contacts with the service than before the outbreak. In addition, there was a small group of people who were newly connected to the service during (and often due to) COVID-19 and who started to use the service and thereby also contributed to the increase in online support use. The instalment of containment measures in week 12 was accompanied by a substantial increase in the unplanned use of online support (without appointment), which lasted for a few weeks. The planned use of online support (with appointment) also seemed to gradually increase over a longer time than the unplanned contacts, but without the group of new service users, this increase was not statistically significant compared with the first 11 weeks of 2020.

These findings indicate that the COVID-19 outbreak and related restrictive measures had quite an impact on the use of online support. A possible explanation for the sudden, substantial and temporary increase in unplanned online support use is that people were considerably worried and experienced a high level of anxiety especially during the first weeks of the crisis, causing more people to contact the service (more often). Several authors have pointed out that people with intellectual disabilities (like people without intellectual disabilities) are likely to experience high levels of stress and frustrations during the COVID-19 pandemic and that measures posing restrictions on their usual activities and contacts with other people further contribute

to this (Brooks et al., 2020; Courtenay & Perera, 2020; De Vries et al., 2020). In a previous study, we found that DigiContact was often used to ventilate worries and frustrations with an aim to relieve oneself of them (Zaagsma et al., 2019). A lack of accessible information on the virus and the containment measures (Courtenay & Perera, 2020) may also have contributed to the increase in unplanned online support use as, especially during the first weeks, people with intellectual disabilities were left with questions that caused them to contact the service. The finding that the unplanned online support use decreased after a few weeks may have been caused by the initial feelings of worry and anxiety subsiding. This resonates with the concept of homeostatic effects on subjective well-being: that each person (irrespective of any disabilities) has a certain set point of well-being and a homeostatic control makes us return to this set point automatically after a deviation (Cummins 2017; Cummins et al., 2011). However, it is also possible that the unplanned use of online support did not decrease because the need for support diminished, but because service users experienced that unplanned contacts were not (sufficiently) effective in helping them and stopped to initiate these contacts. For example, it is possible that service users experienced that DigiContact staff could not give them the answers and reassurance regarding COVID-19-related questions or worries that they had hoped for.

The (un)availability of services and the influence that support staff can exert on the use of services may also have played a role in the patterns of online support use. During the consternation of the first few weeks of COVID-19, onsite support professionals and people with intellectual disabilities had to find and get used to a new strategy to be in contact with each other, which leads to a temporary interruption of (or at least an irregularity in) onsite support contacts. This may have resulted in an initial increase in people seeking (more) help online, as DigiContact may have been part of this new strategy of providing services. Service users who had unplanned contacts during the first weeks of COVID-19 were offered the possibility of having a standing appointment with the service (planned contacts). This may have contributed to the decrease in unplanned contacts and the slow increase of planned contacts. The fact that arranging more online support capacity took some time may have played a role in the finding that planned online support use started to increase slower and later than the unplanned contacts.

Although this study provides some useful insights into how the use of online support evolves during the first weeks of the COVID-19 pandemic, we acknowledge that these results are preliminary. For the interpretation of our findings, it would have been valuable to also include data on the use of other services in general and contacts with onsite support professionals specifically. Furthermore, this study focused on

the first weeks of the COVID-19 pandemic only. Although these first few weeks constitute an interesting period because of the sudden need to change the way support was provided, it would also be useful to look at the impact during a longer time frame.

The findings of this study suggest that by including online support as an addition to regular onsite support for people with intellectual disabilities living independently, service provider organizations are able to increase their responsiveness towards changes in the demand of support by service users and to compensate (at least partially) for changes in onsite support availability during a crisis like COVID-19. This ties in with a finding of a previous study, in which we found that online support could move and adapt to fluctuations in support needs more easily compared with regular onsite services (Zaagsma et al., 2020). However, it should be noted that the online support service in this study had already been operational for several years when the COVID-19 pandemic started, which enabled a fast response. Setting up a similar service quickly in reaction to COVID-19 would, in all likelihood, have been very difficult, if not impossible. The relevance of offering online services extends beyond the current COVID-19 pandemic. In the recent decades, austerity measures in many countries have led to a reduction in onsite support availability and eligibility (Malli et al., 2018), and in this context, service provider organizations often see remote support (e.g. online) as a way to organize services more efficiently (Niemeijer et al., 2010; Tassé et al., 2020) and enhance support availability for those who need it. However, it is important to point out that previous findings indicate that online support should not be seen as a cost-saving substitute for all onsite support contacts, but rather as a valuable addition to onsite support (Zaagsma et al., 2020). In conclusion, this paper shows the value of incorporating online support as a standard component of a broader system of professional services for people with intellectual disabilities who live independently during a societal crisis, such as the current COVID-19 virus outbreak. By already being operational when the outbreak happened, DigiContact enabled the system of services to be more flexible and responsive towards shifting levels of demand for professional support during the hectic first weeks that were possibly due to fluctuations in the support needs of people with intellectual disabilities and in the availability of onsite support.

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PART III

Experiences with DigiContact: some very specific personal perspectives on support and inclusive research

CHAPTER 6

The experiences of support users with 24/7 remote support

Zaagsma, M., Van de Velde, D., Koning, M. H. M., Volkers, K. M., Schippers, A. P., & Van Hove, G. (2021). 'When I need them, I call them and they will be there for me'. Experiences of independently living people with intellectual disabilities with 24/7 available online support. *Disability and Society*. https://doi.org/10.1080/09687599.2021.1932756

ABSTRACT

eHealth applications are increasingly being used in services for people with intellectual disabilities. DigiContact is an online support service that uses videoconferencing techniques to enable people with intellectual disabilities to contact a team of specially trained support workers 24/7. In this qualitative and participatory study we aimed to explore the experiences of independently living people with intellectual disabilities with what it is like to be supported online. Five online support users were each interviewed twice and the transcripts were analysed using a phenomenological hermeneutic method. Choice and control played a central role in their shared experiences, as well as the relationship with online support staff. The results indicate that the suitability of online support depends on the needs, capabilities and preferences of each individual support user. This underlines the importance of a personalised approach to the planning and delivery of online support.

INTRODUCTION

Technology is increasingly being used in the care for and support of people with disabilities. This is also the case within the professional care sector for people with intellectual disabilities, where the generic term eHealth is often used for (health) services and information delivered or enhanced through the Internet and related technologies (Eysenbach, 2001). Two review studies on the use of eHealth in the field of intellectual disability care (Oudshoorn et al., 2020; Vázquez et al., 2018) have shown that publications in this area focus on initiatives in either therapy and treatment or support for daily functioning. Regarding the latter category, eHealth is mostly used as an instrument to support the learning of specific daily living or vocational skills, and much less as a self-supportive tool or remote professional support (Oudshoorn et al., 2020; Vázquez et al. 2018). Although this indicates that studies regarding the use of remote support for daily functioning are still relatively scarce, the practice of offering remote online support has been expanding and is expected to continue doing so in the years to come (Friedman & Rizzolo, 2017; Tassé et al., 2020) .

In remote support, people with intellectual disabilities and their support staff typically use online devices such as (smart)phones, personal computers and tablets to get into contact with each other (Tassé et al., 2020; Taber-Doughty et al., 2010). Although the use of remote support is surrounded by several ethical and safety concerns (e.g. Perry & Beyer, 2012; Niemeijer et al., 2010), there are also several reasons that validate its use. For people with intellectual disabilities, a remote (online) delivery of support can have several advantages. First, it can increase the accessibility and flexibility of professional support (Zaagsma et al., 2019; Zaagsma, Volkers, Koning et al., 2020). For example, during the current global COVID-19 virus online support could be continued and even scaled-up during periods of 'lock-down' and social distancing (European Association of Service providers for Persons with Disabilities, 2020; Zaagsma, Volkers, Swart et al., 2020). Second, remote support may increase the sense of independence, autonomy and privacy as the physical presence of support staff at home decreases (Brewer et al., 2010; Tassé et al., 2020; Wennberg & Kjellberg, 2010). Third, remote support has the potential to be more targeted, focused and specific, as it can be provided when needs arise rather than regardless of immediate needs (Perry et al., 2009).

For service organizations it can also be beneficial to offer (part of their) services remotely, as it may help to increase their sustainability. Not only can technological innovations improve or enrich services, they can also help to differentiate one's

service offer from that of others and to enable a more efficient organization of services (Brewer et al., 2010; Niemeijer et al. 2010). These aspects may be extra important for organizations in countries where socio-political shifts have led to social care reforms (e.g. resulting in decreasing care budgets and tightened eligibility criteria) and place the implementation of values like the participation, inclusion and self-direction of people with disabilities under pressure. Such shifts are likely to have various disadvantageous consequences for people with (intellectual) disabilities and their families (Goodley & Lawthom, 2019; Goodley et al., 2014; Malli et al., 2018) and many organizations search for ways to be able to continue their services to the people who need them. Technology, for example in the form of eHealth applications, can be used as a part of this strategy.

All together, these reasons formed the incentive for the Dutch service provider Philadelphia Care Foundation to develop a remote, online support service named DigiContact for people with mild intellectual disabilities (IQ 50–69) or borderline intellectual functioning (IQ 70–85) who live independently in society. DigiContact offers 24/7 online support by using video-conferencing techniques to enable communication between support users (people with intellectual disabilities) and a team of about 25 support workers who are especially trained to provide online support. Contact is also possible without video component by regular phone. DigiContact is offered as part of a broader range of services: it is generally combined with onsite support at home or at a community center, courses and/or onsite support regarding work (Vijfhuizen & Volkers, 2016).

When evaluating a new support service like DigiContact, it is important to include the perspective of the people who use the service, in this case people with intellectual disabilities. A few studies have focused on the expectations, experiences and/or perceptions of people with intellectual disabilities regarding the use of eHealth in support of daily functioning: either in response to the use of eHealth in general (Frielink et al., 2020) or in the form of remote support (e.g. De Wit et al., 2015; Tassé et al., 2020; Zaagsma et al., 2019, Zaagsma, Volkers, Koning et al., 2020). These studies give some insights into what people with intellectual disabilities regard as possible advantages and disadvantages of the use of eHealth, and remote support specifically. Perceived advantages were for example more independence and control over one's life (Frielink et al., 2020; Tassé et al., 2020), a safe and secure feeling (Tassé et al., 2020; Zaagsma et al. 2019, Zaagsma, Volkers, Koning et al., 2020) and an increase in professional support accessibility (De Wit et al. 2015; Zaagsma et al. 2019; Zaagsma, Volkers, Koning et al., 2020). Privacy concerns (Tassé et al., 2020), the dangers that come with using the Internet (Frielink et al., 2020), and the risk

that eHealth applications will be implemented as a substitute for all onsite support (Frielink et al., 2020; Zaagsma, Volkers, Koning et al., 2020) were some of the perceived disadvantages. Although these studies are important for understanding more about the potential value of remote, online support for people with intellectual disabilities, they do not provide an account of how online support is perceived by persons who use DigiContact. Knowing more about this is helpful for understanding why some persons have more positive experiences with online support than others. The current study was designed to give an in-depth account of the experiences of a small group of people who use the online support service DigiContact. The aim of this paper is to zoom in on the experiences of individuals and to describe in detail how they experience online support and give meaning to their experiences.

METHOD

This study used a qualitative research design, in which interviews with DigiContact support users were conducted and transcripts were analysed using a phenomenological hermeneutic method described by Lindseth and Norberg (2004). Strongly inspired by the phenomenological hermeneutical interpretation theory developed by Ricoeur (1976), this method aims to obtain knowledge of the essential meaning of lived experiences (Lindseth & Norberg, 2004). The study was carried out by a duo of researchers and relied on a participatory research strategy in which an academically trained researcher (first author) and a co-researcher with intellectual disabilities (third author) worked together. The co-researcher was actively involved in identifying and clarifying the research topic, recruiting participants, data collection (construction of interview guide, planning and conducting interviews) and data analysis. Four senior researchers (second, fourth, fifth and sixth author) fulfilled advisory and coaching roles, mainly regarding qualitative and inclusive research methodology.

Participants

Participants were selected using a purposive sampling strategy (Patton, 2005). We aimed to include individuals who used online support as their main form of professional support as this would guarantee the use of a sample with sufficient experience with online support. From the entire DigiContact case load, a senior support professional working for DigiContact was able to locate ten online support users for whom the service was either the only or the main source (as in: most intensively used) of professional support during at least the previous six months (December 2017 – May 2018). These ten support users were contacted through their case workers (senior support professionals who coordinate services), who were

employed by the service organization that also offers DigiContact. Five of them did not want to participate in this study, for which they expressed different reasons: two felt uncomfortable about being interviewed, two had recently participated in an (unrelated) interview study and did not want to be interviewed again, and one opted out for reasons unknown. Five support users did agree to participate. In the following paragraphs, they are introduced through a short description of personal and professional support characteristics. Pseudonyms are used to protect participant anonymity.

Chris (35) lives alone in a semi-rural area and has a part time job. He is single. He has a mild intellectual disability (IQ range 50–69) and has been receiving professional intellectual disability services for 21 years. Five years ago Chris started to use DigiContact. Recently, he put a hold to all professional support services except for DigiContact. Chris uses a tablet to contact the service on average twice a week (video connection).

Dave (46) lives alone in a semi-urban area and has a full time job. He is single. Dave's IQ level is unknown. He was registered for professional support about one year ago, after his long term relationship broke up. He was found eligible for online support from DigiContact only. Dave uses his landline phone to contact the service once a week (audio connection).

Carol (71) lives alone in an urban area and doesn't have a job or any other fixed day-time occupation. She is divorced. Carol's IQ level is unknown. She started receiving professional intellectual disability services four years ago, after she was diagnosed with cancer and underwent several surgical procedures. Since then Carol is supported at home by two different onsite support workers. Since two years, she also uses DigiContact support. She uses a tablet or mobile phone to contact the service about three times a day (audio or video connection).

Michael (56) lives alone in a semi-rural area and has a full time job. He is a widower. Michael has borderline intellectual functioning (IQ range 70–85), and has been receiving professional intellectual disability services for 36 years. Currently, he is supported by an onsite support worker with whom he meets regularly at a community center. Five years ago Michael started using DigiContact support. He uses his tablet or mobile phone to contact the service about two or three times a week (audio or video connection).

Ben (39) lives alone in a semi-rural area and has a full time job. He is single. Ben has borderline intellectual functioning and has been diagnosed as having 'autism'. He has been receiving professional intellectual disability services for 25 years. Ben is supported by an onsite support worker with whom he meets at a community center. Five years ago, he also started using DigiContact support. He uses his tablet or mobile phone to contact the service about three times a week (audio or video connection).

Data collection and procedure

We used semi-structured interviews to collect data. An interview guide was developed, which included five main topic areas: (a) general information on the participants' lives (to get to know each other); (b) use of support (an exploration of the availability and use of professional and natural supports); (c) the context and history of online support use (when, why and how DigiContact was introduced to them); (d) the experiences with online support in relation to support needs (views on if and how online support meets their needs); (e) evaluation of online support (how participants feel about being online supported). Each main topic started with an open-ended question, after which follow-up questions were based on the participant's responses. Each participant was interviewed twice because including all main topics in one interview would be too much of a burden for the participants. This also allowed for more time to obtain the participants' trust and increase the likelihood of them feeling at ease and expressing themselves freely. The first interview focused on topic areas a, b and c. The second interview focused on topic areas d and e.

The interviews were conducted by the two researchers together (first and third author). As the co-researcher did not have prior experience with interviewing, he received training in interview techniques before and during data collection. While the co-researcher observed and made field notes during the first few interviews, his role shifted over time towards him taking more and more the lead in asking questions. Participants were interviewed at home, during a four-month period (June – September 2018) and lasted between 42 and 67 min. The time between the two interviews varied from six to thirteen weeks. All interviews were audio-recorded with participant approval and transcribed verbatim. We included member validation as a validity check method (Green & Thorgood, 2014): all participants received a typed summary of their interviews in accessible language to check for accuracy. They all felt that the summary represented their experiences well and no adjustments were made.

Data analysis

Analysis of the transcripts was based on the guidelines described by Lindseth and Norberg (2004) and followed three steps: (1) the formulation of a naïve understanding; (2) structural analysis; and (3) the formulation of a comprehensive understanding. Throughout each step, the first author and co-researcher worked together and discussed their methods and findings by peer debriefing with two senior researchers (second and sixth author).

The first step started with listening to the interview recordings and reading all transcripts multiple times (first author only) to get an overall picture of the data and to grasp its meaning as a whole. The two researchers then came together to discuss and compare their first impressions and interpretations. Together they formulated a naïve understanding, which is a preliminary interpretation of the meaning of the data in its entirety. We attempted to interrelate the accounts of the participants, by undertaking a process of going back and forth between the transcripts and our interpretation. The naïve understanding was presented to and discussed with one participant, one online support worker and one onsite case worker. They all agreed with the naïve understanding and no adjustments were made.

The second step consisted of thematic structural analysis and was intended to validate the naïve understanding. Connections and patterns in the data were uncovered by dividing the data into meaning units, which are pieces of text (of any length) that convey one meaning. Each meaning unit was then condensed and expressed as concisely as possible in everyday words. The two researchers did this independently from each other and then again compared and discussed their meaning units and condensations until consensus was reached. Next, we reflected together on the condensed meaning units and, where relevant, abstracted them into subthemes and assembled them further into themes. To facilitate this process, we copied each meaning unit and its condensation on to a piece of paper, so we could (re)position them while assembling similar condensations.

The third step consisted of identifying relationships between themes and interpreting the findings in relation to the research question and the study context. The first author read all transcripts again, while taking into consideration the research question, the naïve understanding and the results of the structural analysis. Through thorough discussions, both with the co-researcher as well as with the senior researchers, a comprehensive understanding of the findings was formed and formulated. The comprehensive understanding was checked for its recognisability and relevance by four participants, as well as one online support worker and one onsite case worker.

Although they all felt that the comprehensive understanding represented their feelings and experiences well, they also made some remarks that were used to add nuance to the comprehensive understanding.

Ethical procedure

The Medical Ethics Review Committee of VU University Medical Center (FWA00017598) confirmed that official approval was not required as the Dutch Medical Research Involving Human Subjects Act (WMO) did not apply. 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. Audio-recordings were made after the participants gave their approval and the audio files were destroyed after analysis had been completed. All data were anonymized and subsequently handled and stored with care and respect for privacy.

FINDINGS

Naïve understanding

The participants' accounts showed that having 24/7 access to online support was perceived to be valuable, but that there were also some negative evaluations. Being able to initiate and control their online support contacts (timing them whenever and as often as needed) appeared to enhance the experience of self-direction in support. Online support seemed to have a positive impact on emotional well-being, as its continuous availability gave participants a secure feeling and the opportunity to clear their mind from frustrations and worries immediately. Also, DigiContact was seen as an additional social contact and alleviated feelings of isolation and loneliness. At the same time, participants needed time to get used to online support because it was felt to be different from regular onsite support. Participants struggled with not having an assigned online professional to talk to, which made the support feel less personal. It seemed that their use of online support was not only influenced by their own experiences and expectations, but also by their case worker and informal caregivers, who often stimulated participants to use online support.

Structural analysis

The structural analysis resulted in three themes that reflected the meaning of being supported online: (1) Using online support as a solution; (2) Helping oneself through being in control; and (3) Being in a relationship with a service, not a person. In the following sections the three themes are described and illustrated with quotes from the interviews.

Using online support as a solution

A common experience identified through the analysis consisted of using online support to create a better match between available professional supports on the one hand and support needs and/or preferences on the other hand. Getting the needed or wanted professional support was perceived to be an ongoing struggle. For some participants this was about having access to professional support, for others it concerned getting enough support and/or preferring a different type of support.

For most participants online support was a way to ensure themselves of (sufficient) professional support within a context of care reforms, austerity measures and strict support eligibility. Participants who had been receiving services for quite some years had experienced the impact of the long-term health care reforms. Their recollections indicate that this had been a stressful period during which they became aware of their vulnerability because of the uncertainty as to whether and how professional support would be continued. As DigiContact was introduced during that period, the participants linked its introduction to the reformations, reinforcing their perception that this new service was (at least partially) there to replace onsite support. Although negative feelings and opposition prevailed at first, participants soon realized that the service offered them the possibility to maintain more or less the same intensity of support they were used to:

> *Instead of every week you get it* [onsite support at home] *just once a month or once every three months. If you want more you have to call DigiContact when something is bothering you. In fact, I get just as much support. It still is three times a week. But now I call DigiContact twice a week and once a week I go to the meeting place.* (Ben)

Dave used online support as a full alternative to onsite services as his support needs were considered to be too mild to be eligible for onsite services: "*We did apply for it* [onsite support]*, but like before with other things, I fell through the cracks. They said to me: 'Yes, you are not smart, but you are good enough' and so that was it*". His need for professional support stemmed from a nearly absent natural support network. He often felt isolated and lonely and having access to online support meant that he could at least talk to someone: "*At first I thought: Okay, this* [DigiContact] *could be good for me. Because, if you are alone, well, you've got to make the best of what is there*". Carol used online support to scale-up the intensity of professional support beyond the possibilities of onsite services. Since being diagnosed with cancer, she suffered from terrible pains that restricted her in her (social) activities. Instead of the active life she used to lead, she was now usually at home alone. Her online support contacts

were timed multiple times a day and helped to breach her feelings of loneliness as well as to distract her from and alleviate the pain. Carol expressed the possibilities of online and onsite support in terms of availability as follows:

> *Of course, I can phone A or C* [onsite support workers]*, but they cannot always come to me, because they are busy themselves. That is why I am so happy with them* [DigiContact]*. And I keep repeating it: when I need them, I call them and they will make time for me. I can't do that with A and C, when they are not there.*

Online support was also seen as a relatively reliable future option, as onsite support eligibility might decline further.

Unlike the others, Chris did not use online support to ensure himself of sufficient professional support. Instead, he felt that online support matched his personal support preferences better than onsite support. After a long history of receiving professional services, he had been unhappy with his onsite support. When DigiContact was introduced, he immediately felt that this would improve services for him. For him, being in control of the timing and frequency of his support contacts was a big advantage (see also theme 'Helping oneself through being in control'). As support workers no longer entered his home, he felt that online support workers respected his privacy more and interfered less with his business:

> *When it comes to support, the real life support I had, they played mother knows best to me. They did not give me much room to learn or to discover.* [...] *I say that* [DigiContact] *means progress. I knew it right away, to me it is the invention of the century.*

As described above, the participants felt that online support had something to offer. It helped them to align their professional support services with their support needs and preferences, in terms of availability, intensity as well as type of support. Although participants were aware of this and seemed to have made a conscious decision to use online support, they were also influenced by people around them, especially their case workers and close family members. The influence of case workers was crucial, as they were the ones who introduced DigiContact to the participants, advised them to get connected, explained the potential advantages and stimulated them to call in: "*Yes, they recommended it to me. Yes, the onsite workers*" (Carol). They were also the ones who initiated and arranged the instalment of the technical connection in the participants' houses. Close family members also played an important role, as a positive attitude of family seemed to be a precondition as well as important facilitator

of using online support: *"I did talk to my family about it* [DigiContact] *and they liked the idea of online support"* (Michael).

Helping oneself through being in control

The continuous availability of online support combined with being able to decide when contact was needed, played a central role in the participants' experiences. Deciding when and how often support was needed, seemed to contribute to a sense of control and ownership over their support. Participants could time their contacts according to their need(s) as well as convenience. This contrasted with their onsite support experiences, where they generally felt to have a limited say in when and how often they had access to their onsite support worker:

> *Yes, they* [his two onsite support workers] *just did not want to adjust their agendas. Their appointments were fixed and when I wanted to make an appointment, it was not possible.* [...] *They are difficult. Difficult. Well, now you no longer are dependent on them. You don't even need to be at home or make an appointment when you need support. It is when I want and when it's a good time for me and when I feel like it.* (Chris)

Being in control over one's own support contacts was linked to an experience of helping oneself. Having an active role towards their own support contacts made participants realize that they themselves played a major role in solving their problems:

> *I use DigiContact as an outlet, so to speak. When I have had a terrible day or when I don't feel well in my head. Or when something is bothering me, I think about things a lot. Then I* [with an emphasis on 'I'] *can call them to clear my head.* (Chris)

Although participants valued being able to determine the timing and frequency of their support contacts, for most of them this was neither an obvious nor an easy thing to do. They had to adopt a more (pro)active role towards their support than they were used to. Participants talked about having to get used to this: learning how to become aware of and recognize their own needs, as well as how to act on it. The following excerpt illustrates that this process took some time and practice:

> *They can see that too often I keep worrying about certain issues. They tell me I should call them. They want me to take the initiative to call and get rid of my frustrations. I didn't do that at first, but I do now more and more often. I think this is something I have to learn.* (Michael)

Some participants felt hesitant to contact the service if they did not have an appointment or when it was late at night, even though they had been told they could. They worried that the online support staff would not have time for them and that their issues or story would not be urgent enough:

> *Yes, I mean, then I don't have an appointment, so I can't just... At least, that is what I think at such moments. That I can't just say like well, I will call them now. However, they say I can, so maybe... Unless something extreme happens, that is different, but normally...no.* (Dave)

The opportunity to seek and find professional support whenever wanted or needed, meant that there was no need to postpone contact. This seemed to have a positive impact, especially on the emotional well-being of participants. Simply knowing support is available around the clock gave them a safe and secure feeling:

> *They told me I can always call them whenever something is worrying me or when my head is spinning. Then I can call them every day, but also every evening and every night. That makes me feel relaxed, like yes, yes, yes, because I can get things off my chest, even when I lay tossing and turning in my bed.* (Ben)

Not postponing contact also could prevent a problem from getting bigger and from lingering in the mind:

> *Look, it is possible that if there is a problem, your support worker* [onsite] *will come two or three days later. But now, you can just call and tell them like 'Hey, I got a problem' and get rid of it immediately.* (Chris)

The physical distance between support users and online support workers also contributed to the experience of helping oneself. The fact that online support workers were not physically present (as in: in the same room), seemed to reinforce a focus on the strengths, capabilities and problem solving skills of support users. As a result online support was perceived to be more about coaching than about taking over certain tasks or doing things together, and this made some participants feel like they had solved issues relatively independently with just some coaching from the support workers: "*Yes, they can tell me things and then I can think about it. And take a decision whether to do something or not. Or about what I do with their information*" (Chris). This was felt to have the potential to stimulate personal growth in both skills and self-confidence. However, there were also drawbacks to this physical distance. First of all, it was seen as restricting the range of support needs DigiContact could

help with. For example, a participant talked about only being able to get advice, while he actually would have preferred practical support. Secondly, the physical distance made it difficult for online support staff to see beyond what support users (are willing to) show of themselves and their surroundings. Although this brought an increased experience of privacy, participants also stressed that it should not be assumed that everybody can handle the responsibility of being open about their problems and feelings.

Being in a support relationship with a service, not a person

Another distinctive feature of the online support service that played an important role in the participants' experiences, was the fact that support users do not have contacts with a fixed online support worker. After all, when someone contacts DigiContact, he or she talks to the support worker who happens to be on duty at that particular moment. This had consequences for the way participants experienced their relationship with the online support staff. The support contacts were perceived to be relatively impersonal as both parties did not know each other (well).

There were two sides to the experience of not knowing each other. One side was about the support user not knowing the online support staff, which resulted in some participants not feeling confident and secure enough to open up: "*DigiContact is certainly helpful, but sometimes I find it difficult to explain certain things. I, for me, I do not find it very direct*" (Michael). A feeling of trust and security did improve over time, as participants got to know the online support workers a little better and as a result felt more at ease about confiding in them. A certain level of reciprocity in exchanging personal information was felt to be helpful, as were annual meet-and-greet sessions where participants could meet staff members in person. Nonetheless, for some participants a situation was created over time in which some of the online support workers were trusted and others not: "*Because you build up a bit of trust with the person you are talking to, and well, with the person you get the next time, you don't know what it will be like*" (Dave). In addition to the difficulty of knowing and trusting an entire team of support workers, the experience of feeling a connection with a support worker was important. Participants described that they felt more at ease with some support workers than with others and this could endanger getting good support: "*There are at least two* [online support workers] *I don't have a connection with.* [...] *To get the right kind of help, you've got to have a connection. If that is missing, it doesn't feel right to me*" (Ben).

The other side of the experience of not knowing each other, was that participants sometimes felt that online support workers did not know them well enough. This

could be annoying because they had to introduce themselves and share their story repeatedly. Some participants stressed that not being known well, entailed the risk that support was not tailored to their personal needs. Ben talked about how this used to be a problem for him, but that over time the staff has gotten to know him well enough:

> *It does not bother me any longer that I talk to someone else every time, as everybody knows me by now. They all know what's bothering me, so they all know about my autism and that I followed an assertiveness training.*

Comprehensive understanding

The structural analysis validated the naïve understanding to a large extent but at the same time clarified some aspects, such as how the participants saw their online support experiences as embedded within the context of their broader, individual lives and circumstances. First, care reforms and accompanying changes in (the availability of) services reinforced a situation in which participants were searching for ways to get the support they needed and wanted. DigiContact was seen and used as a way to shape professional supports towards better alignment with their needs and preferences. Second, the participants were often stimulated by their case worker and close relatives to use online support. Third, the participants' support history also played an important role, as their experiences with onsite support served as a benchmark for interpreting online support experiences. This comparison resulted in online support being experienced as a very different way to be supported.

This perception of online support as a different way of being supported was grounded in the experiences with four unique online support characteristics: (1) the 24/7 availability; (2) support users can initiate contact; (3) support is provided by a team of support workers; and (4) the online support staff are stationed in one location. These characteristics had certain implications for the way support contacts were realized as well as for the nature of the relationship with support staff. The 24/7 availability and being able to initiate contact not only meant that participants had continuous and immediate access to professional support, but also that they could determine the timing and frequency of their support. The fact that online support was provided by a team of support workers situated at one location implied that participants were not supported by a fixed support worker and that support was delivered from a distance. Figure 6.1 is a visual representation of how the four online support characteristics and their implications relate to the participants' experiences and the meanings given to the experiences.

How the participants experienced and used online support seemed to be influenced by how they personally felt about the four online support characteristics and their implications: whether they valued them positively or negatively and the relative importance of these implications for them. Since this evaluation was based on internal values and personal contexts, this differed between participants. Figure 6.2 illustrates this by presenting the experiences of the participants in profiles. Online support seemed better aligned (more green than red) with the preferences and needs of participants who found it relatively important to be able to choose and decide themselves when and how often support contacts were needed and/or to be able to seek support always without having to postpone contact (Chris and Carol). These participants employed online support as a way to get the type of support needed or preferred. At the same time, online support was less aligned (more red than green) with the preferences and needs of participants for whom building a relationship with a fixed professional was a prerequisite for feeling safe enough to discuss problems and/or who found it important to have someone present to help with questions and problems (Dave and Michael). These participants merely used online support as a way to get (enough) support.

For each participant, the interplay between characteristics, their implications and experiences and attached meanings is a dynamic process which may shift over time and from one situation (or problem) to the next. For example, after a while a person can get used to certain online support characteristics and value them differently. Also, someone may prefer to contact the online support service for certain issues or questions and not for others (for example only when postponing is not desirable). People with access to both online and onsite services can make their own decisions regarding whom they seek contact with for what kind of support.

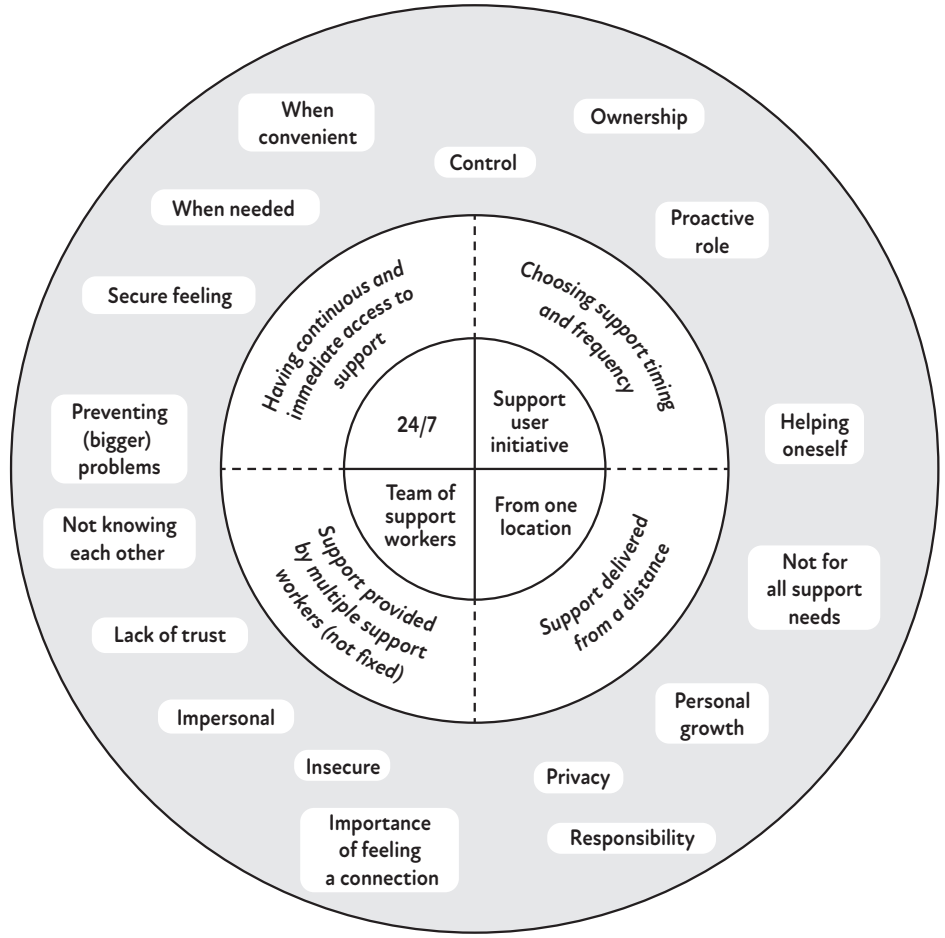

Figure 6.1: Visual representation of how DigiContact characteristics (inner circle) and their implications (middle circle) relate to user experiences (outer circle).

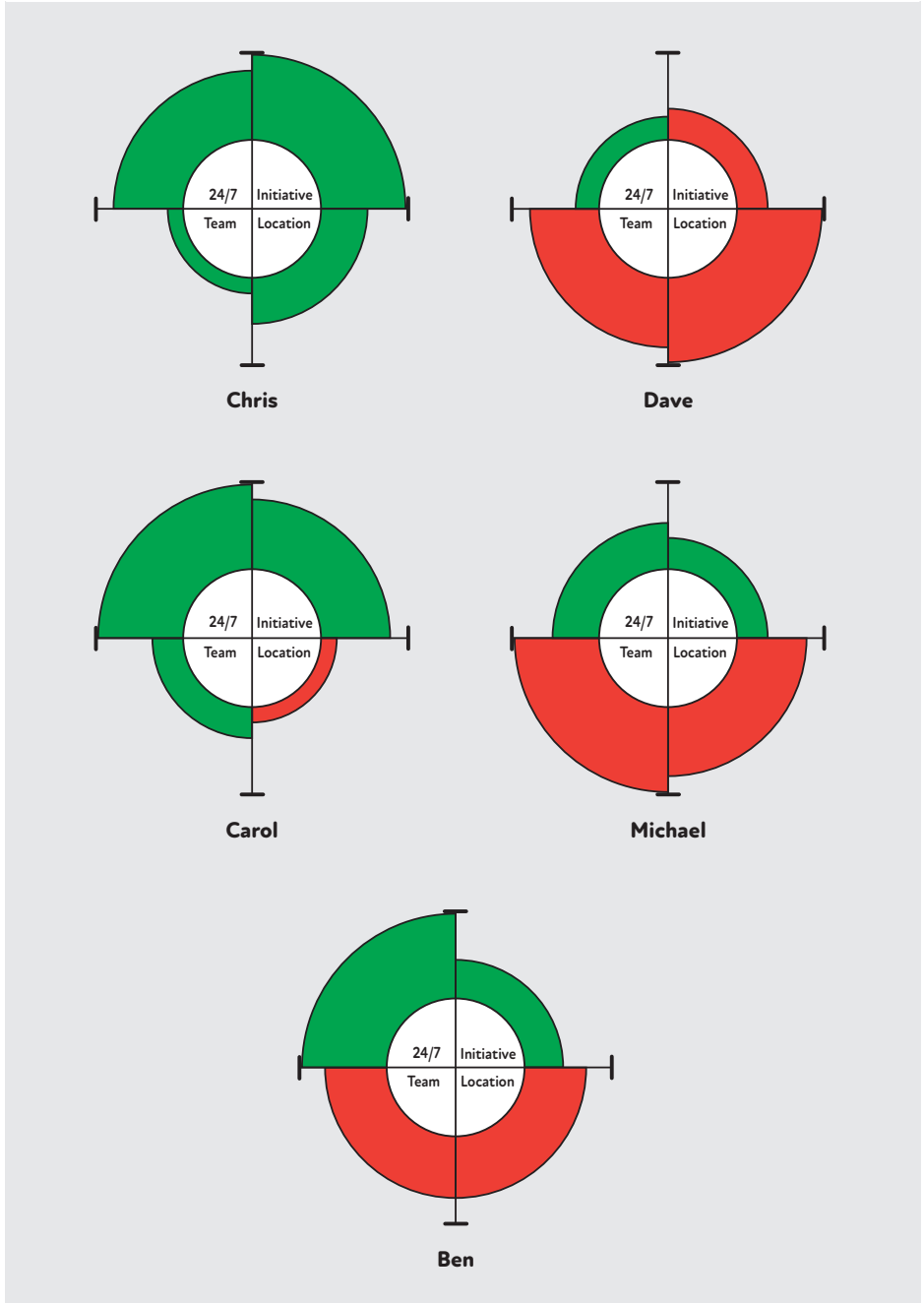

Figure 6.2: Participant profiles of the experiences with DigiContact. Each profile consists of four sectors that represent the participant's experiences with the four unique online support characteristics and their implications. The colour of a sector represents whether a characteristic and its implications are experienced as predominantly positive (green) or negative (red). The size of a sector represents the importance of the characteristic and its implications: the bigger the sector, the more important.

DISCUSSION

This study provides insight into the lived experiences of five independently living people with intellectual disabilities with the nature and meaning of being supported by the remote, online support service DigiContact. The participants' experiences demonstrated many facets which are dynamic as they move and change through time, situations and contexts. When seeking to understand what it is like to be supported online, it is therefore crucial to be sensitive to the contexts and lives of individual support users. The findings show that the participants varied in how they experienced the different aspects of being online supported. Nevertheless, there were also shared experiences that make up the essence of what it meant for them to be online supported. The main findings of this study are discussed using two key aspects within the participants' experiences: (a) choice and control, and (b) interactions with support staff.

Choice and control

Being able to choose and control one's support played a central role in the participants' experiences with online support at two different levels of the support process: the planning of services (meso) and the day-to-day delivery of support (micro). Regarding the planning of services, participants generally felt that their level of control over their use of online support was limited as there were not always suitable and adequate alternative services to choose from. An advantage of having access to DigiContact was that this (at least) provided them with an (extra) source of support. Which services were available and in what intensity, was felt to be determined by local authorities in charge of assessing eligibility and the provider organization's services portfolio. The national care reforms in the Netherlands and the consequences of related austerity measures for (the availability of) services made it difficult for some participants to get the support they needed and wanted. This corresponds to a recent review study on the effects of global austerity measures (Malli et al., 2018). This study concluded that cuts in (the funding of) disability services had led to poor alignment with care needs which in turn seemed to negatively affect the well-being of people with intellectual disabilities. Besides having few service options, we also found that family members and case workers had a strong influence on the participants' decision to get connected to and use DigiContact. Especially case workers were highly influential as they were the ones who introduced the service to the participants, advised them to use it and arranged for its installation. Such (inter) dependency on other people in the planning of services was also described by others (e.g. Smith, 2013; Williams & Porter, 2017).

In contrast with the process of service planning, participants were able to choose and control their day-to-day use of online support. Being the one to initiate contact was generally seen as a positive aspect of online support, as the participants could decide for themselves if, when and how often they needed support. This enabled them to shape their contacts according to their needs and wishes, an advantage of eHealth that was also found by Frielink et al. (2020). It also seemed to have an empowering impact on some participants as they became aware of their own active role in solving their problems. Moreover, having continuous (24/7) and immediate access to online support meant that support could be mobilized without having to postpone contact, which not only gave some participants a secure feeling, but also made it possible to prevent problems and concerns from lingering on or increasing. This was also found in two previous studies on DigiContact (Zaagsma et al. 2019; Zaagsma, Volkers, Koning et al., 2020). The current study shows that besides having several advantages, being the one to initiate support contacts can have a downside as having to decide when support is needed, maybe (too) stressful or too difficult for some.

Interactions with support staff

The interactions between DigiContact support staff and participants were characterized by the physical distance between both parties and the fact that participants did not have contacts with a fixed support staff member. The experiences of the participants show that although these characteristics can have an certain advantage, there can also be serious drawbacks. On the positive side, some participants felt that the physical distance between themselves and the online support staff stimulated an active role towards solving issues. By providing support from a distance, online staff were less likely to take over and instead adopted a 'hands-on-the-back' coaching style that facilitated personal growth in developing problem-solving skills and self-confidence. This is an interesting finding in the light of studies stressing that in their work, support staff often experience a conflict between having a duty to care, manage risks and protect on the one hand and having a duty to recognize and promote autonomy on the other hand (Hawkins et al., 2011). By providing support from a distance the focus seems to shift towards promoting the autonomy of support users. Online support staff helped participants to make choices and steer their life according to their own wishes, without there being a need for them to be completely self-reliant or independent. This corresponds with the idea of relational autonomy, meaning that people are (in varying degrees) interdependent on others in order to exert control and agency in one's life (Dowling et al., 2019; Morris, 2004; Perkins et al., 2012). Having an active role regarding initiating and designing their own support contacts as well as in solving their problems also resonates with the concept of self-management, as Van de Velde et al., (2019) found that actively

participating in and taking responsibility for the care process are important attributes of self-management.

On the negative side, some participants felt that online support staff were limited in what they could do for them, because they were not physically present in the same room which made it impossible to carry out certain tasks together. This corresponds with a previous study in which we found that individual support users used DigiContact support mostly for mental health related issues and as an extra social contact (i.e. someone to see and talk to), and not so much for practical issues (Zaagsma, Volkers, Koning et al., 2020). In addition, some participants expressed the worry that online support staff are limited in what they can see and pick up on. Although beneficial for experiencing privacy, these participants also felt that this asks for a certain competence and responsibility of support users: being able and willing to signal potential problems timely and to be open about them.

Besides the physical distance between support staff and support users, to be supported online by DigiContact means having contacts with different support workers and not having a choice regarding whom one speaks to. At the time of writing this paper, the online support team consisted of 25 support workers. As a consequence, participants and online support workers did not know each other (well), which made their contacts feel relatively impersonal. According to the participants, this brings the risks of support users not feeling confident and secure enough to open up and discuss certain issues, and of support staff not knowing individual support users well enough to know how to optimally support them. Various studies have stressed the importance and value of creating trusting and caring relationships between people with intellectual disabilities and support staff (Clarkson et al., 2009; Giesbers et al., 2019; Pallisera et al., 2018; Petner-Arrey & Copeland, 2014). Time, staff continuity and feeling 'the right chemistry' between both parties seem to be conditional for creating an optimal support relationship (Giesbers et al., 2019; Roeden et al., 2011). In this respect, one might wonder whether a service like DigiContact is able to meet all support needs and be a suitable alternative for everyone to (onsite) support by a fixed support worker.

Strengths and limitations of this study

The greatest strengths of this study lie in the appropriateness of our design and methods as well as in the rigour we adopted in our procedures. The phenomenological hermeneutic method we used for analysing our data (Lindseth & Norberg, 2004) enabled us to get an in-depth account into the complexity of the experiences of people who use the online support service DigiContact as their main form of

professional support. The techniques of prolonged engagement, peer debriefing and member checking have been used to assess and enhance the credibility and confirmability of our findings (Frambach et al., 2013; Green & Thorgood, 2014). Our participative strategy, in which a co-researcher with intellectual disabilities and an academically trained researcher worked together throughout all phases of this study, proved to be very valuable as it helped us to formulate interview questions more accessibly, to gain the trust of participants during interviews and to incorporate a broader view by interpreting the transcripts together.

The use of a small sample can be regarded as both a strength and a limitation of this study. While it allowed for a more in-depth engagement with each individual participant, it also strongly limits the generalizability of our findings. Besides small, our sample was in some respects specific. All participants were 35 years or older and used online support as their main form of professional support. Moreover, three participants had been receiving onsite intellectual disability services for more than 20 years. It is likely that these characteristics influenced the participants' experiences with online support in such a way that others, for example young people or people new in intellectual disability services, might not recognize them. In future studies we would look for larger samples to include and compare the experiences of a broader group of online support users, including young people (18–25 years), people who use online support as a relatively small part of their professional supports and people who are new to the intellectual disability service delivery system. The findings of this current study provide valuable input on aspects regarding support user experiences and evaluation that can be included in such studies.

Implications for practice

The limited generalizability of this study's findings does not affect its capacity to illustrate the complexity and nuance that are important within the discourse on the role and value of eHealth and remote support within the care for people with intellectual disabilities. The findings show that the suitability of online support seems to depend on the preferences, needs and capabilities of individual support users. For example, online support seems to be more suitable for persons who highly value being able to decide when and how often they need support than for persons for whom having a trusted relationship with a professional is a prerequisite for feeling secure enough to discuss concerns or issues. Such aspects are likely to make the difference between whether DigiContact can function as a full, all-round service able to stand on its own, or rather as an addition to support from a fixed onsite support worker.

As online support does not seem to suit every person equally well and in the same way, it is important that service organizations adopt a personalised approach to its planning and delivery. Not only should this approach be aimed at determining the suitability of online support for individual support users, it is also important to look at how the support itself can be adapted to match someone's needs and preferences, for example with respect to contacts with or without video connection. As a person's experiences with online support can change over time (for example due to changes in circumstances), a personalised approach remains important for as long as a person uses online support. Therefore, it is recommendable for service organizations to invest in an ongoing dialogue with each support user on his or her online support experiences. A personalised approach to online support corresponds with what various authors from the research field of disability studies and the use of assistive technology have stressed, namely the importance of matching technologies with the needs, preferences and expectations of individual persons and their environments (e.g. Federici et al., 2014; Krantz, 2012; Leopold et al., 2015; Scherer & Federici, 2015).

In contexts characterized by social care reforms, the use of remote, online support is often seen as a cost-saving measure from which organizations benefit more when its implementation concerns larger groups of support users. This study shows that although some people with intellectual disabilities experience online support as a valuable addition to (Carol) or worthy alternative for (Chris) onsite support, others consider it to be not useful for them (Dave). Such differences between people underline that online support cannot be regarded nor implemented as a generic solution to social and political challenges.

Conclusion

Exploring the experiences of support users is indispensable when evaluating new eHealth initiatives for people with intellectual disabilities, as it provides useful insights into the complexity of individual support arrangements. This study suggests that 24/7 online support can have both benefits and drawbacks for people with intellectual disabilities and that its suitability depends on the needs, preferences and capabilities of individual support users. Therefore, the online support service DigiContact is not a 'one service fits all' solution, which underlines the importance of a personalised approach to its planning and delivery.

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CHAPTER 7

The work experiences of remote support professionals

Zaagsma, M., Koning, M. H. M., Volkers, K. M., Schippers, A. P., & Van Hove, G. (2022). 'It really is quite a different ballgame.' A qualitative study into the work experiences of remote support professionals. *Journal of Applied Research in Intellectual Disabilities, 35*(5), 1153-1161. https://doi.org/10.1111/jar.13001

ABSTRACT

Background

Professional support for people with intellectual disabilities is increasingly provided remotely. This study explores what support staff of the Dutch remote support service DigiContact experience as distinctive aspects of their job as a remote support professional.

Method

Semi-structured interviews were held with ten DigiContact support workers. The transcripts were analyzed through a qualitative content analysis process.

Results

Six themes were identified that reflect distinct aspects of the participants' work within the DigiContact remote support context: being encouraged to adopt a solution-oriented coaching support style; being limited in one's support options; facing considerable diversity; providing support as one team; dealing with unpredictability; and navigating the dynamic within work shifts.

Conclusions

The way support is organized and delivered can have substantial implications for support professionals. Working at a service like DigiContact seems to call for specific skills, knowledge, affinities and experience, and for appropriate support and facilitation from organizations.

INTRODUCTION

Professional support for people with intellectual disabilities is increasingly provided remotely through the use of online devices like smartphones, computers and tablets (Friedman & Rizzolo 2017; Taber-Doughty et al., 2010; Tassé et al., 2020). Research has shown that a remote provision of support can have several benefits, such as an enhanced efficiency in services and an increased accessibility of support (e.g., Brewer et al., 2010; Cullen et al., 2012; De Wit et al., 2015; Niemeyer et al., 2010; Zaagsma, Volkers, Koning et al., 2020). The effects of the COVID-19 pandemic have increased the uptake of remote support initiatives, as organizations search for ways to improve the continuity of their services during phases of lockdown and active social distancing measures (Doody & Keenan, 2021; Wos et al., 2021; Zaagsma, Volkers, Swart et al., 2020).

A remote provision of support departs from the way in which services for people with intellectual disabilities are usually delivered, which is through onsite support staff (Stancliffe & Lakin, 2007). A remote support delivery may impact the experiences of both those who are supported (people with intellectual disabilities) and those who provide support (professionals). Studies on the experiences of people with intellectual disabilities linked a remote provision of support to an increased sense of independence and control over one's support (Brewer et al., 2010; Tassé et al., 2020; Zaagsma et al., 2021), feelings of security and safety (De Wit et al., 2015; Tassé et al., 2020), and concerns related to privacy issues (Tassé et al., 2020). Similar findings were reported by Frielink et al. (2021), who explored the expectations and perceptions of people with intellectual disabilities, relatives and professionals regarding the use of eHealth, a broader concept that included remote support.

As far as we know, the experiences of remote support workers in intellectual disability services have only been examined by De Wit and colleagues (2015), who explored the experiences of remote support staff as part of their feasibility study on a web-based support program for people with mild intellectual disabilities or chronic psychiatric disorders. In addition to greater flexibility in their scheduling, the staff felt that their support became more directed towards encouraging support users to draw on their personal strengths and skills when executing daily tasks. Broadening our view by looking at other care sectors, studies from mental health care and social care for the elderly show that remote care workers experience a need to adapt their way of communicating with care users as the possibilities to use nonverbal communication are limited (e.g., Barbosa & Silva, 2017; Mallen et al., 2005; Rees & Stone, 2005). Although video calls allow for the transfer of nonverbal communication signs, the

process of perceiving and interpreting nonverbal signals may still be relatively complex (Barbosa & Silva, 2017; Reese & Stone, 2005).

As remote support is expected to become more common in the field of intellectual disability (Friedman & Rizzolo, 2017; Tassé et al., 2020), it is important to understand the specificities and complexities that come with the task of providing professional support remotely. The purpose of this paper is to contribute to this understanding by exploring the experiences of support staff of the Dutch remote support service DigiContact. This service offers 24/7 available remote support for daily functioning to people with intellectual disabilities who live relatively independently in their own homes. The support is provided during live contacts in the form of both (online) video calls and (offline) regular phone calls. We specifically aim to answer the following question: What do DigiContact support workers experience as distinctive aspects of their job as a remote support professional?

METHODS

Design

A qualitative research approach was adopted, in which one-off semi-structured interviews with support workers of the remote support service DigiContact were used to collect data. These interviews were part of a broader study in which the support practice of DigiContact support staff was explored (Zaagsma et al., 2022). Data from the interviews were inductively analysed with respect to the research question.

Context: DigiContact

DigiContact is a remote support service of the Dutch service provider Philadelphia Care Foundation. The service offers 24/7 available and remote professional support for daily functioning to people with intellectual disabilities who live in their own homes, either alone or with a partner/family. The support is provided by specially trained support workers during live contacts in the form of video calls (online) and audio-only calls (online and offline). During video calls, it is usually not possible to look straight at each other and make eye contact at the same time. This is due to the position of the camera, which is above the screen on which the video image is displayed. DigiContact uses a system in which a specially coated (half-mirrored) glass panel is positioned at a certain angle in front of the support workers' screen that places the camera optically in the middle of the video image. This enables support workers to look at the person on the screen and creates the impression of direct eye

contact for both support workers and people with intellectual disabilities. Table 7.1 provides an overview of DigiContact support characteristics.

DigiContact was originally developed and implemented as part of a broader package of services for people with intellectual disabilities who live in their own homes (generally alone, with a partner, or with family) and who have been found eligible for access to specialist long-term intellectual disability support services (Vijfhuizen & Volkers, 2016). Its remote support is usually combined with onsite support from a support worker who visits support users at home or at a community center. Over the recent years, its support user group has increased substantially, and now also includes people in supported accommodation settings and people with dementia in early stages or mental health problems. Around the time we collected the data for this study (date January 2020), around 1500 support users were connected to the service, of which about 80% were independently living people with intellectual disabilities.

Table 7.1: Characteristics of DigiContact support

Characteristics	Description
24/7	Support is available 24 hours a day, 7 days a week.
Support is provided from a distance	Support workers are working from one central location (with call-centre facilities).
Devices are used to realize contact	Support users use either their own device (e.g., tablet, pc, smartphone, landline phone) to contact the service or a tablet they receive on loan from the service provider organization. Technological support is available in the form of technicians who assist either from a distance or at home. Contacts can be with or without video component. For video, access to the Internet is necessary. Without Internet connection, contact is possible through regular (landline) phone.
Planned and unplanned support	Contacts can be planned and unplanned. Planned contacts are with appointment, usually according to an agreed on time interval. Unplanned contacts are without appointment, whenever and as often as a support user needs support.
No fixed contacts between support workers and support users	Support users can not choose which support worker they speak to: they talk to the support worker who picks up their call. Support workers provide support to those support users who call in during their shifts.

DigiContact support workers work in rotating shifts to enable the 24/7 availability of the service. They are especially recruited and trained to provide remote support (e.g., on their ability to perform sedentary work and their affinity with technology). Newly hired support workers go through an extended period of on-the-job training, organized through successive periods of observing colleagues, supervised working and a buddy system in which they are linked to a more senior colleague with whom they have regular meetings to discuss their work.

Sampling and recruitment

A combination of convenience and purposive sampling procedures (Patton, 2005) was employed. At the time of planning and organizing the interviews (December 2019), the DigiContact support staff team consisted of 25 remote support workers. Three support workers were excluded a priori, because they had joined the team less than six months before (exclusion criterion) and therefore had not had much opportunity to build up experience with working at DigiContact. An informational e-mail with an appeal to participate in an interview was sent to the remaining 22 support workers. Seven support workers responded and confirmed their willingness to participate (convenience sample). Based on three characteristics of this group of seven (sex, length of time working at DigiContact, and having previous experience with providing onsite support), five additional support workers were selected (purposive sample) with the intention of obtaining a final sample that was representative of the original group of 22 support workers. These five support workers were contacted again personally. One of them did not want to participate, because (s)he felt not experienced enough to reflect on her/his work (this person had been working at the DigiContact service for seven months). Another support worker was not interviewed as we failed to plan an interview due to conflicting agendas. This left us with a final sample of ten participants (see Table 7.2).

Table 7.2: Characteristics of the participants and the DigiContact support staff team

	Participants (*n* = 10)	**Team (*n* = 22)[a]**
Woman, %	80	73
Years of experience with online support, *M* (SD)	3.1 (1.9)	2.7 (1.8)
Experience with onsite support, %	90	86

[a] Excluding support workers (*n* = 3) who had been working at DigiContact for less than 6 months when the recruitment for interviews took place.

Data collection

A guide for semi-structured interviews was developed based on insights into the daily practice of DigiContact remote support staff, acquired through a content analysis of seven DigiContact documents (manual, job description, two informational documents for new staff members, two brochures for support users and their families, and a text on the service organization's website) and 40 transcripts of interviews with support users and case workers from previous studies on DigiContact (Zaagsma et al., 2019; Zaagsma, Volkers, Koning et al., 2020; Zaagsma et al., 2021). The interview guide included four main topics: values and goals in support, activities and strategies, working in a team, and conditions for providing good support. For each main topic several open ended questions were developed. Although the participants provided support to a broader range of service users, the focus of the interviews was on support for independently living people with intellectual disabilities.

All interviews were conducted face-to-face (between December 2019 and March 2020) by the first and second author together, and they lasted between 47 and 86 minutes. The interviews were carried out in Dutch, as this was the native language of all participants and the researchers. Each interview was audio-recorded with participant approval and transcribed verbatim. Member validation was used as a validity check method (Green & Thorogood, 2014): each participant received a typed summary of their interview to check for accuracy. Although all participants felt that the summary represented their experiences well, one participant provided additional input to nuance her/his views regarding the conditions for providing good support. Quotes that are included in the results section, were translated by a professional with an English language proficiency of a native speaker.

Data analysis

The transcripts were analyzed through a qualitative content analysis process based on a general inductive approach as described by Thomas (2006). All authors were involved in data analysis. First, each transcript was read thoroughly and coded by the first author and at least one other author. Codes applied to the same transcript by different authors were compared and discussed if necessary. Next, the first author grouped the codes into categories, and the categories into themes. The categories and themes were further refined through discussion with the second author. Table 7.3 summarizes the final categories and themes.

Ethical procedure

The Medical Ethics Review Committee of VU University Medical Center (FWA00017598) confirmed that official approval was not required as the Dutch

Medical Research Involving Human Subjects Act (WMO) did not apply to the study of which the interviews were part. The researchers 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. Audio-recordings were made after the participants gave their approval and the audio files were destroyed after analysis had been completed. All data were anonymized and subsequently handled and stored with care and respect for privacy.

RESULTS

Support is delivered remotely

The first support characteristic that played a prominent role in the experiences of the participants was the fact that support is provided from a distance (through video calls or regular phone calls). This support characteristic was associated with two themes that show that providing support can be both facilitated and hindered by the distance.

First, providing support from a distance was felt to *encourage a solution-oriented coaching support style*. This style is characterized by a focus on (a) the questions and/or issues that are bothering support users at the time of the contact, and (b) the intention to stimulate support users to take on an active role –as much as possible- in thinking about possible answers and solutions and deploy their own skills, knowledge and talents to solve issues (and through this empower them). More information on this support style is provided in a partner paper on what DigiContact support workers do to support people with intellectual disabilities and how they do this (currently under review). The participants talked about how not being present in the same room as a support user facilitates the adoption of a solution-oriented coaching support style. To begin with, they felt that the distance prevented them from taking over tasks and stimulated the adoption of a coaching style in their contacts:

> *We need to empower the clients, to me that is very important. And I think we are pretty good at that, because we are at a physical distance. I feel this makes it easier to stimulate their independence, as we are not able to take over much.* (Participant 5)

Table 7.3: Overview of themes, categories, and the underlying support characteristics

DigiContact support characteristics	Themes	Categories
Support is delivered remotely	Being encouraged to adopt a solution-oriented coaching support style	Being stimulated to adopt a coaching support style
		Being enabled to focus on the issue(s) for which contact is sought
	Being limited in one's support options	Getting a full picture of the support user's situation is difficult
		Missing nonverbal signals in audio-only contacts
		Being limited in what one can do to help
No fixed contacts between support workers and support users	Facing considerable diversity	Needing to be a 'jack of all trades'
		Adopting a personalized approach is complicated
	Providing support as one team	Presenting oneself as a representative of the service
		Aiming for a high level of uniformity in support
		Sharing tasks and responsibilities with colleagues
Support contacts can be planned and unplanned	Dealing with unpredictability	Not knowing what to expect
		Not being able to prepare
	Navigating the dynamic within work shifts	Making quick mental switches between support contacts
		Multi-tasking during support contacts

In addition, the participants also felt that the distance enabled a strong focus on the issue for which contact is sought. Not only did they experience relatively little distraction from things or people in the support user's environment, but they also felt that not being in the same room (and not knowing each other well personally) made it easier to come to the point quickly:

> *We are not visiting someone, so the situation is not one of 'Hi, how are you and what happened since last we saw each other and how about a cup of coffee?'. We generally skip all that. So this digital contact creates a different venue.* (Participant 3)

Second, providing support from a distance was felt to *limit their support options*. The participants talked about how communicating through a video call or regular phone call (audio-only) made it difficult to get a full picture of the support user's situation. It was, for example, often impossible to gather information from the support user's environment and the people in it. This may especially be the case when the focus in the conversations is primarily on the issue(s) for which contact is sought. Some participants stressed that having onsite work experience with (independently living) people with intellectual disabilities is important, as this can lead to more awareness of (and sensitivity towards) how complex and multi-faceted the situations of support users may be:

> *I consider it important that we have some experience in onsite support, because it means we have visited people at home and that we have seen how things go within the family. Without that experience it would be more difficult to assess situations.* [...] *It would be ideal to combine this job with working onsite one day a week. To keep in touch with the problems that clients face.* (Participant 9)

Regarding audio-only contacts, the participants acknowledged that they risked missing nonverbal signals that can be important for understanding a support user well:

> *It gets to be very challenging when you have to miss out on visual information.* [...] *You've got no idea how the other person is looking or what he is thinking. It helps to be able to see someone's face. I see non-verbal language as an important part of the conversation. Without that information you may well miss the underlying layers of the conversation.* (Participant 8)

Finally, the participants also felt that not being present in the same room limited their options as to what they can do to help support users, as they were largely restricted to supporting by talking only:

> *Well, we have limited options of course, because when you are present, you can help the client by pushing a bit or by starting with practical matters. However, we can help by talking only or by showing something with our hands. This challenges me to look for how I can help someone best.* (Participant 5)

No fixed contacts between support workers and support users

The second support characteristic that played an important role in the participants' experiences, was the fact that there are no fixed contacts between support workers and support users. This means that instead of providing support to a certain subgroup of support users, DigiContact support workers offer their assistance to all support users who call in during their work shifts. This can be any one of the total group of about 1500 connected support users. For a support worker, it is not uncommon to have between 20 and 30 support contacts with different support users during one (daytime) work shift. This characteristic was associated with two themes.

First, the participants felt that their work was characterized by an experience of *being faced with considerable diversity* amongst support users (e.g., with respect to their support needs, communication styles, and/or socio-cultural backgrounds), and the issues for which the service was contacted. This diversity was generally felt to make their work interesting and dynamic. However, this diversity also required them to be a 'jack of all trades':

> *I like the fact that the questions and problems of our clients are so varied.* [...] *We have more clients, with more issues and questions. We need to know a lot of many different things, which is quite demanding* (Participant 2).

In addition, the diversity was felt to complicate the task of adopting a personalized approach. In this respect, participants stressed the importance of having access to up-to-date information on each individual user, as well as on previous professional support contacts:

> *I do think that one of the basic aspects of this job is being able to adapt to the person you are talking with. You can do this by observing. We get to speak to so many clients that we do not know all of them well. The clients who call in often we know quite well, but others we do not know so well. That makes the*

information in the client file on how to relate to this person very important, indeed. (Participant 10)

They also talked about the essential importance of being quite receptive and sensitive to the needs and preferences of individual support users, and able to flexibly adapt one's approach.

Second, being a support worker at DigiContact was characterized as a team effort, and it was felt to be important to *provide support as one team*. The participants talked about how they presented themselves as a representative of the service:

Sometimes clients want to know something about you personally, which is generally fine. However, you are first and foremost a representative of DigiContact and not [own first name]. *That is necessary to prevent clients from forming an attachment with you as a person which will lead to the client wanting to speak with you every time they call in. That is not the purpose of DigiContact. And it should not be anyone's purpose at Digi, I think.* (Participant 8).

Besides stressing their intention to adopt a personalized approach to support (accommodating to the needs, wishes and preferences of individual support users), the participants talked about how important it is that a support user is supported in more or less the same way by different support workers:

We are working with so many colleagues. When all of us deal with issues [of a certain client] *in more or less the same way and stick to that approach, a client gets to know what we as a service can offer and is likely to expect that. It will reduce uneven expectations.* (Participant 3)

In order to realize this, the participants committed themselves to an intensive collaboration with colleagues in order to align their approach and strategies. Finally, participants felt that working as one team also meant that they shared tasks and responsibilities. They talked about the comforts of having a colleague near when they need advice or support, and being able to 'check out' when their shift ends as there is always a colleague who takes over. Together, such aspects of their job were experienced to lower the pressure of supporting so many support users:

You know that this is a non-stop business, there will always be a colleague ready to take over once your shift ends. That makes it easier to let go of the responsibility, and not get too emotionally involved. You are close to the client

and you have a warm contact, but you need to close the door behind you at the end of your shift. (Participant 3)

Support contacts can be planned and unplanned

The third support characteristic that played an important role in the participants' experiences, was the fact that support users can contact the service with or without an appointment. The opportunity to call in without an appointment (unplanned) is used fairly frequently: about a quarter of all support contacts comes about without an appointment. This support characteristic was associated with two themes.

First, the unplanned support contacts led to a feeling of *having to deal with unpredictability*. The participants talked about how not knowing in advance who will call in and about what, brought uncertainty regarding what to expect. While this uncertainty was for some participants stressful, for others this just made their job more exciting. As one participant put it:

So we always need to be prepared for the worst. Because we are frequently confronted with some tough situations. You may just lift the phone and find someone at the other hand who claims to be at the end of their tether and wants to end her or his life. At such a moment you need all your wits. (Participant 1)

Having unplanned contacts also made it impossible to prepare oneself for a contact:

It happens that more than half of your contacts with clients are unplanned. And once clients call in, you can't just tell them: 'Wait a minute, be quiet, I need to look you up.' You do need that information, but you've got to look it up as you go. So sometimes you can prepare and sometimes you can't. (Participant 4)

Second, unplanned contacts were associated with an experience of *navigating the dynamic* within a work shift. This was characterized by alternating periods of high-intensity activity (many contacts coming in closely together) and relative calm. Regularly, the pace of incoming calls was so high, that participants felt they had little time, or no time at all, to rewind or reset their mind in between contacts. They expressed that they had to make quick mental switches in order to keep going and give each support user genuine attention and commitment:

It really is quite a different ballgame. It is important to be able to switch quickly between contacts and clients. During onsite work you move from one client to the next and you have some time in between, while cycling or walking or

driving. During online work you don't have that opportunity. Also, it might be the case that one call is really tough, because the client's problems are so big or so distressing, but the next call deserves your full attention as well, regardless of the seriousness of that client's issues. (Participant 2)

In addition, the participants felt that multi-tasking was an important part of their work, as they had to find and read information within several electronic client file systems for different support user groups during their contacts:

So when the conversation starts, we search for the right [electronic client file] *system. We look up what we have on how to relate to this specific client and we scan the most recent reports.* [...] *So our work really involves multitasking.* (Participant 1)

DISCUSSION

This study provides insight into the work experiences of support staff from the remote support service DigiContact. Through semi-structured interviews with ten members of the DigiContact support staff team, we identified and described aspects that were considered to be distinctive to their work as a remote support worker. The findings show that how support is organized and delivered can have substantial implications for support workers and their practice of supporting people with intellectual disabilities.

To begin with, a remote delivery of support was found to bring both opportunities and limitations to the process of supporting people with intellectual disabilities. On the one hand, not being present at the same spot as the support user facilitated a focus on those issues for which support was sought, as well as the adoption of a coaching role towards support users. The coaching role of support workers was recognized by DigiContact support users (Zaagsma et al., 2021), and corresponds to the findings of De Wit et al. (2015), who found that the support provided by staff of a web-based support program encouraged people to draw on their own personal strengths and skills when executing daily tasks. On the other hand, the distance between support workers and support users was also seen as limiting in terms of the opportunity to gather information and one's range of action. Again, this was acknowledged by support users, as they felt that DigiContact could not address all their support needs due to the distance, and that it was difficult for support workers to see beyond what they show and talk about (Zaagsma et al., 2021). The findings specifically underline the complexity of support contacts realized without

video-input. Not being able to register facial expressions and body language was felt to make it difficult to sort out a support users' true feelings. This matches with the writings of several authors on the challenges of providing remote care (e.g., Barbosa & Silva, 2017; Mallen et al., 2005; Rees & Stone, 2005), as described in the introduction. However, while it has been stressed that nonverbal communication is also relatively complex in video calls (Barbosa & Silva, 2017; Reese & Stone, 2005), the current study did not confirm this. Although the data did not provide information on this, it may be that the use of a half-mirrored glass panel in front of the support workers' camera, which creates the impression of making direct eye contact, played a role in this.

In addition, the participants' work experiences were impacted by two support characteristics that are more specific to the DigiContact service. First, DigiContact support workers do not have contacts with a fixed subgroup of support users. As a consequence, they provide support to a very large and diverse group of people with intellectual disabilities. This was experienced to make the task of adopting a personalized approach in support relatively complex and resulted in support workers providing support as one team. This was experienced to lower the pressure of supporting such a large group of support users, as the responsibility was shared amongst all colleagues and there was always someone available for (practical and/or emotional) support. A parallel can be drawn with other studies that have shown that support from colleagues can be effective in helping workers in the field of intellectual disability services deal with work-related stressors (e.g., Judd et al., 2017; Mutkins et al., 2011; Ryan et al., 2021; Vassos et al., 2017). However, providing support as one team was also experienced to make the job of DigiContact support workers more complex, as they had to find and invest in ways to collaborate well and to coordinate support plans and actions with all colleagues.

Second, the fact that support users can contact the DigiContact service without an appointment made the work of its support staff relatively unpredictable and contributed to fluctuations in the pace of incoming calls. Not knowing in advance who will call in and about what (and not being able to prepare oneself) was felt to be both challenging and exciting. Periods of being frequently faced with a continuous stream of incoming calls, left support workers with little to no time for relaxing and resetting their mind in between calls. Research has shown that a high workload is positively associated with symptoms of burnout amongst support workers (Gray-Stanley & Muramatsu, 2011; Kowalski et al., 2010; Vassos & Nankervis, 2012). This association seems to be stronger when support workers experience little control over their workload (Vassos et al., 2017), as is the case with unplanned support contacts. Peer support (checking on each other, offering emotional support, enabling a colleague

to take a break) is therefore of essential importance for DigiContact support staff, and should be regarded as an integrated part of the job that is facilitated by the organization.

Limitations and future research

A substantial part of the identified distinctive aspects were related to the specific way the DigiContact service organizes its support delivery. As a result, these aspects may not be recognizable to the support staff of other remote support services. For example, not every remote support service will give support users the possibility to call in without an appointment, and therefore not all remote support workers have to deal with the unpredictability that comes with unplanned contacts. However, the possibilities and challenges related to providing support from a distance might be recognizable for support staff of all remote support services. We recommend that future research focuses on exploring the experiences of support staff of other remote support services than DigiContact, in order to enable the identification and description of distinctive aspects of the work that are broadly recognizable.

Implications for practice

The findings of this study do not only contribute to an enhanced understanding of the specificities and complexities that can come with the task of providing remote professional support, but also indicate that there are organizational and professional preconditions that facilitate the task of providing good quality remote support. With regard to organizational preconditions, the findings underline the importance of a well-functioning and quickly accessible digital information infrastructure (e.g., electronic client files), so that complete and up-to-date information on support users can be shared between onsite and remote support staff. In addition, as video calls are preferred over audio-only calls in terms of being able to use different types of communication (also nonverbal), it seems advisable for organizations to promote and facilitate contacts with video input as much as possible, for example by offering support users the needed equipment (devices) on loan.

With regard to professional preconditions, the findings suggest that there are certain competencies that may be valuable for support staff working in remote support contexts. Service organizations can use such competencies to guide the recruitment, selection and training of (new) support staff. For instance, for DigiContact support workers it seems that having a wide set of knowledge and skills (both at the level of individual staff members as well as on the level of team composition), the ability to work both independently and in a team, and strong cognitive skills (e.g., sustained attention, speed of information processing, and cognitive flexibility) will be helpful

for dealing with some of the complex aspects of their job. In addition, the findings indicate that having onsite work experience might help remote support workers to stay in touch with the background and complexity of the lives of some support users. This pleads for facilitating and stimulating remote support staff to also work some hours as a support worker in onsite settings. However, it is important to stress that almost all participants in this study (9 out of 10) had indeed worked as an onsite support worker before they started at the DigiContact service. We do not have enough empirical evidence regarding if remote support staff without onsite support experience feel like they miss this in their work.

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CHAPTER 8

A closer look at the quest for an inclusive research project

Zaagsma, M., Koning, M., Van Andel, C., Volkers, K., Schippers, A., & Van Hove, G. (2022). A Closer Look at the Quest for an Inclusive Research Project: 'I Had No Experience with Scientific Research, and then the Ball of Cooperation Started Rolling'. *Social Sciences, 11,* 186. https://doi.org/10.3390/socsci11050186

ABSTRACT

The original adage of the movement of people with disabilities 'Nothing about us without us' is fortunately more and more adopted in the research world. There is, for example, increasing recognition of the importance and value of actively involving people with intellectual disabilities in research projects on topics that are relevant to them. In a current doctoral research project, a co-researcher with an intellectual disability was recruited to work together with the doctoral researcher. Now that this project is nearing completion, it is time to look at some aspects of their collaboration and see what we can learn from this process. In several (joint) meetings, the researchers reflected on their personal experiences with working and researching together. Our reflections are presented using three overarching themes: preparations for the collaboration, collaborating as a complex process, and conducting research together. The discussion focuses on what can be inferred from these personal experiences with regard to the following three topics: how inclusive research can be organized best, the possible benefits of the collaboration for the researchers involved, and the possible impact of the collaboration on the quality of the research.

INTRODUCTION

The position of people with intellectual disabilities in scientific research has changed significantly in recent decades. Whereas for a long time they were not involved in research (others spoke for them), since the end of the 1990s, we have witnessed efforts to take a different approach. Their involvement in this regard has morphed from being exclusively research participants to gradually becoming more actively involved in the various stages of the research process. Bigby, Frawley and Ramcharan (2014a) differentiate between three different approaches to how people with intellectual disabilities are actively involved in research: (1) an advisory approach (people with intellectual disabilities provide advice to academic research teams), (2) a leading and guiding approach (people with intellectual disabilities initiate, lead, and execute their own research about issues important to them), or (3) a collaborative group approach (people with intellectual disabilities work in an equal partnership with academic researchers). Each of these approaches creates opportunities, in different ways and to different degrees, for people with intellectual disabilities to influence research and help take decisions relating to aspects such as research topics, design, and used methods.

The literature on this topic cites various good reasons why it can be both important and valuable to have people with intellectual disabilities take an active role in research projects. For example, the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) emphasises the right of people with disabilities to be involved in issues affecting them. In addition, being actively involved in scientific research can have a beneficial effect on the individuals directly involved (e.g., learning new skills, gaining insight into the experiences of (other) people with intellectual disabilities) and by extension on other people with intellectual disabilities and by extension on people without disabilities working with the latter (Frankena et al., 2015; Stack & McDonald, 2018). It is also experienced that involving people with intellectual disabilities can contribute to the quality and relevance of research. For example, researchers with an intellectual disability can have a 'technical' contribution by developing materials that are appropriate for the research and its participants (Nind, 2014; Frankena et al., 2015; Puyalto et al., 2016). Individuals with intellectual disabilities are also recognized as advocates who can help to concretize more abstract terms such as autonomy, empowerment, participation, and inclusion, bring good practices to the fore, and who take the lead in uncovering barriers (regarding, for example, accessibility, supportive relationships, or transition to adulthood) (Chalachanová et al., 2021).

When people with intellectual disabilities take on an active role, the term often referred to is inclusive research. In an article from 2018, Walmsley et al. attempted to define a 'second generation' of inclusive research, taking into account the evolutions that have occurred since the beginning of the 21st century. According to these authors, inclusive research can be described as follows (p. 758):

- Research that aims to contribute to social change, that helps to create a society, in which excluded groups belong, and which aims to improve the quality of their lives.
- Research based on issues important to a group and which draws on their experience to inform the research process and outcomes.
- Research which aims to recognize, foster, and communicate the contributions people with intellectual disabilities can make.
- Research which provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others.
- Research in which those involved in it are 'standing with' those whose issues are being explored or investigated.

Practices of inclusive research are increasingly being realized in different places around the world and with different 'target groups'. In this regard, we are inspired by research centres and groups with years of experience. The fact that they have realized many projects, built a large network, presented and published a lot but also (and above all) that they have been able to exert a lot of influence on local practices and policies offers opportunities to learn from them. We would like to briefly describe two inspiring examples below. To begin with, in Ireland, we can learn from the intense cooperation between the National Federation of Voluntary Service Providers, Trinity College Dublin, and University College Cork. Garcia Iriarte et al. (2014) and Salmon et al. (2018) report on the pathways this network developed to conduct research about topics that are important for persons with disabilities. They worked with training workshops, organized a continuous dialogue about their projects, used creative tools (such as role plays) to develop skills of researchers and co-researchers, worked hard to make sense with the teams of the data, and presented their work in local, national, and international meetings. At the same time, these researchers are able to keep a very critical stance towards their own work not wanting to become the very type of research it aims to challenge (Salmon et al., 2018). A second example is located in the USA, where Nicolaidis et al. (2019) report on the practices of AASPIRE-USA regarding trying to develop guidelines for the promotion of the inclusion of autistic adults as co-researchers. They put a strong focus on being transparent about partnership goals, clearly defining roles and choosing partners, creating processes for effective communication and power sharing, building and maintaining trust, disseminating

findings, encouraging community inclusion, and fairly compensating partners. It is important to learn that for persons with autism (the group that is often strongly entwined in a clinical model), the time has come to participate in research. The lessons learned in research projects with people with autism can help us to make the framework for research projects and the communication about the projects clearer for colleagues-researchers with intellectual disabilities as well.

As a result of the growing attention to inclusive research and the increase in research initiatives with an inclusive approach, the knowledge shared (through publications) on this topic is growing. The publications can be roughly divided into two groups. There are articles that primarily focus on personal experiences of inclusive research and reflections on collaborative research (e.g., Strnadová et al., 2014; Dorozenko et al., 2016; Riches et al., 2017). In addition, other publications attempt to arrive at assertions that can be generalised across inclusive research initiatives, such as attributes that should be taken into consideration when conducting inclusive research (Frankena et al., 2018), competencies that are considered important for researchers with and without intellectual disabilities in inclusive research initiatives (Embregts et al., 2018), and contextual and team-level factors and processes that foster and maintain inclusive research (Schwartz et al., 2020).

Through this article, we want to align ourselves with the tradition of incorporating personal experiences. For the first two authors (both researchers, of which one has an intellectual disability), this article represents the culmination of an extended period of collaboration within a research project (see 'The research project'). The first author positions herself in a tradition of doctoral students opting for a more inclusive approach in their research work. Already in 2008, Björnsdóttir reported on the tensions that inclusive research during a PhD trajectory evokes within a competitive academic environment and the danger of academic researchers falling into the same trap of the exclusion that they criticize society for (Björnsdóttir & Svensdóttir, 2008). By focusing on the tension between inclusive research and traditional ethical guidelines at research institutes and universities, Morgan wanted to make future PhD researchers aware of possible incompatibilities linked to, e.g., disclosure, the tension between empowerment and protection, and the application of shared partnership, equality, and transparency within an academic context (Morgan et al., 2014). Moreover, Dorozenko's recent call for PhD students working with inclusive research to have sufficient reflexivity and critical reflection (e.g., regarding the risks of repeating oppressive power relations) was very inspiring for the collaboration described here (Dorozenko et al., 2016).

The aim of this article is to reflect on our own research collaboration by exploring our personal experiences of how our collaboration in research works best, as well as the benefits that our collaboration has brought to us personally as well as to the quality of the research. We hope that our experiences can provide support to other researchers who wish to set up and conduct inclusive research. This article was realised thanks to the substantial contributions of several people who are all co-authors. Mark and Miriam form the research duo that worked together on a research project for several years (see 'Context'), and for this article, they reflected on their collaboration. Geert, Karin, and Alice were involved in this research project as supervisors and advisors. Not only did they advise the research duo on 'technical' research issues but also on conducting research inclusively. Christine was asked to help the research duo compile and situate experiences (see 'Materials and Methods'). With regard to the writing of this article, Geert, Miriam, and Mark took the lead, and the other three co-authors reviewed previous versions of this article.

CONTEXT

The research duo

Mark and Miriam both work as researchers at Philadelphia Care Foundation (PCF) in the Netherlands. PCF is a care organization for people with an intellectual disability, which offers a wide range of support services throughout the Netherlands. Over a period of almost four years (December 2017- October 2021) Mark and Miriam worked together on a research project into the experiences with an online support service for people with intellectual disabilities living independently (more on this in the next section). In addition, Mark works several hours a week as an assistant on other projects within PCF. Mark and Miriam introduce themselves below.

Mark: *I am 45 years old. I was born prematurely and for a long time I believed I had a developmental disorder. I went to a special education school. For a long time, I felt like I had a hard time making friends, but I did have contacts with other people. Once I finished school, I had various jobs in administration. I often felt like I wasn't taken seriously at work. I also had the feeling that I was only half-participating in society. I had the feeling that something was wrong, but I did not know what it was. In 2005 I was diagnosed with PDD-NOS, a form of autism. That's how I ended up coming into contact with Philadelphia. Then things started to change. There were opportunities at work to focus on my talents in a partially sheltered way, I was able to develop myself. This was enhanced when I joined various client councils within the organization. I felt I was being taken more seriously. I mattered. Through people at the client council, I came into contact with Miriam in 2017. She*

was looking for a colleague to conduct research together. At the time, I had no experience with research, let alone scientific research. Back then, I couldn't have told you what research involved. And then the ball of cooperation started rolling.

Miriam: *I'm 40 years old. I went to a mainstream school and completed studies at university, where I was able to gain a lot of knowledge and skills in the area of scientific research. After my studies, I did various jobs conducting research. Sometimes these were projects in which we tried to involve the 'target group', such as young people in mainstream education. However, these were not truly inclusive projects. As such, when I joined Philadelphia in 2016 I had no experience with inclusive research.*

The research project

The project that Mark and Miriam worked on involved research into the online support service DigiContact. This service is offered by the PCF as part of a broader package of support services for people with intellectual disabilities living independently (in their own homes) (Vijfhuizen & Volkers 2016). DigiContact offers 24/7 remote support, where people with a support need can contact a team of specially trained support workers via either an app or link on their mobile phone, tablet, or computer or via a standard telephone. The aim of the project was to compile knowledge on the experiences of both support users and professionals of DigiContact regarding the potential value of its support for people with intellectual disabilities living independently. During the course of the project, five sub-studies were performed of which each focused on a different question. A scientific article was drafted in English on each sub-study (Zaagsma et al., 2019; 2021; Zaagsma, Volkers, Koning et al., 2020; Zaagsma, Volkers, Swart et al., 2020).

The research project started in 2015 with a different researcher duo. After one year, both members of this duo left the project because neither of them wanted to continue working as researchers. After this, Miriam started working on the project in February 2016. During the first year, she worked with another co-researcher for several months. Mark was recruited as a co-researcher in 2017. For Miriam, the research project formed the basis for her PhD at the Amsterdam UMC (Vrije Universiteit). Throughout the project, she was able to devote 32 h per week to the research project. When Mark was recruited, he was offered a contract to work on the research project for an average of 8 h per week. He also worked a varying number of hours on other projects within the PCF. Besides Miriam and Mark, three senior researchers (fourth, fifth, and sixth author) were involved in the different

sub-studies into DigiContact. They provided advice for the research and supported Miriam in her PhD.

MATERIALS AND METHODS

In this article, we reflect on the personal experiences of Miriam and Mark with conducting research together during the research project on the potential value of 24/7 online support. By doing so, we align ourselves with the tradition of an auto-ethnographic approach, in which personal experiences are described and analysed in order to understand broader cultural experiences (Ellis et al., 2010).

During the course of the research project, data on the collaboration were logged in various ways. To begin with, both Mark and Miriam independently kept a logbook in which they wrote down their personal experiences, thoughts, questions, doubts, and difficulties on a weekly basis. During the first weeks of the project, Mark was supported by Miriam on how to keep a logbook (e.g., by discussing together what to note, when to do this, with how much detail, etc.); after this, he continued to do this by himself. In addition, Mark and Miriam had regular conversations together about the research and their collaboration in particular. These conversations were not always planned in advance and did not have any fixed structure. Notes of these conversations were recorded in the logbooks.

In preparation for this article, five meetings were organized and held (in the spring and summer of 2020), in which Miriam and Mark reflected on their collaboration under the guidance of a moderator (3rd author). This moderator was able to reflect on their experiences and ask questions from an outsider's perspective. At the start of these meetings, the moderator, Miriam, and Mark discussed topics that would be interesting to explore. Examples of topics were: expectations of conducting research together, how different research activities (e.g., analyzing data) were carried out, and perceived facilitators and barriers in the process of collaborating. Before each meeting, the moderator prepared a list of questions she could use to fuel the conversation when needed (e.g., 'What were difficult moments during the project (and why)? What are you proud of (and why)?'). The notes in the logbooks were used as input for the meetings, with Mark and Miriam going through them in advance to refresh their memories. To prepare for this, a plan of action was drawn up by the researchers together. This plan included a guideline regarding what to do (e.g., what to pay attention to, how to make notes of topics that seemed important) and a plan on when to do this (the work was spread out over multiple shorter sittings because the collection of notes was quite comprehensive). Following up on this

plan, the researchers worked independently from each other to review their own notes without needing further support. The five meetings took place remotely via videoconference, on account of the COVID-19 measures in place at the time. Three of the five meetings were conducted jointly. In the other two meetings, the moderator talked with each researcher individually, focusing in particular on elements that were related to Mark and Miriam's unique and highly personal perspective. Each meeting was recorded and subsequently transcribed by an external agency.

The transcripts of these five meetings and the logbook notes formed the research material. To decide on which reflections and experiences to present, Miriam and Mark went through the material while keeping the three topics of reflection in mind (i.e., how inclusive research can be organized, the possible benefits of the collaboration for the researchers involved, and the possible impact of the collaboration on the quality of the research). They started this process separately from each other. Both of them read all the transcripts and notes. To assist with ease of comprehension, Mark also listened to the audio recordings of the meetings, as this helped him retain his attention and grasp the meaning of what was being said. They both used marker pens to highlight parts of text on a given topic, always writing the gist of the text in the margin. They each made a list of the experiences they personally found important. These lists were shared with each other by e-mail. As a next step, Miriam and Mark compared and discussed the experiences on their lists in order to come up with a joint overview in which their experiences were integrated. This process took place (mostly) via videoconference calls due to COVID-19 restrictions being still in place. This overview was shared with the other authors in order to decide together with them on which experiences needed to be highlighted in this article. The starting point in this was to present experiences that we were convinced would interest other individuals involved in inclusive research.

FINDINGS

The experiences are discussed and explained on the basis of excerpts from the meetings. These excerpts were translated into English by a certified translator. The experiences are presented using three overarching methodological themes: preparing for the research collaboration, collaborating as a complex process, and conducting research together.

Preparing for the research collaboration

The first methodological theme describes the period leading up to the collaboration and emphasises the importance of good preparation.

Philadelphia opts for inclusive research

The decision to adopt an inclusive approach in the research project did not appear to be a priority for either researcher in the first instance. The decision to set up and conduct inclusive research was not made by the researchers themselves. It was the steering committee of the research project (with representatives from the PCF and the senior researchers from the university) that put forward and decided on the idea of inclusive research at the outset of the project. Both Miriam and Mark were candid and stated that at the time of their application, they were primarily interested in the topic of the project and the accompanying work activities. The inclusive nature of the research project was for them an attractive and interesting extra. Miriam:

> *The position first attracted me because of the subject of the research project: the digitisation of care for people with intellectual disabilities, and studying client experiences. The possibility of obtaining a PhD on the subject was also interesting … I didn't have any experience with inclusive research, although I did have ideas and expectations about it. I saw it as a nice challenge to take on, and an enriching experience. I expected to learn from my colleague what it is like to live and work with an intellectual disability. And that it would provide openings to make the research more accessible and allow people to participate in it.*

Mark was interested in DigiContact and wondered whether this form of support would suit him if he lived independently. Above all, Mark was looking for:

> *…a job that would give me more influence. The job was also all the more interesting because it was a paid job.* [Mark was already doing certain tasks for the PCF, but these had been voluntary up until that point]. *Plus, I am the kind of person who is always eager to learn, and I am interested in other people. The research project gave me the opportunity to meet other people. Working together intensively with someone on a new area of work also gave me a safe feeling.*

The search for a good research duo

Making the decision to set up and conduct inclusive research is one thing. We learned in this research project that everything stands or falls with the quality and sustained commitment of the research team. The research project we report here was suspended on two occasions after people quit the project. The first research duo (the predecessors of Miriam and Mark) quit at the same time because neither of them wanted to continue working as researchers. After Miriam started on the project, she worked briefly with another co-researcher before starting work together with Mark (and finishing it together). This collaboration ended after several months

because the role of co-researcher did not match well with their talents and ambitions, and the level of support that was needed to enable their participation in research activities was beyond what the organization and Miriam could provide. During this collaboration, there was no job coach involved, as was the case in the collaboration between Mark and Miriam (see also 'Time (and a lot of organizing) as an important factor' and 'Roles, allocation of tasks and decision-making').

This difficult start meant that in the search for replacements, other strategies were tried out in order to put together a research duo that could collaborate effectively together. For example, the initial approach for recruiting the co-researcher was to disseminate flyers with accessible information about the research project and the role of the co-researcher. The candidates who applied were interviewed and hired by staff from the PCF but not by the other researcher (Miriam). When the search for a co-researcher started again, a more focused approach was taken, and Miriam was involved in the interviews with candidates. The support person for the client councils at the PCF (someone with a good idea of the ambitions and talents of clients) had focused interviews with persons whom he thought would not only be suitable but would also be interested in the research project. With regard to suitability, specific attention was paid to verbal and social skills (with a view to conducting interviews) and the ability to travel independently (e.g., by public transport). Mark was seen as a highly suitable and motivated candidate. Following both a telephone conversation and face-to-face contact between Mark and Miriam, they concluded that their expectations matched well. Moreover, both had a good feeling about these first contacts and could see themselves working together intensively for a longer period of time. "*It was immediately obvious to me that it was a good match*," says Mark on the subject.

The first time they clicked turned out to be an important basis for the subsequent collaboration. According to Miriam:

> *When we needed to search for something, or when things weren't going so well, we could always fall back on the experience of that first connection. For example, issues were discussed openly and we were able to look for solutions together in an open and pleasant way.*

Collaborating as a complex process

An organization may decide to organize and facilitate inclusive research, and researchers may decide to participate in it, but this is no guarantee that the research

will run smoothly. The second methodological theme addresses the difficulties we experienced in working together as a research duo.

Time (and a lot of organising) as an important factor

As happens with many employees, Mark had to make arrangements with his former employer before he could join the research team. The fact that Mark, as a person with a disability, could not simply decide to change jobs is notable in this regard. He explains:

> *After the job interview for the position of co-researcher, and the happy moment when I heard that I had been hired, I immediately started to find out whether it was administratively possible to take on the job ... As someone with a disability, I have to deal with the UWV[15]. This is a good institution because it ensures that I can participate in the labour market. But at that point it was also holding me back from self-development. Even though I felt I no longer fitted in at my previous job, the UWV felt that my permanent job was more important because it offered me income security. Fortunately, Philadelphia identified this problem and enlisted the help of a job coach. Despite the mediation of the job coach, we could not get in contact with my then employer. In the end, Philadelphia started looking for additional projects for me within the organization alongside the role of co-researcher; that way the job coach had a credible story and convinced the UWV that this new workplace was suitable for me. This all took four months. I remember these months as a period with a lot of uncertainty, disappointment and hope. In the meantime, Miriam and I were in touch every now and then. We also went out to dinner once. When we met up, we discussed everything that had to be arranged, but Miriam also talked about the state of play of the research. As such, we were both up-to-date with the situation.*

All this shows that finding people with disabilities to perform the role of co-researcher can be difficult, even if it is a paid job. The system gives priority to security of income rather than self-development and learning new skills. It was a tense period for Miriam as well, as conducting inclusive research with the co-researcher not being able to actively participate yet was not easy. Fortunately, her manager at the PCF took care of all the 'organising work' so that she could focus on the research work.

15 The 'Employee Insurance Agency' [Uitvoeringsinstituut Werknemers Verzekeringen] is a Dutch government body responsible for implementing employee benefit schemes.

As we can see, this research project had a challenging start. Miriam was obliged to keep waiting for her co-researcher and had to manage the first sub-study and the data collection for the second sub-study on her own. Mark was on the side lines and witnessed a few developments (including a series of interviews) that he would have preferred to have been involved in. Despite the fact that Mark was given a lot of time to familiarise himself with the subject of the research at the start, it is clear that analysing research data that one has not collected themselves is not the best and most pleasant way to join a project. Nevertheless, Mark says that he has good memories of his first weeks in the research project. He felt he could make a contribution for other people with disabilities and that the research was meaningful and not just for himself. Mark felt highly appreciated and was impressed by the fact that so many people were interested in the research (he participated in a working group and attended a conference): a new world appeared to be opening up.

Getting to know each other really well

The first weeks in which Miriam and Mark worked together were crucial in laying the groundwork for a good collaboration. They took the time to get to know each other well. Mark was introduced to the rest of the department. Moreover, his first day at work was rather special. Mark explains:

> *As we had had regular contact in the preliminary stage, the first working day was a very pleasant start to the whole experience. Moreover, the first day -a Saturday- was a conference day. This took place at a hotel in Amsterdam. Miriam had to give a presentation about DigiContact. I only had to go along and listen. But once there I was introduced to everyone as the co-researcher, and in a room full of researchers! Important contacts were made that day for the research project, and I was given a lot of information, but in bite-sized chunks. It was a special start for me with all the contacts and information. That week I was also given an article in English that Miriam wrote, to read.*

Besides this very intensive start (for Mark), Miriam and Mark learned that there is more to working together successfully. Miriam:

> *It was essential to take our time, have regular lunches in addition to the necessary functional talks, or catch up on things going on in our lives outside of work. These conversations were crucial for building a good working relationship. We got to know more about each other, we learned how we could work together, and each other's habits, for example the fact that I like to have a quiet start to work in the*

morning, became clearer. That way, you can get on the same wavelength, and it is important to maintain a good working atmosphere. (Figure 8.1)

Finding enough time to connect with each other outside of working on research activities together was sometimes challenging, for example, due to Miriam wanting to make pace in order to meet certain deadlines (related to her PhD planning) and Mark experiencing the pressure of working on several projects (besides this research project) at the same time.

Conducting research for and within a large organization such as PCF also means that getting to know that organization and being introduced to it and its broader research network are important. Mark explains:

Fortunately, I already knew a number of people in Philadelphia through my work in the client council. I attended a lot of meetings on the research project, and got to know many people from Miriam's research network. After a few months, I was also able to make a contribution in presentations about the research project. In the beginning, I mostly talked about my role as co-researcher; but after a while I could also give more and more in-formation about the research itself. (Figure 8.2)

Figure 8.1 Going for pizza (10th of July 2018)

Figure 8.2 Mark presenting (21st of June 2018)

The need to keep reflecting

As Mark recounted:

We did a lot of research together in the first few weeks. That seems normal, because I had no experience with scientific research. But the fact was, I only worked on the research project for 8 hours a week, while Miriam worked for 32 hours a week. So we took the time to find out where I could be most useful. It

was important in this regard to look not only at what needed to be done, but also at what our interests and talents were. That's why it is so important to get to know each other. We decided not only to touch base each week regarding the practical aspects of the research project, but also to set aside time two or three times a year to discuss our collaboration in more detail. Conducting the research together was an important part of the project; so this was taken seriously. We also kept a logbook, this was also important for the research.

In this research project, working together to a clear structure proved valuable. For example, Mark and Miriam worked together on a fixed day of the week as much as possible, and this day started with a meeting where there was an opportunity to catch up in general and to discuss the work. They always made clear agreements about who would take on which tasks. These agreements were put into an overview that was accessible to both researchers.

The flexibility that is sometimes required when conducting research was an additional challenge for Mark, as he was also working on other PCF projects. For example, the interviews could not always be planned on the fixed working day, and there were not always tasks for the full eight hours, or, conversely, there were too many tasks. Mark took up this challenge together with a job coach: this coach taught him how to make overviews of the activities he needed and wanted to do, plans were revised, and in his digital agenda, he learned to work with time blocks in different colours (each project a different colour).

Roles, allocation of tasks and decision-making

Looking back on the collaboration, a number of things stand out with regard to roles, allocation of tasks, and decision making. For example, before starting the collaboration with Mark, Miriam had had a difficult experience working with a previous co-researcher, which stayed at the back of her mind and made her feel unsure about working with a co-researcher. It is clear that the PCF played a highly valuable role in this regard: the foundation created the conditions that facilitated both parties in their collaboration. For example, by hiring a job coach for Mark, Miriam could be a colleague for him and did not (also) need to take on the role of a support worker. By finding several projects for Mark, he could get started without being thrown in at the deep end.

Mark and Miriam allocated tasks in mutual consultation. As Mark had substantially less time available for the project than Miriam (8 versus 32 h per week), it was not possible for him to be involved in all activities in the same way. In this respect, a

distinction was made between activities that they performed either together or independently from each other and activities in which Mark adopted the role of advisor. The starting point for this distinction was their personal skills and interests, as well as the expectations regarding in which activities Mark's participation and input would add the most value to the project. Miriam explains:

> *Mark discovered he really liked to work on data analysis, and we both felt that his involvement led to broader and richer insights. This made us decide that Mark would spend a relatively large part of his time on analysing, and less on, for example, writing texts. Making such decisions was sometimes difficult, as in some situations Mark wanted to be involved in something, I remember specifically one time when we had to prepare for a presentation, but we decided that he would not be involved because there wasn't enough time.*

When several sub-studies were per-formed at the same time, it was easier for Mark to first finish his work on one sub-study before moving on to the next.

During the research project, Mark never took 'the lead' over a sub-study. Questions such as whether this would have produced more results, or given more scope for experimenting with different research methods, therefore remain unanswered.

Collaboration during the COVID-19 pandemic

This research project was hit full-on by the COVID-19 pandemic. Mark and Miriam were about to start with a new round of data analysis, and they had to find a way to continue this activity remotely. They describe below how working remotely disrupted their working rhythm, appointments, and rituals. Mark:

> *During the final phase of our research, the Netherlands was struck by corona. This meant that we had to work from home; I felt very limited in the options available. We drifted apart a little bit because we had less contact with each other, and we weren't able to motivate each other as much. We did call every week and we were in contact via WhatsApp, but we sometimes lost the focus of our research.*

Miriam:

> *In the first chaotic phase of corona, we lost sight of each other for a while. We learned to find a new digital rhythm. We were lucky that many of the interviews were already completed and we already had the research material. We called each other once a week to clarify and divide up the work. It was also an opportunity to*

> *catch up. The analyses had to be carried out remotely. Fortunately, the lockdown didn't stay very strict for too long, and we were eventually able to sit together again in person. But after a few months, we had to switch back to digital as the measures were tightened again. We went back to videoconferences, and trying to find each other with regular phone times. And in the meantime, we had to continue working on our own tasks.*

Having to work together remotely guided the researchers towards analysing data more independently from each other. Before COVID-19, data analysis was largely performed together, in the same room, using post-it papers or other materials to record codes and cluster them (see also 'Analysing'). Now the researchers had to change tactics. They read and coded the transcripts separately and independently (and without further support) from each other. Mark and Miriam were both comfortable with this, as they felt they had built up sufficient experience with coding in previous studies. They printed transcripts, highlighted pieces of texts, and wrote their codes in the margins. The clustering of codes in sub-themes and themes proved to be more difficult to do together remotely, as they missed the (visual) grouping processes they had used before. Fortunately, this process could be picked up again after a few months when it became possible to (occasionally) work together in the same room.

Conducting research together

Conducting research involves certain activities. This third methodological theme addresses our experiences of conducting research tasks together. Two specific tasks that took an important position in several phases of the research project were chosen: interviewing and analysing.

Interviewing

For the research project, two rounds of interviews were completed during the collaboration between Miriam and Mark. In Mark's own words:

> *I was going to do qualitative research, this is a term I didn't really grasp - especially at the beginning. Here, conducting research together meant first preparing questions together. These questions had to fit the research topics we wanted to know a lot about. We learned to first draw up a research question together and then turn it into research, so that we got answers to these questions. I always tried to prepare our meetings for this. I wrote down ideas to ask questions about between our meetings, so I was prepared for the next work meeting with Miriam. That way, my share in the topic list became increasingly clear. Besides consultation sessions, we also shared files within Philadelphia; we shared and*

emailed with each other regularly and came up with the best possible list of questions. We also drew up a letter of invitations together; I also called the potential participants to arrange appointments. At the start, I had no personal experience with interviewing, so we went to do a trial interview with someone I knew well. This data was not used for the research project. We interviewed both supervisors and clients who used DigiContact. We usually had several interviews with these clients. In between the interviews, we were able to sit together and discuss. This allowed me to grow in my role as interviewer. In the beginning, Miriam asked most of the questions and I supplemented her from time to time, but by the end the roles were reversed.

Analysing

As regards the analysis of the interview data, Miriam and Mark worked closely together to find the most convenient way to make everyone's share as rich as possible. Mark became a highly active researcher during the analysis (Figures 8.3 and 8.4). As he says himself:

The analysing often started during the interview itself. We noted our observations individually during the interview, and used them as the first step in the analysis. There was an external person who would type up all the interviews for us verbatim. If these typed texts came back, they had to be anonymised; that was quite a job, a task we could divide up. Bullet-point summaries of the interviews were also made, Miriam usually did this. The people we interviewed were subsequently approached to check whether we had correctly understood them; this is referred to as a member check. Miriam went back to the professionals and I handled the clients. In-depth analysis is something that takes a lot of time. I learned that the different perspectives sometimes contrasted with each other, and I knew that I could make a difference with my perspective as an expert by experience compared to the insights of the professional researcher. We also focused a lot on the different research questions, which required going through the research material again several times. Sometimes I preferred listening to audio recordings of the interviews rather than reading the transcripts. So that's what I did. We used different methods to perform the analysis. Sometimes we wrote our findings on post-its. We also sometimes highlighted sections of interviews when we were taking excerpts from them. Whenever I learned new things in other projects, I would present them to Miriam and we would see if they could be used in our collaborative research. For example, visual analysis methods were also used: things were then grouped and pasted together like a collage. At other times, we would perform the analysis with several people on the research team and look at the data from the broader research team.

Figure 8.3 A analysis session with the entire research team (8th of March 2018)

Figure 8.4 An analysis session of Mark and Miriam (3rd of June 2019)

DISCUSSION

At the start of this article, we explained that we would reflect on three topics, based on our personal experiences: (1) how best to organize inclusive research, (2) the possible benefits of the collaboration for the researchers involved (Mark and Miriam), and (3) the possible impact of the collaboration on the quality of the research. In this discussion, we first look at what we can infer about these topics from the research material presented. We then briefly compare our results with the recent research literature on inclusive research.

Regarding our experiences on how to organize inclusive research, it is clear that this was difficult during the start of this research project. For example, the first research duo quit after a year, the co-researcher of the second duo quit after a few months, and after that, it took a long time before Mark and Miriam could really start working together. Our experiences led to several insights. First, we experienced that not everyone is motivated, ready, and able to become a member of a team doing inclusive research. It is therefore important to recruit researchers and co-researchers who are suitable partners in inclusive research. It also underlines the importance for organizations and research institutes that want to engage in inclusive research to provide education and training on inclusive research methodologies (Garcia Iriarte et al., 2021) for researchers (both academic researchers and co-researchers). Second, we learned that hiring people with disabilities as paid researchers can come up against various administrative hurdles. A research job is often temporary and not always stable over longer periods of time. Many people with disabilities are caught in the 'golden safety net' of social security: they have a good monthly income; however, this can be at the expense of further self-development and taking on new challenges.

Third, we learned that the party who commissions the research (in this project, a large service organization) can play an essential role in inclusive research, a role that does not have to result in interference with the body of the research. In this project, the PCF really 'stuck its neck out' for the final duo. For example, Mark was offered more than one project to provide him with a stable income. In addition, the unavoidably slow pace of inclusive research was well understood: more time was allocated to the research project. In this project, introducing a job coach proved to be a golden asset. This job coach could work in a supportive manner in the function of what Morgan et al. (2014) named transparency. The job coach could also, especially during the first phases of the research, help to inform and clarify certain aspects. This intervention allowed both researchers to really work as colleagues, and thus this aspect of power imbalance could be mitigated.

As regards the benefits to both researchers of conducting research together, the research data show benefits to the co-researcher: Mark got a job that allowed him to have a more direct influence on the quality of life of people with disabilities. A (research) world opened up to him in which he gained respect, and he states that this had a great influence on his self-confidence and his ability to acquire new skills. He learned to listen carefully to people, ask the right questions, and see that the perspective of the experienced expert could really contribute something to the research. The academic researcher also personally benefitted from the opportunities that were created for Mark to have a voice, to exert control, and to make decisions, as this made sure that this project was not 'just another' PhD that only reflected the perspective of non-disabled experts or researchers (Bjornsdottir & Svendottir, 2008; Dorozenko et al. 2016). The academic researcher also learned from their long-term collaboration about ways in which they could best work together and conduct research together. In this regard, it was especially difficult situations from which she could learn, such as a previous collaboration with a different researcher with intellectual disabilities in which the roles of being a supporter and being a colleague became too intertwined.

Finally, as regards the quality of the research, we would like to emphasise in particular the fact that Mark, as a co-researcher, seized opportunities through his involvement in various projects to take methods from one research project to the next. For example, methods for visually grouping data were contributed in a very creative way and provided additional depth. In this regard, we go further than Björnsdóttir and Svensdóttir (2008) who state that well-executed inclusive research is of the same value as non-inclusive research. In our research project, the inclusive approach led to a higher value—something that can be deduced, for example, from the very high

number of articles that were eventually published within this PhD. In addition, the slow pace at which the research advanced also ensured that all research steps were prepared and experienced more intensively by both researchers (see, for example, the way Mark describes how research questions and interview questions were meticulously coordinated (see 'Interviewing')).

In this final section, we compare our research findings with some other sources on inclusive research. Several authors, including Nind (2011), Dorozenko et al. (2016), and Tilley et al. (2021), call for continued attention to and a critical reflection on power processes in inclusive research. In our project, Miriam was determined (after a previous rather unsuccessful collaboration with another co-researcher) not to take on a 'carer role' vis-à-vis her new colleague. Mark had to be a genuine colleague. Hiring a job coach for Mark clearly made a difference in this regard, as already discussed in the second paragraph of this discussion. At the same time, the findings also show that when a co-researcher has significantly less time available for the research project than the academic researcher, this has the potential to contribute to an imbalance in power. Besides this search for collegial roles, it is also noteworthy that Mark was able to learn a great deal during the various sub-studies regarding conducting interviews and analysing data. This contributed to feeling more self-confident about his research skills. Whereas in some projects, co-researchers are only or primarily involved in data collection, in this research project, the co-researcher was involved in all phases of research, as well as data analysis. Mark joined the project at a point when the data of a sub-study needed to be analysed. From the outset, he clearly contributed an experience-based perspective, but this came into a sharper focus when he was able to try out a number of methods (e.g., highlighting parts of the texts he was given). Still further, he was able to collaborate with several people from the research team for analysis (at these moments, the 1-on-1 with Miriam was opened up) and contributed his own analysis methods (a visual grouping method). It is clear that advancing insight, time, and growing research competencies all contributed to an increasingly equal power balance between the researchers. This brings us to the three approaches to inclusive research as outlined by Bigby et al. (2014a) and presented in our introduction. We believe we can say that, despite all the barriers, this research can for the most part be situated in the collaborative group approach (i.e., people with intellectual disabilities work in an equal partnership with academic researchers) (Bigby et al., 2014b). Mark was given the space to realise his dream of having a job that would allow him to influence the quality of life of people with a disability. He took full advantage of the opportunity to bring the perspective of the experienced expert into the research project and to influence the progress of the research. In our

opinion, there were significant attempts in this research project to take seriously the (power) balance between researchers with and without disabilities.

As a final topic of the discussion of our findings, we return to Walmsley et al.'s (2018) view of inclusive research. In studying the 'second generation' of inclusive research projects, they advocated for a special consideration for the difference that can be made by co-researchers with disabilities and for the possible impact they (also) have on the quality of life of people with disabilities. In our research project, Mark joined the team with the clear intention of making a difference for people with disabilities. We believe that, partly due to the way in which he took responsibility within the project, the DigiContact support service (being the object of the research project) was put in the picture both from the perspective of experience experts and as a realistic support option. Regarding the latter, it was shown that although DigiContact is not a miracle cure that can replace all onsite support and works equally well for everyone, it does offer people an additional support alternative that can contribute to their possibilities to participate healthily in society.

When looking back at our reflection process, we feel it would have been valuable to include more people who were also involved in or had an impact on our collaboration. For us, it was an important insight that 'others' played an important role in our collaboration. This was especially the case for the job coach who supported the co-researcher regarding various work-related issues and the organization that commissioned the research project and created the conditions under which our collaboration was shaped. For this reason, it would have been interesting to involve these parties and also include their experiences and points of view. For future reflections on inclusive research processes and experiences, it is advisable to think (in advance) about which actors play a role in (or have an impact on) the collaboration and to include their voice in reflection processes as well.

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CHAPTER 9

General Discussion

Support is essential for enabling people with intellectual disabilities to pursue a good quality of life within their communities. In contemporary policies and practices, the emphasis is on providing personalised and community-based supports that aim to promote people's social inclusion, self-determination and self-direction. While service organizations look for ways to best put this into practice, they are confronted with several societal and political challenges that press them to use resources (monetary and staffing) responsibly. This encourages service organizations to look for new ways to organize and deliver their support, and many of them opt for the possibilities of technology. It was this interest that led the Dutch organization Philadelphia Care Foundation to develop the remote support service DigiContact and implement it as part of its broader service portfolio for people with intellectual disabilities who live in their own homes in society.

The aim of this thesis was to gather knowledge regarding the added value of including DigiContact in a broader range of services for people with intellectual disabilities who live independently in society. Five inclusive studies were conducted which focused mainly on the experiences of support users (people with intellectual disabilities), their case workers and DigiContact support workers.

This final chapter consists of four sections. In the first section an overview is provided of the main findings, using both the research questions as defined in the general introduction, as well as the researchers' experiences with adopting an inclusive approach to research. The second section contains a reflection on and discussion of the potential added value of DigiContact. In the third section the methodological considerations of this thesis are addressed. In the fourth and final section of this chapter the implications for policy, practice and research are discussed.

OVERVIEW OF MAIN FINDINGS

What does DigiContact support entail?

Two chapters shed light on the support that is provided by the DigiContact service. In *chapter 2* the support needs that are addressed during the support contacts were explored. The findings show that the support focused on a broad variety of issues, ranging from being related to the mental and/or physical health of support users to practical concerns and contacts with other people. The service was most frequently used to have someone to see and chat with, and to talk about events or things that cause worries and stress with the aim of getting rid of these feelings. This indicates that the service plays an especially important role in addressing a need for social connection and in releasing stress and frustrations to prevent a further accumulation of stress. The type of issues for which the service was contacted were more of less the same irrespective of time of day and time of week. This indicates that round-the-clock access to professional support responds to an existing need.

In *chapter 3* we explored what DigiContact support workers do during their contacts with support users to assist them, and how they do this. The findings show that their support focuses on strengthening coping and problem solving capabilities and on giving support users control over the way they confront difficulties. In doing so, they partner up with support users and adopt a coaching support style in which they provide a listening ear, encouragement and guidance for taking on an active role towards struggles and problems. To enable and facilitate the support process, the support workers collaborate closely with onsite support staff in order to create a safe and welcoming digital environment. This was experienced to be hampered by the absence of fixed contacts between support users and -workers (i.e. every time a support user calls in (s)he is supported by the support worker who happens to pick up the call: this can be a different support worker each time), due to which extra attention and efforts on behalf of the support workers was felt to be needed.

What is the role of DigiContact support within the context of a broader offer of available supports?

Chapter 4 describes a study in which the support situations of nine support users were mapped to explore how the use of DigiContact support relates to the use of other available supports and services. The findings demonstrate that support from DigiContact was used as an addition to regular onsite support at home and facilitated a tailor-made delivery of professional support in three ways. First, the continuous and unlimited availability of DigiContact enabled the support users to seek support whenever and wherever a need or question arises. Second, the service offered them

an extra support option that is (sometimes) preferred over regular onsite support at home. Third, DigiContact support can move with and adapt to fluctuations in support needs more easily compared to regular onsite support services. Compared to onsite support at home, DigiContact support was used for a relatively small selection of support needs. While onsite support at home focused on the complete range of support needs, DigiContact mostly functioned as an extra social contact and a readily available outlet for stress and frustrations which helped people to balance and control their emotional state of mind.

The finding that DigiContact support can move with and adapt to fluctuations in the need for professional support quickly, was illustrated by the findings in *chapter 5*. These findings show that the use of DigiContact support increased significantly during the first weeks of the COVID-19 pandemic, as support users had more (unplanned) contacts than before and more people were connected to (and started to use) the service. These findings indicate that the DigiContact service enabled a high level of flexibility and responsiveness towards shifts in the levels of demand for professional support that were possibly due to (a combination of) a temporary increase in the intensity of support needs (e.g., due to increased anxiety) and a decline in the availability of onsite support.

Wat are the experiences of support users and professionals with Digi-Contact support?

Two chapters zoom in on the experiences of support users and support workers. *Chapter 6* provides an in-depth account of the experiences of five support users with what it is like to be supported by the DigiContact service. This chapter shows that although there were shared experiences amongst the support users, their experiences varied substantially (both between and within support users). The experiences were presented using three themes. First, all support users saw the service as a means to shape their use of professional support towards a better alignment with their personal needs and preferences, since they could time their remote support contacts based on when, where and how often they felt they needed support. However, the support users differed as to whether they felt it had been a free choice to be connected to the DigiContact service, since not all of them had had suitable and adequate alternatives to choose from. Second, taking decisions regarding if, when and where support is needed was experienced to lead to an increased awareness of one's own active role in addressing issues and difficulties, and this was felt to facilitate personal growth in developing problem-solving skills and self-confidence. This was reinforced by the remote delivery of the support, as this was experienced to stimulate the service's support staff to adopt a non-directive (hands-on-back) coaching style.

However, not every support user was found to be able to benefit from this to the same extent, since deciding if, when and where support is needed was for some quite stressful and difficult. Third, having contacts with different support workers (and not being able to choose whom one gets to speak to) made the support contacts feel relatively impersonal. While some support users were not (so much) bothered by this, others felt not sufficiently safe to open up and discuss certain issues. Altogether, the findings of this chapter indicate that DigiContact support can have both benefits and drawbacks, and that its suitability depends also on the personal needs, preferences, capabilities and situations of individual support users.

Chapter 7 sheds light on the perspective of support workers: what it is like to work at the DigiContact service. Three characteristics in the way the support is organized and delivered were found to play a central role in the support workers' experiences: providing support remotely, not having contacts with a fixed subgroup of support users, and the possibility for support users to call in as needs arise (without an appointment). Providing support remotely (through video calls or audio only phone calls) was experienced as bringing both opportunities and limitations to the practice of supporting people. Opportunities consisted of the facilitation of a solution-oriented coaching support style (since not being in the same room as the support users prevented support workers from taking over tasks and enabled them to guide support users towards using their own skills, knowledge and talents to solve issues) and a focus on the issues for which support is sought. Limitations consisted of being restricted in one's range of action as well as in their opportunities to gather information. With regard to the latter, this was felt to be especially complex during contacts without video component, as not seeing the facial expressions nor the body language of support users made it difficult to understand them well. Not having contacts with a fixed subgroup of support users implied that the support workers provide support as one team to a large and diverse group of people. This was felt to complicate the task of adopting a personalized approach in their support contacts and made it important to invest efforts into collaborating closely with colleagues (e.g. coordinating support plans and actions). On the other hand, it also meant that the responsibility of this task was shared amongst colleagues and someone was always available to fall back upon. The fact that support users can contact the service at any time was seen as making their work relatively unpredictable and contributed to fluctuations in the pace of incoming calls. Not knowing in advance who will call in and about what (and not being able to prepare oneself) was felt to be both challenging and exciting. The findings of this chapter suggest that working as a DigiContact support worker requires specific skills, knowledge and affinities, as well as appropriate organizational support and facilitation.

Adopting an inclusive approach to research

Chapter 8 contains a reflection of the involved researchers (the PhD candidate and a researcher with intellectual disabilities) on their experiences with collaborating and conducting research together. The findings shed light on how an inclusive approach to research can be organized and on the benefits conducting research together can have. Regarding the organization of an inclusive research approach, the findings underline the importance of recruiting researchers who are suitable partners in inclusive research (in terms of motivation, abilities and readiness). In addition, facilitation of their collaboration by the employer organization was seen to be of essential importance. This facilitation consisted amongst others of taking care of administrational hurdles, allowing for a slow pace in research and providing support in the form of a job coach. Regarding the benefits of conducting research together, a distinction can be made between benefits for the researchers and benefits for (the quality of) the research project. For the researchers, conducting research together was experienced to add to the opportunities to exert influence and to acquire new skills and insights. For the research project, the collaboration was experienced to have resulted in the use of other (new) methods of research and a more intensive preparation and execution of all research steps.

THE ADDED VALUE OF DIGICONTACT

Including DigiContact in a broader range of services can add value

Many people with intellectual disabilities who live in their own homes in society need support from specialized services to participate in local community activities, to build and maintain relationships with other people, and to have control over how they live their lives. In these services, support is usually provided by one or a few support professionals with whom the person meets onsite and according to a regulated schedule in terms of timing, frequency and duration (Stancliffe & Lakin, 2007). This changes when the DigiContact service is included in a broader offer of available services. With DigiContact, specialist support becomes continuously available and on demand deployable. This gives people with intellectual disabilities the possibility to take place in 'the driver's seat' regarding their own use of support and to deploy support whenever, wherever and as often as they feel this is needed or wanted.

The findings of this thesis indicate that including DigiContact in a broader offer of services can be of substantial added value for independently living people with intellectual disabilities in several ways. At the same time the findings also indicate that the service cannot be seen as a 'panacea' that is equally suitable for every person

and every situation. The potential added value of DigiContact is discussed below using eight themes (Table 9.1 provides an overview). The first three themes relate to how DigiContact contributes to more opportunities for providing people with professional and specialized support that is closely aligned with personal needs and preferences. The next three themes relate to how DigiContact support provides a unique entry point for improving people's functioning and well-being. The last two themes bring nuance to the picture of the potential added value of DigiContact by discussing that there are also limitations to what this service can do for its users.

Table 9.1: Overview of themes describing the potential added value of DigiContact

Themes
Contributing to the opportunities for providing tailor-made professional supports
1. DigiContact broadens the available support options
2. DigiContact enables the provision of sufficient support
3. DigiContact enables more continuity in the availability of support
Providing a unique entry point for improving functioning and well-being
4. DigiContact enhances opportunities for choice and decision-making
5. DigiContact can prevent (larger) problems and an accumulation of stress
6. DigiContact can promote the learning and strengthening of adaptive skills
Nuancing the potential added value
7. DigiContact as a valuable addition to onsite support
8. DigiContact as not being equally suitable for all

Contributing to the opportunities for providing tailor-made professional supports

1. DigiContact broadens the available support options

The findings show that including DigiContact in a broader offer of services results in a more diverse range of support options for people with intellectual disabilities living independently. That is, while these people are generally supported onsite by one or a few professional(s) in the home situation and according to a predetermined and restricted time schedule (Stancliffe & Lakin, 2007), DigiContact offers support that is round-the-clock available, on demand deployable (by people with intellectual disabilities themselves), and provided by multiple and varying support workers. A more diverse range of support options increases the possibilities of offering the type of support that is well aligned with the specific needs and preferences of individuals. This was found to be reflected in two different 'levels' of the support provision process: the planning of services and the day-to-day use of professional support (*chapters 4 and 6*).

As to the planning of services, including DigiContact in the range of available services increases the likelihood that a package of supports can be compiled that matches the specific needs and preferences of individuals. For most support users who participated in the studies performed, this package consisted of a combination between remote and onsite support, with onsite support at home being used as the primary service (i.e. their main source of professional support) and DigiContact as an addition (see theme 7). However, there were also support users who saw and used the service as an equal partner to onsite support (e.g. Carol, *chapter 6*) or even as their preferred service (Chris, *chapter 6*). These seemed to be individuals for whom it is important to be able to decide for themselves when and where support is needed and wanted. For one of them (Chris), the preference for DigiContact also appeared to stem from that this support offers more room for autonomy (see theme 4), since the support workers do not physically enter his home and focus on what he wants assistance with (instead of on what they think is important). This suggests that DigiContact can be an attractive support option for persons who lack motivation for being supported by regular (onsite) services and therefore run the risk of being cut off from professional support.

As to the day-to-day use of support, people with access to both DigiContact support and onsite support can decide which of the two services suits a particular situation or problem best. DigiContact can be preferred in certain situations, even by people for whom onsite support is their overall preferred option. This seems to be especially the case when a question or problem is experienced as of such urgence that delaying contact with a professional (if one has to wait until an onsite support worker is available) is not without risk (see also theme 5). Another motive for preferring DigiContact support was that talking about certain issues can sometimes be easier with a person one does not know well.

The finding that DigiContact contributes to a more diverse range of support options for people with intellectual disabilities living independently, is promising. Many DigiContact support users either have a diagnosis of, or are expected to have, mild intellectual disabilities. People with mild intellectual disabilities form a heterogeneous group of people in terms of both personal and environmental characteristics, which results in a broad variety of support needs (Moonen, 2017; Nouwens, Lucas et al., 2017; Snell et al., 2009; Soenen et al., 2009). Sufficiently differentiated support options are needed in order to cater to such diverse support needs. However, there are indications that, at least in the Netherlands, there is still insufficient differentiation in care and support services for people with mild intellectual disabilities (Nouwens, Smulders et al., 2017; Soenen et al., 2015). Including DigiContact in the range of

available support options can therefore be seen as a valuable step towards a more differentiated approach to the support of people with (mild) intellectual disabilities living independently. Within this approach it is taken into account that many of these people need (and will continue to need) professional support, as their natural support network can be small or limited in its capacity to provide support (Harrison et al., 2021; Lippold & Burns, 2009; Van Asselt-Goverts et al., 2013).

2. DigiContact enables the provision of sufficient support

It is a common misconception that people with mild intellectual disabilities have merely a mild need for support. Some of them need considerable support to enhance their opportunities for participation in society (Snell et al., 2009). The support a person needs is not a direct derivative of their level of intellectual functioning alone, but is also determined by other personal factors (such as their adaptive skills and health) and the environments in which they function (Thompson et al., 2009; Verdugo et al., 2020). With regard to the latter, the demands from contemporary society on people's functioning seem to have increased due to the growing expectation that they are to participate as full citizens in all domains of society, while various developments (like the disappearance of relatively simple jobs and the increase in digitization of activities) may actually make it more difficult to participate (Snell et al., 2009; Woittiez et al., 2018). As a result, there may not only be more people who struggle without support, but the support that is needed may also become more intense. This highlights the importance of having access to sufficient support for people with mild intellectual disabilities.

Having access to sufficient support is unfortunately by no means always realized. In the Netherlands, the reforms in the national long-term care system seem to have made this more difficult for people with disabilities who live in their own homes in society. These reforms reinforced a shift from specialized care (from professionals) to care provided by natural support networks and general facilities (Maarse & Jeurissen, 2016; Van Ginneken & Kroneman, 2015), without considering that the natural support networks of many people with (mild) intellectual disabilities can be relatively small and/or have a limited capacity to provide support (e.g., Harrison et al., 2021; Lippold & Burns, 2009; Van Asselt-Goverts et al., 2013, 2015). Also, general services do not always have the expertise (e.g. knowledge, communication skills) to offer good care and support to people with intellectual disabilities (Ali et al., 2013; Mastebroek et al., 2014, 2016).

The findings of *chapters 4 and 6* suggest that DigiContact can contribute to realise access to sufficient support for independently living people with intellectual

disabilities. As DigiContact is available round-the-clock and people can call at any time (without needing an appointment), they have ongoing access to specialized support. By contacting the service when and where a need for support arises, they are able to supplement the support they need up to an adequate level. A number of the participating support users specifically mentioned that the introduction of the Social Support Act in 2015 had led to a reduction in the number of available onsite support hours (*chapter 6*). This had created a gap between their need for support and the intensity and frequency of the available support, and they felt that they could (at least partially) bridge this gap by contacting the DigiContact service for support whenever necessary. This is valuable in light of several studies that show that austerity measures reducing the availability of professional support (e.g. stricter eligibility criteria for services, a reduction in the number of available care hours) can have a negative impact on the lives of people with intellectual disabilities, in the form of less participation in meaningful activities, a lower self-esteem, more dependence (sometimes unwanted) on family members, a higher risk of social exclusion and reduced well-being, and ultimately possibly also an increase in the use of more intensive (and more expensive) forms of care as difficulties and problems are more likely to accumulate (e.g., Forrester-Jones et al., 2021; Grootegoed & Tonkens, 2017; Hamilton et al., 2017; Malli et al., 2018). Including DigiContact within a broader set of professional services may help to mitigate or prevent such negative effects.

In addition, the findings of *chapters 4 and 5* show that the intensity of DigiContact support is relatively flexible and agile, as people can quite easily and quickly start to contact the service more or less often. Although there are limits to increasing the intensity of the support (as the intensity of the contacts over a longer period of time needs to fit within the agreements made and allowances allocated), much is possible as long as the fluctuations cancel each other out in the longer term. The indication that the intensity of DigiContact support is relatively flexible and agile is valuable since the need for professional support is not a static given (Thompson et al., 2014; Verdugo et al., 2020). For example, support needs may shift due to changes in people's life goals, aspirations, and health. In addition, life events may happen that cause people to go through difficult times, and the environments in which people function may change (e.g. a new job, moving out on their own). Moreover, even when a person's support needs stay the same, their need for professional support may still shift when the availability of natural support changes (like when a parent is no longer able to provide as much support as before). It is important that a system of supports is sufficiently flexible to move with such changes and it is promising that the findings of this thesis indicate that the DigiContact service can contribute to this. It is the researchers' personal observation that support services are offered all too

often as an 'all or nothing' option in which the choice lies predominantly in whether or not to include a service in the system of supports around a person. When the offer of services does not suit a person, (s)he is often referred to a different sector (e.g. mental health care). It is promising that the delivery of DigiContact support is based on a very flexible approach, as it has the potential to contribute to a varied delivery of professional supports.

3. DigiContact enables more continuity in the availability of support

This thesis also indicates that including DigiContact in a broader package of services can contribute to greater continuity in the delivery of professional support for independently living people with intellectual disabilities. There are situations in which onsite services are not (or less) available, while DigiContact can continue as usual or, in some cases, even compensate for a decline in the availability of onsite support. A good example of such a situation can be found during the first few months of the COVID-19 virus outbreak (spring 2020), when sharply rising COVID-19 infection rates motivated the Dutch government to institute a period of lockdown and install various social distancing measures. These measures had a restrictive impact on the provision of non-residential care and support services, as many sheltered workplaces, day care centers, and community centers temporarily closed their doors and (in-home) care and support services for independent living people were put on hold as much as possible (De Vries et al., 2021; Kruse et al., 2020; The Netherlands Institute for Social Research, 2020). The findings described in *chapter 5* suggest that DigiContact was able to play a valuable role during this period as its support could be continued and the capacity for support contacts could be temporarily increased. This not only allowed more people to make use of remote support, but also made it possible for people to call in for support more often. The potential value of this is underlined by various studies that indicate that this period was experienced as significantly disruptive by (some) people with intellectual disabilities (De Vries et al., 2021; Doody & Keenan, 2021; Embregts et al., 2020; Parchomiuk, 2022).

There are more situations in which it is not possible to continue the delivery of onsite support. Think for example of periods in which onsite support workers are sick or on vacation, and it is not possible or desirable to replace them with colleagues. In fact, a lack of continuity in services is quite common and is largely due to high turnover rates (Bogenschutz et al., 2014; Friedman, 2018). Friedman (2021) shows that continuity and security, amongst others in the provision of services, significantly increased the perceived quality of life of people with intellectual disabilities. *Chapter 4* shows that DigiContact is sometimes seen as a way to continue (some degree of) support during periods when onsite support is temporarily not or less available. This is especially

interesting considering the growing shortages of care workers (ABF research, 2022; Liu et al., 2017), as this will make it increasingly difficult to fill gaps in the support staff planning. A service like DigiContact may be able to play a modest but potentially valuable role in this, as it enables the provision of (at least some) support to a large group of support users with a relatively small group of support workers. At the same time, it is also important to nuance this by emphasizing that DigiContact support cannot (for everyone) be considered a suitable full replacement for all onsite support (see theme 7).

Providing a unique entry point for improving functioning and well-being

4. DigiContact enhances opportunities for choice and decision-making

In recent decades, intellectual disability services have become more focused on increasing the possibilities and opportunities that people have for shaping their lives according to their own wishes and preferences. The construct of self-determination is often used to indicate the extent in which people act as the primary causal agent in their lives and make choices and decisions free from undue external influence or interference (Wehmeyer, 2001; Wehmeyer et al., 2020). The importance of promoting the self-determination of people with intellectual disabilities is underlined by studies in which an association between an enhanced self-determination and a better quality of life was found (e.g., Lachapelle et al., 2005; Nota et al., 2007).

For many people with intellectual disabilities, making one's own choices and decisions is unfortunately not yet a given. Traditionally, people with intellectual disabilities were often regarded as being incapable of making responsible decisions (Stiker, 2019). Although this view has largely changed, it still happens regularly that other people, either consciously or unconsciously, make decisions for them or place pressure on them regarding certain decisions (e.g. Callus et al., 2019; Curryer et al., 2018). Personalized community-based services such as small-scale group homes and independent living situations have been found to offer more opportunities for self-determination than larger congregate settings (Kozma et al., 2009; McConkey et al., 2016). Nevertheless, also independently living people with intellectual disabilities can experience restrictions in their choice and decision-making opportunities (Bigby et al., 2016; Bond & Hurst, 2010; Morris, 2004; Pallisera et al., 2020). A care-based view of support with an emphasis on protecting people with intellectual disabilities by containing risks and taking care of them still seems to prevail, also within services aimed at independent living (Pallisera et al., 2018; Petner-Array & Copeland, 2014). Some support workers still have a (sometimes subtle) belief that people with intellectual disabilities do not have the capacity for full autonomy and that it is therefore legitimate to play a somewhat dominant role in making decisions regarding

their lives (Morris, 2004; Pallisera et al., 2020). Fullana et al. (2019) found that such beliefs can also be internalized by people with intellectual disabilities themselves. An important point to stress is that, in order to have control over one's decision-making, a person does not need to make decisions alone without the help or involvement of others. On the contrary, for many people (with and without disabilities) control can actually be enhanced thanks to the help or assistance of other people (e.g. Williams & Porter, 2015).

The findings of this thesis indicate that the support provided by DigiContact encourages and assists people to make their own choices and decisions. In the discussion on how DigiContact support does this, it is useful to follow Bigby et al. (2016) and make a distinction between choices regarding (the use of) supports and services, and choices regarding everyday issues. With respect to the first, the findings described in *chapters 2, 4 and 6* show that DigiContact enables people to make their own decisions regarding if, when, how often, and where support from a professional is needed and/or wanted. This was generally highly appreciated by most support users who participated in our studies, because it contributes not only to an experience of control (and a sense of ownership) over one's support, but also to an increased awareness of one's own role in tackling problems (*chapter 6*). However, it should be noted that some support users felt they had had a limited say in the decision to get connected to the service in the first place, because there had not always been suitable and adequate alternatives to choose from, and/or because they were influenced (sometimes pressed) by their case workers and family to get connected to DigiContact (*chapters 4 and 6)*.

With respect to choices regarding everyday issues, the findings of *chapters 3, 6 and 7* show that DigiContact support offers substantial room for making decisions regarding how they confront daily hassles, and that it stimulates people to do so. To start with, support users can decide for themselves about which questions and problems they want to contact a professional. The support workers respond to this by focusing in their contacts with support users as much as possible on these issues (*chapter 3*). Also, their support activities are directed towards coaching support users to adopt an active role regarding their own questions and problems by focussing on their personal strengths, capabilities, and skills. They take over as little as possible, and ask questions to make support users think about possible solutions or strategies for a certain issue. This support style was facilitated by the fact that people are supported from a distance, as this makes it impossible for support workers to take over tasks or do things together with support users (*chapters 6 and 7*). Some support users felt that, by assisting them with solving problems themselves, DigiContact

support contributed to more autonomy, independence, and confidence in one's own competence regarding being able to deal with potential difficulties (*chapter 6*).

It is interesting to reflect on these findings in light of the Casual Agency Theory that explains how people become (more) self-determined (Shogren et al., 2017; Wehmeyer et al., 2020). According to this theory, people need to develop volatile and agentic actions as well as action-control beliefs in order to become self-determined. Volatile action is self-initiated and based on conscious choices that reflect a person's own preferences. Agentic action is directed towards a freely chosen goal. Action-control beliefs consist of the conviction that one has what it takes to achieve a goal. These characteristics reinforce each other: by applying volatile and agentic actions, people develop a sense of personal empowerment by becoming more confident about being able to reach their goals. To increase the causal agency (and self-determination) of a person, it is important to strengthen volatile and agentic actions and action-control beliefs. DigiContact support seems to offer unique opportunities to support both volatile and agentic action and the development of action-control beliefs. First, people with intellectual disabilities are facilitated and stimulated to contact the service when an issue arises which they feel they need support on (link with volatile action). Second, people are stimulated to think about what they want to achieve and how this can be realized (link with agentic action). Third, the support could contribute to more self-confidence in one's own abilities to cope with difficulties (link with action-control beliefs). This suggests that with and by means of DigiContact support, people can become more self-determined.

5. DigiContact can prevent (larger) problems and an accumulation of stress

Besides providing a unique entry point for contributing to the development of people's self-determination, the findings also indicate that support from DigiContact can have a preventative impact on both functioning and well-being of the people who use it. When the service is contacted shortly after a person has been confronted with a question or difficult situation, it becomes possible to identify problems early on and to intervene by looking together for solutions or ways to cope (*chapters 2, 3, 4 and 6*). This can prevent problems from arising or from developing into larger or more serious problems (and in some cases possibly even into crisis situations). When it is not possible for DigiContact support workers to assist with certain issues themselves, for example because they are not physically present in the same room, they can inform a case worker or contact person from the support user's network in time (*chapter 3*). In case of a crisis situation, the support workers can quickly inform and mobilize parties such as emergency services. Merely realizing that due to

DigiContact a professional is always, and from anywhere, available can give people a safe and reassured feeling (*chapters 4 and 6*).

The findings specifically show that contacting the service to talk to a professional when difficult and stressful situations arise, can have a beneficial impact on the emotional well-being and mental health of its users, because stress and frustrations can be ventilated more often and at times when this is most needed (*chapters 2, 4 and 6*). In this respect it is not always necessary to look for solutions, as it was often felt to be sufficient to offer a listening ear. By being able to express stress and frustrations early on and more often, a further build-up of can be prevented. Some support users experienced this could even, in some situations, prevent negative consequences such as emotional outbursts of anger, depressive feelings and alcohol abuse (see *chapters 2 and 4* for examples).

These findings correspond with research indicating that social support has a protective moderating role in the relationship between stress and (the development of) mental health problems or behaviors labeled as problematic or challenging (e.g. Lunsky & Benson, 2001; Saltzman et al., 2020; Scott & Haverkamp, 2014). The role of social support in mitigating the impact of stress is perhaps especially important for people with intellectual disabilities, as there are indications that they experience (severe) stress more often than people without disabilities (Hartley & MacLean, 2009; Hatton & Emerson, 2004; Schuengel & Janssen, 2006). This might be due to people with intellectual disabilities being more likely to encounter adverse and stressful experiences like abuse, neglect, poverty, discrimination and social exclusion throughout their lives (e.g. Mason-Roberts et al., 2018; Santoro et al., 2018; Vervoort-Schel et al., 2021). Besides causing a great deal of stress on their own, such experiences can lead to a chronic overactivity of biological stress systems which increases the overall susceptibility to stress (Repetti et al., 2007; Wijnroks, 2013). In addition, there are also indications that people with intellectual disabilities are more likely to encounter so-called daily life stressors in the form of situations that are experienced to exceed one's ability to cope (e.g., in the areas of social interactions, unexpected events, and having little control over decisions; Dulin et al., 2013). The finding that DigiContact service is often used as a source of social support in stressful times and difficult situations is therefore promising. This is further underlined by studies which show that people with (mild) intellectual disabilities have relatively small social networks and that professionals make up a significant share of these networks (Lippold & Burns, 2009; Mithen et al., 2015; Van Asselt-Goverts et al., 2015). This suggests that for many people with intellectual disabilities DigiContact can be a valuable source of social support.

A related aspect is that people with (mild) intellectual disabilities relatively often experience feelings of loneliness (Bigby et al., 2016; Gilmore & Cuskelly, 2014; Petroutsou et al., 2018). Loneliness seems to be a vulnerability factor for mental health problems like depressive symptoms (Heiman, 2001; O'Hara et al., 2010). It is therefore encouraging that the findings show that DigiContact is also quite frequently contacted to connect with someone and talk about small things and everyday life (*chapters 2 and 4*). This suggests that DigiContact may contribute to the prevention of the start or worsening of feelings of loneliness.

6. DigiContact can promote the learning and strengthening of adaptive skills

Limitations in adaptive behaviour play an important role in the opportunities that many people with mild intellectual disabilities have regarding their participation in society (Moonen, 2017, 2020). Adaptive behaviour consists of the collection of conceptual, social and practical skills that have been learned and are performed by people in their everyday lives (Schalock et al., 2021; Tassé et al., 2012). Which adaptive skills a person needs, depends on the demands of the environments and activities in which that person takes part or wishes to take part in. To increase people's opportunities for participation, it can therefore be a worthwhile strategy to invest in the learning or strengthening of adaptive skills. This can be done through training programs that are aimed at the acquisition of specific skills (e.g., O'Handley et al., 2016; Ramdoss et al., 2012; Sandjojo et al., 2020), but can also be realised within support for day-to-day living.

The findings of *chapters 2, 3 and 4* suggest that the DigiContact service offers a unique opportunity to stimulate the acquisition of adaptive skills. Since its support can always be deployed, people can learn new skills and strengthen existing skills by practicing them in real life situations and at a moment that a certain skill is most relevant. This is encouraging, as many people (regardless of whether they have an intellectual disability or not) benefit from learning in concrete situations in which new skills are directly related to, and can be applied in, their daily lives (Kolb, 2015; Woolf et al., 2010). The issues on which DigiContact support focuses (*chapters 2 and 4*) correspond to the different types of adaptive skills: conceptual (e.g. support on reading and understanding a letter, planning one's week activities), social (e.g. help with understanding how an argument with another person arose and how this can be resolved), and practical (e.g. assistance with the use of public transportation and searching information on the Internet). It seems relevant to add that the demands placed on people's adaptive skills may have risen over time, as societies have become more complex in some respects (Egard & Hansson, 2021; Woittiez et al., 2018). For example, most communication with governments nowadays takes place online, and

many jobs are becoming more complex as simpler tasks are increasingly taken over by technology.

The term experiential learning is often used to refer to the process of learning through concrete experiences (e.g., Kolb, 2015; Morris, 2019). David Kolb (1984) developed a widely known model of the experiential learning cycle, in which experiential learning is depicted as a four-stage cycle which begins with a concrete experience and is subsequently followed by reflective observation (observing and reflecting on the experience), abstract conceptualization (creating ideas and theories around the experience), and active experimentation (using these ideas to make decisions and take action). The knowledge that has been collected regarding the support practice of DigiContact support workers (*chapter 3)* indicates that their support caters to each of these four stages. That is, the support workers try to stimulate and support people in thinking about their situation and/or problem (reflective observation) in order to better understand what is going on and what a possible approach could be (abstract conceptualization), as well as to transform their ideas into a concrete plan of action (active experimentation). With regard to the first stage of Kolb's model (concrete experience), DigiContact may also give an impulse, as knowing that the service is always and from anywhere available was found to give (some) people a secure feeling (*chapters 4 and 6*) and could build up confidence in one's own abilities (*chapter 6*). As a result, people may be more open to seek out and engage in new and challenging experiences, thereby creating more opportunities for learning.

The suggestion that DigiContact can facilitate the learning of adaptive skills through facilitating experiential learning suggests that its support can contribute to closing the gap between the personal competencies of people with mild intellectual disabilities and the demands of the environments and activities in which they (want to) participate. By doing so, DigiContact may be able to improve not only the functioning of its users, but also their experience of valued personal outcomes such as an increased independence and more opportunities to engage in community activities that enrich their lives. This is supported by studies showing that higher levels of adaptive skills are associated with a better quality of life (Balboni et al., 2020; Simões et al., 2016).

Nuancing the potential added value

7. DigiContact as a valuable addition to onsite support

The findings of this thesis indicate that DigiContact support is generally seen and used as a valuable addition to onsite support. A large majority of the participating support users combined the service's remote support with onsite support (*chapters*

2, 3, 4 and 6). Only a few support users (Chris and Dave from *chapter 6*) used DigiContact as a stand-alone support service. The finding that remote support was generally seen as an addition to onsite support can up to a certain extent be explained by the fact that DigiContact support was experienced to have a number of potential limitations: a) the absence of a personal and trusted relationship with the support workers, b) the distance makes it impossible to provide assistance with matters that require physical assistance, and c) a proactive role regarding the own use of support is needed to be able to benefit from the possibility to call in when a need arises (see also theme 8). Another aspect that seems to play a role is that most participating support users had been using intellectual disability services for a long time before they started with DigiContact. They may therefore have become accustomed to the way onsite services are delivered (i.e. through onsite support at home on a regulated and scheduled time interval; Stancliffe & Lakin, 2007). This is supported by the finding that the support users in *chapter 6* used their experiences with onsite services as a benchmark against which they evaluated their experiences with DigiContact. All taken together, this indicates that for many people onsite support is still indispensable and DigiContact support cannot be considered to function as a full substitute for onsite support.

The finding that DigiContact is generally used as an addition to onsite support does not necessarily detract from its potential added value. For most participating support users, it seemed to be precisely the combination between onsite and remote support that created the most value. Both services were experienced as having something different to offer. For example, while onsite services offer the possibility to be supported by a (more or less) steady support worker who is physically present, DigiContact offers support that is continuous and on demand available, which makes it possible to intervene timely when problems arise. By combining both services in a blended care form (Sheehan & Hassiotis, 2017; Timmer, 2015; Wentzel et al., 2016), people are enabled to make decisions regarding which type of support suits their needs and preferences in a given situation best. In this respect, onsite support and DigiContact support can complement each other in such a way that people can benefit from 'the best of both worlds'.

8. DigiContact as not being equally suitable for all

The findings of this thesis show that the DigiContact service is not equally suitable for all people. This is not surprising since there is substantial variation with regard to personal and environmental characteristics, as well as support needs, amongst people with mild intellectual disabilities (Moonen, 2017; Nouwens, Lucas et al., 2017; Snell et al., 2009; Soenen et al., 2009). DigiContact is therefore, presumably like any

other service, not a 'one size fits all' solution. This corresponds to how the service is offered in practice: not as a service that must be used by everyone, but as one of the options from which the best possible package of services and supports can be put together.

The findings also indicate that the suitability of DigiContact depends on the specific preferences, needs and capabilities of individual support users, and on how these relate to DigiContact support characteristics. To begin with, the findings show that there are large differences in how support users feel about being supported by multiple and varying support workers (*chapters 4 and 6*). Some of the participating support users did not like this at all, because it made them feel not sufficiently secure to discuss certain issues, or because they doubted whether the support workers knew them and their situation well enough to support them properly. In addition, not knowing in advance whom they will speak to could be quite stressful. For other support users, talking to different support workers either did not form an issue, or they got used to this after a while. There were also support users whom actually valued talking to different support workers, as they found it easier to talk about certain topics with someone they did not know well, or because it contributed to having more social contacts. Several studies emphasize the importance of having trusting and caring relationships with professionals for people with intellectual disabilities (e.g., Giesbers et al., 2019; Clarkson et al., 2009; Pallisera et al., 2018; Petner-Array & Copeland, 2014). The current findings bring some nuance to this picture by indicating that this may not be equally important for everyone. Moreover, it is important to stress that it is not realistic to assume that within onsite services it is always possible for people with intellectual disabilities to build up a trusting relationship with their support worker, as support staff continuity is often compromised by high turnover rates (Bogenschutz et al., 2014; Friedman, 2018). In addition, there may not always be a good click between a person and his or her support worker(s), and people often cannot choose who supports them (Bigby et al., 2016). Although DigiContact does not offer a solution in this regard, at least with this service it is clear from the start that there will be someone at the end of the line, though not always someone you know (well).

This thesis also shows that a remote provision of support through video calls and regular phone calls was experienced as offering both possibilities (see also themes 1, 3, 4, and 6) and limitations to the practice of supporting people (*chapters 6 and 7*). Especially the limitations make DigiContact support not equally suitable for all kinds of support needs nor for all support users. The fact that the support workers are not physically present in the same room as the support users makes them unable to

engage in hands-on activities and made their support not (or less) suitable for certain questions and problems. It was also difficult for the remote support workers to gather information beyond what support users show and tell, and this was experienced to enlarge the risk of missing information on context that is needed for understanding a support user well. This makes it important that support users are able and willing to communicate openly about difficulties and feelings.

Finally, to be able to benefit from the opportunity to mobilize DigiContact support at unplanned moments, people need to adopt an proactive role regarding their use of support. They should recognize and acknowledge an emerging problem in a timely manner, consider that contacting a professional could help them, and then take subsequent action by contacting the service. *Chapter 6* shows that this is not always easy or feasible for everyone. While some support users picked this up right from the start, others needed time to master this and for still others this remained too difficult or stressful even after some time had passed. As a result, the latter support users continued to have mainly planned contacts with the service, which reduced their possibilities for deciding for themselves if, when, how often and where support is needed.

All taken together, the findings indicate that DigiContact support does not match everyone's needs, preferences and capabilities equally well. There seems to be a better match for people who find it important to have 24/7 access to professional support, who are able to decide for themselves if and when they need support and who have no problems talking to different support workers, than for people who need to (or want to) talk to a support worker whom they know well and whom is present with them in the same room. Other support users have difficulties to identify timely that there is a problem for which contact with a professional would be beneficial. The findings suggest that when there is a better match, support users can be more satisfied with and profit more from DigiContact support (*chapter 6*).

METHODOLOGICAL REFLECTIONS

The value of tapping into experiential knowledge

This thesis shows that it is both meaningful and valuable to give the experiential knowledge of people with intellectual disabilities an important role within the evaluation of new services. In the studies conducted, experiential knowledge of people with intellectual disabilities was strongly embedded in two ways and this has resulted in a detailed and multi-faceted picture of the potential added value of DigiContact. The first way in which experiential knowledge was embedded in the

conduct of research was through making the experiences of support users a main source of information (*chapters 2, 3, 4 and 6*). The second way consisted of integrating experiential knowledge within the implementation of the research project. At the start of the project, the decision was made to adopt an inclusive approach to research (Walmsley et al., 2018) in the form of a collaboration between an academically trained researcher (the PhD candidate) and a researcher with intellectual disabilities. It was expected that this collaboration would allow the experiential knowledge of the researcher with an intellectual disability to enrich both the research process and the understanding of the findings (Frankena et al., 2015; Puyalto et al., 2016; Woelders et al., 2015). Reflecting on our personal experiences with conducting research together (*chapter 8*), it appears that the collaboration did lead to a more intensive preparation of the different research steps, and to more depth in the research process itself (e.g. because the researcher with intellectual disabilities brought in other (visual) methods of processing data). At the same time, the personal experiences emphasized the importance of finding the right people and offering the right support to the researchers involved. As an example, employing a job coach for the researcher with intellectual disabilities proved to be a valuable initiative.

Quality in research

The emergent approach adopted in the research project created flexibility in the initiative to set up certain studies as well as in their design (Creswell & Clark, 2017; Pailthorpe, 2017). By not predetermining how many and which studies would be conducted, they could be designed and arranged in close alignment with (questions from) practice. Most of the research questions that were central to the studies performed were best answered using qualitative methods. Four of the five studies were therefore (largely) qualitative in nature and were carried out according to qualitative research principles. Although procedures differed between studies, several overall strategies were used to improve scientific rigour and enhance quality in research (Frambach et al., 2013).

Several strategies were used to enhance the credibility of the findings. To begin with, two forms of triangulation were used: data source and investigator triangulation (Denzin, 1989; Green & Thorogood, 2014; Mays & Pope, 2000). Data source triangulation consisted of the use of data from different sources (support users, support workers, case workers, documents and administrative data). This helped to make the research more comprehensive and its findings more trustworthy. Investigator triangulation consisted of the members of the research team having different backgrounds (e.g. in research, other work or lived experience) and that the initial coding of raw data was always executed by at least two of the researchers

independently from each other. The findings were always discussed with all members of the research team, which not only ensured that there was room for different ideas and perspectives, but possibly also reduced researcher bias. When there was not sufficient knowledge within the research team with respect to a particular research method, external researchers were brought in to advise or collaborate. This was the case when conducting certain quantitative analyses (*chapters 2 and 5*) and when wanting to adopt an interpretive design (*chapter 6*).

In addition to triangulation, in two studies (*chapters 4 and 6*) the decision was made to conduct two interviews per support user instead of one. The underlying motivation for this decision was that this would not only provide room for more questions, but would also enable the build-up of rapport so that people would be more at ease during the second interview. Finally, within each study, respondent validation was employed in the form of member checking (Lincoln & Guba, 1985; Mays & Pope, 2000; Motulski, 2021). Considerable time and effort was put into providing each participant with an accessible summary and interpretation of their interview(s), and to have personal contact with each of them to discuss the content of this summary and to check for accuracy.

To reduce researcher bias and increase the reliability of the findings, an audit trail was kept in the form of a document in which all the steps and decisions taken were documented. In addition, both executive researchers (the PhD student and the researcher with intellectual disabilities) kept a logbook in which they reflected on their experiences with the research process and their own role within it. The content of the logbooks was regularly discussed between them and was used as data within the study into their experiences of doing research together (*chapter 8*).

With regard to transferability, despite the fact that great efforts were invested into providing as much descriptive details about context and sampling strategies as possible (in order to enable readers to judge whether the findings may or may not be transferable to other, albeit similar contexts), an important limitation of this thesis seems to reside in the transferability of its findings. Three issues are particularly important to point out. First, this thesis focuses on one specific initiative, namely the DigiContact service. The results are not directly applicable to other remote support initiatives or to remote support in general. For example, the results show that specific characteristics of DigiContact support (e.g. its 24/7 availability, and the facts that support users can initiate contact with the service and that there are no fixed contacts between support users and workers) have a large influence on the experiences of both support users and workers (*chapters 6 and 7*). For initiatives in

which remote support is provided in a different way (e.g. when people are supported remotely by their own fixed support worker or during scheduled contacts only), this support is likely to be experienced differently. Second, DigiContact was implemented in a situation in which long-term care reforms had been implemented recently. This played an important role in the experiences of some interviewed support users (*chapter 6*). Despite the fact that in some respects similar reforms are taking place in several countries (Hauben et al., 2012; Ranci & Pavolini, 2015; Spasova et al., 2018), local situations vary. This may result in support from a service like DigiContact being experienced differently. Third, the samples of support users interviewed were in some respects quite specific. For example, the mean age was relatively high, and most had been using onsite intellectual disability services for a long time before they started with DigiContact. It is possible that such characteristics have a direct or indirect influence on the experiences with DigiContact support. It may for example be that younger people are less reluctant to using remote support and have less difficulties with being supported remotely than older people, for example because they use social media more often and therefore have more experience with digital communication (Jenaro et al., 2017; Ramsten et al., 2020). With regard to the use of intellectual disability services, it is possible that people who had been using these services for a long time, had become accustomed to onsite support from one or a few fixed support workers, which makes it more difficult for them to get used to a different way of being supported. As there was little variation on these characteristics within the samples of respondents, we cannot know whether there is a possible association with the experiences with DigiContact support. Overall, these three issues can limit the transferability of our findings, which underlines the importance of caution in applying the findings and our interpretations to other situations and groups of people.

IMPLICATIONS

Policy and practice

The findings of this thesis show that the DigiContact service forms a meaningful and worthy part of a support strategy for people with intellectual disabilities who live in their own homes in society. The principles behind the supports paradigm (Buntinx & Schalock, 2010; Schalock et al., 2021; Thompson et al., 2009) are clearly reflected in this strategy, as DigiContact was found to contribute to more possibilities for offering professional supports with a good fit with the personal needs, preferences, ambitions and goals of individuals (e.g. by creating more variation in the available support options and enabling a quick adjustment in support) and for improving functioning and personal well-being. Giving people control over their contacts with

the service not only acknowledges their possibilities and capabilities, but also places them in the driver's seat (Thompson et al., 2014) regarding their use of support.

It has become clear that DigiContact is not simply used as an efficiency measure of which quality is of secondary importance. DigiContact meets the mission and vision of Philadelphia Care Foundation in supporting people's self-determination, development and participation in society. The foundation invests significantly in safeguarding and improving the quality of its support. Examples of such efforts are the commissioning and funding of the research project on which this thesis reports (in which the added value of the service for its users is taken as an indicator of quality), the fact that a lot of attention is given to in-service training of and support for DigiContact support workers, and to facilitating the support process (e.g. by providing a tablet on loan and technical support when problems arise, and by developing software that is easy and pleasant to use).

Based on the findings of this thesis, several implications for both DigiContact related policy and practice can be formulated. These implications are discussed on the basis of four topics: adopting a person-centred approach to the planning and delivery of remote support, aligning remote and onsite support, equipping people with intellectual disabilities to benefit from remote support, and equipping professionals to support people with intellectual disabilities remotely. Since these implications are based on this thesis' findings, they are specifically related to the DigiContact service. Nevertheless, they may well be of interest to other remote support initiatives and service organizations who are planning (or considering) to offer remote support.

Adopting a person-centred approach to the planning and delivery of remote support

This thesis has shown that DigiContact support is not (equally) suitable for everyone, and that it is not suitable for all in the same way (*chapters 3, 4 and 6*). This highlights the importance of adopting a person-centred approach to the planning and delivery of its support, in which each support user is placed at the centre of his or her own care, and services are adapted to their personal needs, wishes and ambitions (Claes et al., 2010; Ratti et al., 2016; Taylor & Taylor, 2013). This is consistent with the personalized supports model that has been dominant within the field of (intellectual) disability service provision for several decades (e.g. Pearson et al., 2014; Thompson et al., 2014; Tschanz, 2018). Also within research on the topic of the adoption of new assistive technologies, the importance of adapting (the deployment of) new technologies to the needs, preferences and expectations of individuals as well as to their environment has been emphasized (e.g. Federici et al., 2014; Leopold et al., 2015).

In terms of planning services, the wishes, needs and goals of individuals with a need for support should be the starting point for all decisions regarding whether and how DigiContact support is deployed. The degree to which this support suits a person's specific preferences, needs and situation should be a key factor in determining whether the service is included in the overall package of services and the role it will have. The better the match, the greater the role the service will be able to take on (and in some cases, even as a stand-alone service). For individuals for whom DigiContact support is less appropriate, it is important that they maintain access to onsite support services. In addition, it is important that the use of DigiContact is not decided on at one point in time without being subject to reconsideration. Instead, it should be reconsidered regularly, as support needs and personal goals can shift over time (Thompson et al., 2014).

It is essential that the person with the need for support is included as an active participant in all planning and decision-making processes. All parties involved, including the person with intellectual disabilities, should have information on what the different available support options are, what these options can offer, and what their possible advantages and disadvantages are. In this respect, the knowledge acquired through the performed studies can be a valuable source of information and it is advisable that the researchers, together with the service provider, look for suitable ways to make this knowledge accessible to all parties concerned.

The delivery of DigiContact support should also be adapted as much as possible to the wishes, needs and capabilities of individuals. In order to achieve this, flexibility and room for choice are required. A relevant example is that there are persons who have a lot of difficulty with the fact that support is provided by different and varying support workers. This may be a reason for deciding not to include DigiContact in their service package. However, this cuts them off from all possibilities of being able to benefit from the various advantages of this type of support. It would be interesting to see if, and how, more room for flexibility can be made in order to meet the wishes and needs of such persons (for example by allowing them to start with a series of scheduled appointments with a fixed DigiContact support worker) so that they too can start with the service in a way that is safe and pleasant for them and possibly, in time, they may begin to call in as needs arise.

Aligning remote and onsite support

This thesis indicates that many people with intellectual disabilities benefit from the combined provision of DigiContact support and onsite support (*chapters 3, 4 and 6*). When remote and onsite support is combined, it is important that both services

work together on the basis of closely aligned goals, processes and working methods. In order to align remote and onsite support, it is important that DigiContact support workers, onsite support workers and case workers know how they all work and what the possibilities and limitations of their support are. It is also important that they are intrinsically motivated to align their support, and for this they need to trust each other's methods and belief that the combination of both forms of support can be of benefit to support users. A term from inclusive education literature that reflects this well is 'collaborative teaming' (King-Sears et al., 2015; Snell & Janney, 2000). Good mutual communication is indispensable in collaborative teaming. Communication between DigiContact support workers and case workers or onsite support workers takes place to a large extent during scheduled moments of consultation (e.g. intakes and evaluation moments) and written reports on support contacts (a shared electronic client file system). This way, the support workers do not only get more insight into each other's methods, but this may also stimulate the creation of so-called short lines of communication which will make it easier to also contact each other as the need arises.

Not all onsite support workers may be motivated to work with DigiContact. Before this service was introduced, onsite support at home was the standard model of service delivery for people with intellectual disabilities living independently (Stancliffe & Lakin, 2007). While onsite support workers were previously the only party to support a support user in the home situation, they now find themselves in a situation in which they share this task with DigiContact. This brings about a shift in roles, tasks, and responsibilities that not every onsite support worker may see as a positive development. In addition, there may be reluctance resulting from a fear that DigiContact will eventually take over their work. It is important that the service is not positioned and used as an austerity measure or as a potential competitor, but rather as a complementary tool that can be used to improve the lives of people with intellectual disabilities.

Equipping people with intellectual disabilities to benefit from remote support

This thesis has shown that not all people with intellectual disabilities living independently who are supported by the DigiContact service, can benefit equally from its support. A few aspects emerged from the findings that can be used as starting points to better equip (or enable) people to benefit from DigiContact support.

To start with, it is important that people have access to the material that is needed to contact the service. Although both a landline telephone and an online device (e.g.

smartphone, personal computer or tablet) can be used for contacting the service, the findings from *chapters 6 and 7* indicate that it is more complex for support workers to provide good support during contacts without video component since they have less opportunities for gathering information (i.e. from non-verbal signals from the support user and cues from the physical environment). Registration data from the service organization show that a significant proportion of the support contacts with the service takes place via a landline phone connection and therefore does not include a video component. This emphasises the importance of encouraging the use of online devices and video calls. As people with intellectual disabilities lack access to the internet more often than people without disabilities (e.g. Alfredsson et al., 2019; Chadwick et al., 2018; Glencross et al., 2021), this seems to require extra attention from the service organization. In this respect, it is valuable that this organization is committed to lending people tablets and offering support whenever technical problems arise. In addition, it would be useful to consider whether there are more ways to stimulate and facilitate the use of video calls.

Apart from the value of video calls, the use of technology was hardly addressed in the interviews. This may have something to do with the fact that the interviewed support users who (also) had video calls with the service had a relatively high level of proficiency in operating online devices. Support users who are less skilled in this respect may have been inclined to use landline telephones to call in. The fact that Philadelphia Care Foundation has made substantial investments in a user-friendly and reliable system may also play a role in that there was no mention of technological problems.

In addition to equipment, it also seems worthwhile to focus on the skills that people need to benefit (more) from DigiContact. Part of the added value of the support comes from the fact that it is possible to contact the service without an appointment, for example when a problem or issue arises and when stress and frustration levels mount (*chapters 2, 4 and 6*). The findings from *chapter 6* indicate that some people are not able to signal potential problems in time, to act on this by taking the initiative to contact the service, and to talk about what is bothering them. It seems to be a potentially valuable step to look at whether these skills can be strengthened. Another opportunity lies in the use of tools that can support people in this process, such as a plan that support users can use to determine when it is a good idea to contact DigiContact, and biofeedback devices that give a notification when an increase in stress is measured (Gray et al., 2019; Palix et al., 2017).

Equipping professionals to support people with intellectual disabilities remotely

To our knowledge, no previous research has been conducted into the experiences of support workers with supporting people with intellectual disabilities remotely. In this thesis, the experiences of DigiContact support workers are explored both with regard to what they do to support people (*chapter 3*), and what distinctive aspects of their job as a remote support professional are (*chapter 7*). The findings show that the work of a DigiContact support worker requires specific skills, knowledge and affinities. For example, these support workers are expected to adopt a coaching support style and to collaborate with onsite support workers. In addition, they provide support to a very large and diverse group of support users (with a wide variety of support needs), must work closely with one's direct colleagues as one team and are regularly asked to work fast and switch quickly between contacts with support users. This suggests that working as a remote support worker at the DigiContact service is like a discipline in its own right, and that not every support worker is (equally) suited for this and/or will find this job equally attractive. This insight is both relevant and valuable for daily practice, within which professional support is increasingly provided remotely (Friedman & Rizzolo, 2017; Wagner et al., 2022).

The indication that not every support worker is (equally) suited for working as a DigiContact support worker emphasises the importance of a well-targeted recruitment and selection process. During this process, the specific competences that are useful for the task of supporting people with intellectual disabilities remotely (e.g. having a wide set of skills and knowledge, good computer skills, the ability to work well both independently as well as in a team, high resistance to stress and strong cognitive skills) need to be taken into account. *Chapter 7* also mentions the usefulness of having onsite work experience, as this can help support workers to keep in touch with the complexity of support users' daily experiences. This suggests that it may be valuable to look at the possibility of creating jobs that combine the remote support worker role with working a number of hours in onsite support settings.

It also seems to be of essential importance to provide DigiContact support workers with sufficient and proper support and training to help them do their job well and maintain job satisfaction. As far as training is concerned, in addition to focusing on the specific needs and competencies, it is important to pay attention to remote communication skills (and especially non-verbal communication). As far as support is concerned, it is important that support workers are given space and time for sufficient rest and breaks during their shifts, that there are opportunities for

intervision and consultation (organized and unorganized), and that there is a good mutual atmosphere so that social support possibilities are strengthened.

Future research

The findings of this thesis offer various starting points for further research. First, the current findings pave the way for research into the effectiveness of DigiContact support. The studies performed provide a detailed picture of what this support entails and how it can be of value to people with intellectual disabilities living independently. The findings also provide some knowledge of the possible impact that the support can have on people with intellectual disabilities. However, this thesis does not answer questions such as what this impact exactly is, how strong this impact can be and how often an impact is realised. An interesting next step would be to set up and conduct research into the impact of DigiContact support on quality of life related outcomes of its users. This could be done, for example, by means of prospective case studies in which a number of support users are followed over time (from the moment before they start to use DigiContact until preferably a few years later in order to be able to look at the effects in the longer term). The knowledge gained from this thesis can serve as important input to direct which outcome measures should be included in such research (e.g. self-determination, personal development, emotional well-being and social inclusion).

Second, in the light of effectiveness it is also important to look at the possible effects of DigiContact support on other involved parties such as onsite support workers and natural caregivers. It is possible that this support may also play a significant role in their lives. For example, *chapter 4* describes how case workers find it pleasant that the service is always available, as this makes it easier for them to disconnect from work without worrying about the well-being of support users. This seems incredibly valuable, especially in light of the increasing pressure on them due to rising staff shortages (Liu et al., 2017; World Health Organisation, 2022). The extent to which DigiContact provides support to natural caregivers, relieves workpressure and increases happiness at work for (onsite) support workers, are valuable aspects to explore further.

Third, it would also be useful to conduct research aimed at identifying personal and contextual characteristics that influence whether and in what way DigiContact support can be suitable and valuable for a person. This thesis has provided a start by showing, for example, that preferences and needs regarding certain support characteristics as well as previous experiences with onsite support play an important role in this. To be able to investigate this better, larger and more diverse samples of

support users are needed. With regard to the latter, it is important to also include young people and people who are new to the intellectual disability service delivery system.

Fourth, as the service is increasingly being used with other target groups than people with intellectual disabilities living independently (as described in *chapter 1*), it is important to also investigate the potential value of DigiContact for other support user groups. It is possible that the added value of DigiContact differs for people with other (types or intensities of) support needs. An interesting group to investigate further consists of people with intellectual disabilities who live in supported accommodation settings. It would be interesting and valuable to evaluate whether the use of DigiContact in such a setting also has the potential to add value for people with intellectual disabilities.

Finally, the experiences gained from adopting an inclusive approach to research are reason to plea for continued investments in an inclusive way of working in future research projects. During the current project, all involved parties (not only the researchers but also the partners from Philadelphia Care Foundation) have gained a wealth of experience on how to design and conduct inclusive research and on how to create conditions that increase the chances of successful collaboration between researchers with and without intellectual disabilities. By continuing an inclusive approach to research in new projects, the opportunity can be seized to let experiential knowledge enrich these projects as well as to increase knowledge and experience even further. In this regard, it is advisable to offer researchers with intellectual disabilities permanent research positions (like researchers without intellectual disabilities often have) so that they can dedicate themselves to developing their research skills further and to deploy their acquired expertise and skills in new projects.

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SUMMARY

General introduction

In **chapter 1** a general introduction is presented to the topic of remote support for people with intellectual disabilities. The chapter starts with a description of various changes in the field of intellectual disability policies and practices that encourage service organizations to look for new ways to provide personalised and community-based supports that promote people's social inclusion, self-determination and self-direction, and to make use of resources (financial and staffing) in a socially responsible way. Organizations often look at the possibilities of technology for shaping their service portfolio. One way in which technology can be used is to organize and deliver support remotely.

This thesis focuses specifically on the remote support service DigiContact. DigiContact provides people with intellectual disabilities who live in their own homes in society with support for day-to-day living through video calls or regular (audio-only) telephone calls with a team of specially trained support workers. The service is 24/7 available and its support can be deployed on demand by people with intellectual disabilities themselves, whenever and wherever this is needed. The DigiContact service was developed and implemented by the Dutch service provider Philadelphia Care Foundation as one component of a broader range of services for independently living people with intellectual disabilities.

Since the start of DigiContact, Philadelphia Care Foundation has felt the need to monitor and evaluate the service in terms of its quality and usefulness. In this context, a better understanding of what the service can (and cannot) contribute to the lives of people with intellectual disabilities is essential. This thesis aims to contribute to this by gathering knowledge regarding *the added value of including DigiContact in a broader offer of services for people with intellectual disabilities who live independently in society*. Three main research questions were formulated:

1. What does DigiContact support entail?
2. What is the role of DigiContact support within the context of a broader offer of available supports?
3. What are the experiences of support users and professionals with DigiContact support?

Five separate studies were performed (reported on in *chapters 2 to 7*) that explored mainly the personal experiences of people closely involved in the DigiContact support process: support users (people with intellectual disabilities), their case workers (support workers who provide onsite support and coordinate services around support users), and DigiContact support workers. An inclusive approach to research was adopted across the performed studies, as this was expected to enrich both research processes and findings. This approach was shaped in the form of a collaboration between the PhD candidate and a researcher with intellectual disabilities (the experiences with this approach are reported on in *chapter 8*).

Part I: DigiContact support

Chapter 2 describes a mixed methods study that explored the support needs for which DigiContact support is used as well as their prevalence. First, semi-structured interviews were held with 21 support users to explore the support needs for which they contact the DigiContact service. Through an inductive thematic analysis four categories were constructed that reflect themes within their support needs: mental health, social contacts, practical issues and physical health. These categories indicate that the service is used for a broad variety of support needs, of which the themes correspond to important and well-documented issues in the lives of people with intellectual disabilities. Second, to assess the prevalence of support needs, eight DigiContact support workers used a registration form to score items that they felt corresponded to the support needs that were present in each contact they had with support users during a period of two-and-a-half weeks (N = 868 contacts). The findings show that the presence of the different support needs varied widely. The two most frequently scored support needs were 'connecting with someone' (30% of all contacts) and 'talking about worries and stress with the aim to free oneself of them' (24% of all contacts). This indicates that, although DigiContact support is used for different types of issues, it seems to play an especially important role in addressing a need to connect with other people and in releasing stress and frustrations. When comparing the prevalence of support needs between different types of work shifts (early versus late and week versus weekend), only a few significant differences were found. For example, healthy eating and household chores were more often focused on during the weekend than during the week, and advice on conflicts with other people was more often focused on during late shifts (afternoons and evenings) than during early shifts. The findings of this chapter suggest that the DigiContact service constitutes a useful way of providing professional support to independently living people with intellectual disabilities. 24/7 (and on-demand) access to professional support responds to an existing need of (at least some) people and seems to be

especially beneficial with regard to the prevention of feelings of loneliness and supporting people in managing their mental health.

Chapter 3 reports on a qualitative and descriptive study in which different sources of information were used to identify what DigiContact support workers do during their contacts with support users to support them and how they do this: key documents on the service, interviews with support users and their case workers (also reported on in *chapters 2, 4 and 6*), and interviews with DigiContact support workers (also reported on in *chapter 7*). Through an inductive-iterative analysis process seven themes were constructed. Four themes reflect areas of support towards which the support activities were oriented: (1) creating a welcoming and safe digital environment in which support users feel at ease and can share their worries and problems, (2) focusing on the support needs that are bothering the support users, (3) supporting support users to take on an active role towards addressing their own support needs, and (4) collaborating with onsite professionals. Three themes reflect central qualities which guide how the support workers provided support: (5) self-direction of support users, (6) personalisation, and (7) targeted support (i.e., keeping conversations to the point and directed towards the four areas of support). These findings indicate that DigiContact support is based on a partnership between support workers and –users, in which both parties work together towards strengthening support user capabilities regarding coping and problem solving and giving support users (more) control over their support and the way they confront difficulties in their everyday lives.

Part II: The role of DigiContact support

Chapter 4 describes a qualitative multiple case study in which the support situations of nine support users were mapped using semi-structured interviews with these support users and their case workers. A support situation consists of the different sources of support that are available to a support user and what these sources of support helps him/her with. The focus was on exploring (1) the position and role of DigiContact support within a broader mix of supports, and (2) the suitability of DigiContact support for different types of support needs as compared to other available supports. The nine support users were included based on their scores on the Dutch version of the Self-Sufficiency Matrix, as to obtain a selection of cases representing a wide variety of support needs. Regarding the position and role of DigiContact support, the findings show that this support was seen and used as an addition to onsite support at home. The service was used as a tool to provide support whenever a need arises. This was felt to facilitate a tailor-made delivery of professional support by extending the availability of support, by broadening the available support options, and by enhancing the flexibility of support. Regarding the

suitability of DigiContact support for different types of support needs, the findings show that this support was used for a relatively small selection of support needs compared to onsite support at home. It often functioned as a readily available outlet for rising emotions, stress and frustrations with the aim of helping people to balance and steer their emotional well-being. In comparison to onsite support at home, DigiContact support was less often used for practical issues, relationships with other people, and the use of metacognitive strategies. Overall, these findings indicate that DigiContact support can add substantial value for support users when it is combined with onsite support, but that it cannot be seen (at least for the participating support users and at this moment) as a suitable substitute for all onsite support.

Chapter 5 reports on a retrospective, quantitative study that explored the use of DigiContact support during the first weeks of the COVID-19 virus outbreak in the Netherlands, when various restrictive measures imposed by the national government had a strong negative impact on the continuity of onsite service provision. The number of support contacts (per day) during this period was compared to two reference periods: the weeks prior to the COVID-19 outbreak and the same weeks from the previous year. The results show that the use of DigiContact support increased significantly during the first weeks of the pandemic compared to both reference periods. This increase was to a large part attributable to support users having more (unplanned) contacts with the service than before, but also to a small group of people who were connected recently to the service during (and presumably due to) the pandemic and who started to use the service as well. The findings indicate that the start of the COVID-19 pandemic had quite an impact on the use of DigiContact support. The service enabled a responsiveness towards (temporarily) elevated levels of demand for its support which may have been due to people being worried and anxious and not having access to clear and understandable information on the virus and/or the restrictive measures. The fact that during this period there was a temporary interruption (or at least irregularity in) the provision of onsite support may also have played a role.

Part III: Experiences with DigiContact: some very specific personal perspectives on support and inclusive research

Chapter 6 provides an in-depth account of the experiences of five support users with what it is like for them to be supported by the DigiContact service using a phenomenological hermeneutical analysis method. The findings show that, even though there was considerable variation in how DigiContact support was experienced, there were also shared experiences. Three aspects were found to play a central role in these shared experiences. First, the service was experienced to

improve the match between the professional support provided and their personal support needs and preferences in terms of availability, intensity and type of support. For example, DigiContact enabled various support users to get (sufficient) support within a context of care reforms, austerity measures and strict support eligibility. Second, the possibility to exert control over one's support was an important shared experience. Although the support users felt that they had had a limited say in the decision whether to be connected to the service or not, they experienced a high level of control over their day-to-day use of DigiContact support. By being able to call in spontaneously (without an appointment), they could control the timing and frequency of their contacts, and this enabled them to shape their contacts according to their needs and wishes. Third, the interactions with the service's support workers were influenced by the remote delivery of the support and the fact that support users were supported by multiple (and varying) support workers. Their contacts were experienced as relatively impersonal, as both parties did not know each other (well). This made some support users feel not confident and secure enough to open up and discuss certain issues and/or feel that not being known well enough to adapt the support to their personal needs. The findings indicate that DigiContact support can have both benefits and drawbacks for independently living people with intellectual disabilities and that its suitability depends on the needs, preferences and capabilities of individuals.

Chapter 7 offers a view on the experiences of DigiContact support workers. Interviews with ten support workers were held and analysed to explore what was perceived as being distinctive aspects of their job. The findings suggest that the way DigiContact support is organized and delivered has substantial implications both for the support workers personally and for their way of supporting people. For example, providing support from a distance was experienced as both facilitating and complicating their work, as this helped them to adopt a coaching style of support, but also made it more difficult to get a full picture of support users and their situation. Having to provide support to all support users of the service as one team meant that they had to be a 'jack of all trades' (i.e., having a wide set of knowledge and skills), but also that they shared responsibilities with their colleagues. The fact that a substantial part of their support contacts takes place suddenly (unplanned), was experienced as making their job relatively unpredictable and contributed to a high-intensity work dynamic. Not knowing in advance who will call in, when, and about what (and not being able to prepare oneself) was felt to be both challenging and exciting. The findings of this chapter contribute to a better understanding of the specific and complex characteristics that come with the task of providing DigiContact support and which require specific professional and organizational preconditions.

In contrast to the previous chapters, **chapter 8** does not focus on experiences with DigiContact support, but rather on the researchers' personal experiences with adopting an inclusive approach to research. Aligning with the auto-biographical research tradition, the researchers reflected on their experiences with collaborating and conducting research together. This chapter provides insights into how they experienced that their collaboration worked best, the possible benefits of the collaboration for themselves, and its possible impact on the quality of the performed studies. As to how their collaboration worked best several aspects were highlighted; such as the importance of recruiting researchers (with and without intellectual disabilities) who are suitable and motivated partners in inclusive research and the provision of support and facilitation by the employer organization (e.g., in this project introducing a job coach proved to be a successful strategy). Possible benefits for the researchers consisted of having more opportunities to exert influence and to acquire new skills and knowledge. Regarding the impact on the quality of the studies performed, the collaboration was experienced as having resulted in the use of other (new) methods of research and a more intensive preparation and execution of all research steps.

General discussion

Chapter 9 contains a general discussion on the findings of this thesis. After summarizing the main findings, a reflection is provided on the potential added value of the DigiContact service. DigiContact makes specialized support for independently living people with intellectual disabilities continuously available and on demand deployable. Through this, people are enabled to seek support whenever and wherever they feel this is necessary or desirable. The findings indicate that including DigiContact in a broader offer of services can be valuable to (supporting) people with intellectual disabilities living in their own homes in society, in several ways. To begin with, DigiContact contributes to more opportunities for providing people with professional and specialized support that is closely aligned with their personal needs and preferences. DigiContact can contribute to more tailor-made professional support by broadening the available support options, by enabling the provision of sufficient support and by enhancing the continuity in the delivery of support. In addition, DigiContact provides a unique entry point for improving people's functioning and well-being; its support has been found to enlarge the opportunities for making choices and taking decisions, can help to prevent (larger) problems as well as an accumulation of stress, and can play a valuable role in the learning and strengthening of adaptive skills.

The findings also show that there are limitations to what the DigiContact service can do for its users, and that it is not equally suitable for every person and situation. It is therefore not a 'one size fits all' service and is rightly used as part of a range of options from which an optimal collection of services and supports can be put together. The value of DigiContact support seems to lie often in its combination with onsite support, as both types of support have something different to offer. For example, while onsite services for independently living people with intellectual disabilities generally offer the possibility to be supported by a support worker who is physically present in the same room but whose support is not available on a continual basis, DigiContact offers support that is continually available (on demand), but not in the home of the support user. By combining both services in a blended care form, people with intellectual disabilities are enabled to make decisions regarding which type of support suits their needs and preferences (in a given situation) best. In this respect, onsite support and DigiContact support can complement each other so that people can benefit from 'the best of both worlds'.

Besides a reflection on the main findings, this chapter includes a reflection on methodological aspects of this thesis. Attention is specifically paid to (the value of) the adopted inclusive research approach and the strategies that were used to improve scientific rigour and research quality. It is stressed that caution is warranted regarding applying the findings to other remote support initiatives, circumstances and groups of people.

Based on the findings of this thesis, several implications for policy, practice and research can be formulated. Although these implications are specifically related to the DigiContact service, they may also be of interest to other remote support initiatives and service organizations who are planning (or considering) to offer remote support. With regard to policy and practice, the implications are discussed on the basis of four topics. First, it is important to adopt a person-centred approach to the planning and delivery of remote support. The wishes, needs, capabilities and goals of persons with a need for support should be the starting point for all decisions regarding whether and how DigiContact support is deployed. It is in this respect essential that these persons are included as active participants in all planning and decision-making processes. Second, remote and onsite support should be well aligned, with both types of services working closely together on the basis of aligned goals, processes and methods. Third, it is useful to invest in equipping people with intellectual disabilities with the materials and skills that they need to benefit (more) from remote and on-demand support. For example, the use of video calls should be stimulated and facilitated. Also, the abilities to signal potential problems timely

and to take initiative to contact the service and talk openly about problems and feelings can (for some support users) be strengthened. Fourth, it is also important to pay attention to how professionals can be well equipped to support people with intellectual disabilities remotely. Since working at the DigiContact service was found to require specific skills, knowledge and affinities, not every support worker seems to be (equally) suited for this job and a well-targeted recruitment and selection process is advisable. Moreover, it is important to provide support workers with sufficient and appropriate support and training.

With an eye to future research, it seems especially worthwhile to conduct further research into the impact of DigiContact support on quality of life related outcomes for its users. It would also be useful to look at its impact on other involved parties, such as the extent to which DigiContact relieves workpressure and increases happiness at work for onsite support workers and whether it can support natural caregivers. Furthermore, as the service is increasingly being used by other support user groups as well (e.g., people with intellectual disabilities in supported accommodation settings), it is important to investigate the potential value of DigiContact for these support user groups. Last but not least, the experiences that have been gained during the studies performed with adopting an inclusive approach to research are reason to plea for continued investments in an inclusive way of working in future research projects. That way, experiential knowledge will not only enrich these projects, but the acquired knowledge and experience regarding inclusive research will also be expanded.

SAMENVATTING

Algemene inleiding

In **hoofdstuk 1** wordt een algemene inleiding gegeven op het onderwerp ondersteuning op afstand voor mensen met verstandelijke beperkingen. Het hoofdstuk begint met een beschrijving van verschillende veranderingen in het beleid en de praktijk met betrekking tot mensen met verstandelijke beperkingen, die zorgorganisaties ertoe aanzetten te zoeken naar nieuwe vormen van gepersonaliseerde en 'community-based' ondersteuning. Deze nieuwe vormen dienen zowel de sociale inclusie, zelfbepaling en eigen regie van mensen met verstandelijke beperkingen te versterken, als op een sociaal verantwoorde manier gebruik te maken van (financiële en personele) middelen. Organisaties kijken hierbij vaak naar de mogelijkheden van technologie om hun aanbod van diensten mee vorm te geven. Een van de manieren waarop technologie hiertoe kan worden ingezet is door het organiseren en leveren van ondersteuning op afstand.

Dit proefschrift richt zich specifiek op de ondersteuningsdienst DigiContact. DigiContact biedt mensen met verstandelijke beperkingen die wonen in een eigen huis in de maatschappij professionele ondersteuning gericht op het dagelijks leven middels online beeldbelgesprekken en reguliere telefoongesprekken (alleen audio) met een team van speciaal opgeleide begeleiders. De dienst is 24/7 beschikbaar en diens ondersteuning kan op afroep worden ingezet door de mensen met een verstandelijke beperking zelf (waar en wanneer zij dat nodig achten). DigiContact is ontwikkeld en geïmplementeerd door de Nederlandse zorgorganisatie Stichting Philadelphia Zorg en wordt ingezet als onderdeel van diens bredere dienstenaanbod voor zelfstandig wonende mensen met verstandelijke beperkingen.

Sinds de start van DigiContact voelt Stichting Philadelphia Zorg de behoefte om de kwaliteit en bruikbaarheid van deze dienst te monitoren en evalueren. Hierbij is het belangrijk om een beter begrip te krijgen van wat de dienst (wel en niet) kan bijdragen aan het leven van mensen met een verstandelijke beperking. Dit proefschrift beoogt hieraan bij te dragen door kennis te verzamelen over *de toegevoegde waarde van het opnemen van DigiContact binnen een breder aanbod van diensten voor zelfstandig wonende mensen met verstandelijke beperkingen*. Drie onderzoeksvragen werden geformuleerd:

1. Wat houdt DigiContact ondersteuning in?
2. Wat is de rol van DigiContact ondersteuning binnen de context van een breder aanbod van beschikbare ondersteuningsvormen?

3. Wat zijn de ervaringen van gebruikers (mensen met verstandelijke beperkingen) en professionals met DigiContact ondersteuning?

Vijf afzonderlijke studies werden uitgevoerd (deze worden beschreven in *hoofdstukken 2 tot en met 7*), waarbinnen de focus met name lag op het verkennen van de persoonlijke ervaringen van mensen die nauw betrokken zijn bij het DigiContact ondersteuningsproces: gebruikers (mensen die ondersteund worden door DigiContact), hun coördinerend begeleiders (begeleiders die ondersteuning thuis en/of op een ontmoetingsplek bieden en daarnaast een coördinerende rol hebben ten aanzien van de verschillende diensten rond een persoon), en DigiContact begeleiders. Er werd gekozen voor een inclusieve onderzoeksaanpak in de vorm van een samenwerking tussen de promovendus en een onderzoeker met een verstandelijke beperking (dit wordt nader beschreven in *hoofdstuk 8*). Van deze aanpak werd verwacht dat het zowel het onderzoeksproces als de bevindingen zou verrijken.

Deel I: DigiContact ondersteuning

Hoofdstuk 2 beschrijft een studie waarbinnen zowel kwalitatieve als kwantitatieve methoden werden ingezet om de ondersteuningsbehoeften waarvoor DigiContact ondersteuning wordt gebruikt (en hun prevalentie) in kaart te brengen. Eerst werden semigestructureerde interviews gehouden met 21 DigiContact gebruikers om de ondersteuningsbehoeften waarvoor zij contact opnemen met de dienst te verkennen. Middels een inductieve thematische analyse werden vier categorieën geconstrueerd die thema's binnen de ondersteuningsbehoeften weerspiegelen: psychische gezondheid, sociale contacten, praktische zaken en lichamelijke gezondheid. Deze categorieën wijzen erop dat de dienst gebruikt wordt voor een breed pallet aan ondersteuningsbehoeften die overeenkomen met belangrijke en goed gedocumenteerde kwesties binnen de levens van mensen met verstandelijke beperkingen. Vervolgens registreerden acht DigiContact begeleiders gedurende twee en een halve week de ondersteuningsbehoeften die aanwezig waren in hun contacten met gebruikers (N = 868 contacten). De prevalentie van de verschillende ondersteuningsbehoeften bleek sterk uiteen te lopen. De twee meest frequent geregistreerde ondersteuningsbehoeften waren 'connectie maken met iemand' (30% van alle contacten) en 'praten over zorgen en stress om zich daarvan te bevrijden' (24% van alle contacten). Dit wijst erop dat DigiContact ondersteuning weliswaar voor verschillende soorten problemen gebruikt wordt, maar dat het vooral een belangrijke rol speelt bij het voorzien in een behoefte aan contact met andere mensen en bij het uiten van stress en frustraties. Bij een vergelijking van de prevalenties van ondersteuningsbehoeften tussen verschillende types werkdiensten (vroeg versus

laat, doordeweeks versus weekend), werden slechts enkele significante verschillen gevonden. Zo was er tijdens weekenddiensten vaker aandacht voor gezond eten en huishoudelijke taken dan doordeweeks, en tijdens late diensten (middagen en avonden) vaker voor conflicten met andere mensen dan tijdens vroege diensten. De bevindingen van dit hoofdstuk suggereren dat de DigiContact dienst een bruikbare manier is om professionele ondersteuning te bieden aan zelfstandig wonende mensen met verstandelijke beperkingen. 24/7 toegang tot (op afroep inzetbare) professionele ondersteuning komt tegemoet aan een bestaande behoefte van (in ieder geval sommige) mensen en lijkt in het bijzonder waardevol te zijn voor het voorkomen van gevoelens van eenzaamheid en het bijsturen en balanceren van het mentale welbevinden.

Hoofdstuk 3 doet verslag van een kwalitatief en beschrijvend onderzoek waarbinnen verschillende bronnen werden geraadpleegd om zicht te krijgen op wat DigiContact begeleiders doen tijdens hun contacten met gebruikers om hen te ondersteunen (en hoe zij dit doen): sleuteldocumenten over de dienst, interviews met DigiContact gebruikers en hun coördinerend begeleiders (over deze interviews wordt ook gerapporteerd in *hoofdstukken 2, 4 en 6*), en interviews met DigiContact begeleiders (over deze interviews wordt ook gerapporteerd in *hoofdstuk 7*). Via een inductief-iteratief analyseproces werden zeven thema's geconstrueerd. Vier thema's weerspiegelden de ondersteuningsgebieden waar de ondersteuningsactiviteiten op gericht waren: (1) het creëren van een uitnodigende en veilige digitale omgeving waarbinnen gebruikers zich op hun gemak voelen en hun zorgen en problemen kunnen delen, (2) het focussen op de ondersteuningsvragen en –behoeftes van gebruikers, (3) het ondersteunen van gebruikers om een actieve rol aan te nemen ten aanzien van het aanpakken van hun eigen ondersteuningsvragen en -behoeftes, en (4) het samenwerken met begeleiders die ondersteuning thuis (en/of op een ontmoetingsplek) bieden. Drie thema's weerspiegelden centrale kwaliteiten die richting geven aan de manier waarop ondersteuning geboden werd: (5) eigen regie van gebruikers, (6) personalisering van ondersteuning, en (7) gerichte ondersteuning (gesprekken zijn 'to the point' en gericht op de vier ondersteuningsgebieden). Deze bevindingen geven aan dat DigiContact ondersteuning gebaseerd is op een partnerschap tussen begeleiders en gebruikers, waarbinnen beide partijen samenwerken aan zowel het versterken van de capaciteiten van gebruikers op het gebied van het omgaan met en oplossen van problemen, als aan het hen geven van (meer) controle over hun eigen ondersteuning en de manier waarop zij moeilijkheden in hun dagelijks leven aanpakken.

Deel II: De rol van DigiContact ondersteuning

Hoofdstuk 4 beschrijft een kwalitatieve multipele case studie waarin de ondersteuningssituaties van negen DigiContact gebruikers in kaart werden gebracht aan de hand van semigestructureerde interviews met de gebruikers en hun coördinerend begeleider. Een ondersteuningssituatie bestaat uit de verschillende bronnen van ondersteuning die een gebruiker tot zijn of haar beschikking heeft en waar deze bronnen bij helpen. De focus lag op het onderzoeken van (1) de positie en rol van DigiContact ondersteuning binnen een breder aanbod van ondersteuningsbronnen, en (2) de geschiktheid van DigiContact ondersteuning voor verschillende soorten ondersteuningsbehoeften in vergelijking met andere bronnen van ondersteuning. De negen gebruikers werden geïncludeerd op basis van hun scores op de Zelfredzaamheidsmatrix (ZRM), om zo tot een selectie van cases te komen waarbinnen een grote verscheidenheid aan ondersteuningsbehoeften vertegenwoordigd was. Wat betreft de positie en rol van DigiContact ondersteuning, lieten de bevindingen zien dat deze ondersteuning werd gezien en gebruikt als aanvulling op ondersteuning thuis. De dienst werd gebruikt als instrument om ondersteuning te kunnen bieden wanneer een behoefte aan hulp zich voordoet. DigiContact werd gezien als een middel om professionele ondersteuning meer op maat te kunnen bieden doordat het de beschikbaarheid van ondersteuning vergroot, de beschikbare ondersteuningsopties verbreedt, en de flexibiliteit van ondersteuning vergroot. Wat betreft de geschiktheid van DigiContact ondersteuning voor verschillende soorten ondersteuningsbehoeften, bleek deze ondersteuning te worden gebruikt voor een relatief kleine selectie van ondersteuningsbehoeften in vergelijking met ondersteuning thuis. DigiContact fungeerde vaak als een snel beschikbare uitlaatklep voor opkomende emoties, stress en frustraties, om zo het emotioneel welbevinden bij te sturen en in balans te houden. In vergelijking met ondersteuning thuis, werd DigiContact ondersteuning minder vaak gebruikt voor praktische zaken, relaties met andere mensen en het inzetten van metacognitieve strategieën. Al met al geven deze bevindingen aan dat DigiContact ondersteuning van aanzienlijke toegevoegde waarde kan zijn voor zelfstandig wonende mensen met verstandelijke beperkingen wanneer het gecombineerd wordt met ondersteuning thuis, maar dat het (voor de deelnemende gebruikers en op dit moment) niet gezien kan worden als een volledige vervanger hiervan.

Hoofdstuk 5 doet verslag van een retrospectieve, kwantitatieve studie naar het gebruik van DigiContact ondersteuning tijdens de eerste weken van de COVID-19 virus uitbraak. Tijdens deze weken werden er in Nederland verschillende beperkende maatregelen opgelegd die een sterk negatieve impact hadden op de continuïteit van reguliere ondersteuning thuis (en op de ontmoetingsplek). Het

aantal ondersteuningscontacten met DigiContact (per dag) tijdens deze periode werd vergeleken met twee referentieperiodes: de weken voorafgaand aan de COVID-19 uitbraak en dezelfde weken van het voorgaande jaar. Uit de resultaten bleek dat het gebruik van DigiContact ondersteuning tijdens de eerste weken van de pandemie aanzienlijk was toegenomen in vergelijking met beide referentieperiodes. Deze toename was voor een groot deel debet aan het feit dat gebruikers meer (ongeplande) contacten hadden met de dienst dan voorheen. Daarnaast was er een kleine groep mensen die tijdens (en vermoedelijk in reactie op) de pandemie op de dienst werd aangesloten en gebruik ging maken van diens ondersteuning. De bevindingen wijzen erop dat het begin van de COVID-19 pandemie een aanzienlijke impact heeft gehad op het gebruik van DigiContact ondersteuning. De dienst kon inspelen op de (tijdelijk) grotere vraag naar ondersteuning op afstand, die mogelijk te wijten is aan een toename van ongerustheid en angst en aan een gebrek aan duidelijke en begrijpelijke informatie over het virus en/of de beperkende maatregelen. Wellicht heeft het feit dat er in deze periode een tijdelijke onderbreking (of onregelmatigheid) was in de levering van ondersteuning thuis (en/of op de ontmoetingsplek) hierbij ook een rol gespeeld.

Deel III: Ervaringen met DigiContact: enkele zeer specifieke persoonlijke perspectieven op ondersteuning en inclusief onderzoek

Hoofdstuk 6 doet diepgaand verslag van de ervaringen van vijf DigiContact gebruikers ten aanzien van hoe het voor hen is om ondersteund te worden door deze dienst, waarbij gebruik werd gemaakt van een fenomenologische hermeneutische analysemethode. De bevindingen laten zien dat de ervaringen aanzienlijk varieerden, maar dat er ook gedeelde ervaringen waren. Drie aspecten speelden een centrale rol in deze gedeelde ervaringen. Ten eerste werd ervaren dat DigiContact het mogelijk maakte om de geboden professionele ondersteuning beter af te stemmen op persoonlijke behoeften en voorkeuren ten aanzien van beschikbaarheid, intensiteit en soort ondersteuning. Zo stelde DigiContact verschillende gebruikers in staat om (voldoende) ondersteuning te krijgen ondanks hervormingen in de zorg, bezuinigingsmaatregelen en strengere toelatingscriteria. Ten tweede werd de mogelijkheid ervaren om controle uit te oefenen over de eigen ondersteuning. Hoewel de gebruikers het idee hadden slechts beperkte inspraak te hebben gehad in de beslissing om op de dienst te worden aangesloten, ervoeren ze juist een grote mate van controle over hun dagelijks gebruik van DigiContact ondersteuning. Doordat zij spontaan (zonder afspraak) konden inbellen, konden zij hun contacten wat betreft tijdstip en frequentie vormgeven volgens hun behoeften en wensen. Ten derde werden de interacties met de begeleiders als betrekkelijk onpersoonlijk ervaren. Dit was het gevolg van dat de ondersteuning vanaf een afstand werd geboden en

er contacten plaatsvonden met meerdere (en wisselende) begeleiders. Hierdoor kenden beide partijen elkaar vaak niet of niet goed, en dit leidde ertoe dat sommige gebruikers zich niet voldoende veilig voelden om bepaalde zaken te bespreken of dat zij het gevoel hadden niet goed genoeg gekend te worden door de begeleiders om ondersteund te worden op een manier die goed bij hen als persoon past. Deze bevindingen geven aan dat DigiContact ondersteuning zowel voor- als nadelen kan hebben voor zelfstandig wonende mensen met verstandelijke beperkingen en dat diens geschiktheid afhangt van persoonlijke behoeften, voorkeuren en mogelijkheden.

Hoofdstuk 7 biedt zicht op de ervaringen van DigiContact begeleiders. Middels interviews met tien begeleiders werd onderzocht wat zij ervaren als kenmerkende aspecten van hun werk. De bevindingen suggereren dat de manier waarop DigiContact ondersteuning is georganiseerd en wordt geleverd substantiële implicaties heeft voor zowel de begeleiders persoonlijk als voor de manier waarop zij ondersteuning bieden. Zo werd bijvoorbeeld ervaren dat het ondersteunen van mensen op afstand zowel een faciliterende als complicerende factor in hun werk is. Zo maakt dit het aan de ene kant makkelijker om een coachende stijl van ondersteuning aan te nemen, maar maakt dit het aan de andere kant moeilijker om een goed beeld te krijgen van de gebruikers en hun situatie. Daarnaast betekent het feit dat DigiContact begeleiders als één team ondersteuning bieden aan alle gebruikers, dat zij van alle markten thuis moeten zijn (oftewel dat zij brede kennis en vaardigheden moeten hebben), maar ook dat zij verantwoordelijkheden delen met collega's. Doordat een aanzienlijk deel van hun ondersteuningscontacten ongepland (zonder afspraak) plaatsvindt is hun dagelijks werk relatief onvoorspelbaar en is er sprake van een werkdynamiek met een hoge intensiteit. Het niet van tevoren weten wie er belt, wanneer dit gebeurt en wat voor hulp nodig is, maakt het onmogelijk om zich voor te bereiden. Dit werd ervaren als zowel een uitdagend als interessant aspect van het werk. De bevindingen van dit hoofdstuk dragen bij aan een beter begrip van het specifieke en complexe karakter van het werk van DigiContact begeleiders en suggereren dat het creëren van specifieke professionele en organisatorische randvoorwaarden hierbij van belang zijn.

In tegenstelling tot de vorige hoofdstukken, richt **hoofdstuk 8** zich niet op ervaringen met DigiContact ondersteuning, maar op de persoonlijke ervaringen van de onderzoekers met de door hen gehanteerde inclusieve onderzoeksaanpak. In lijn met de autobiografische onderzoekstraditie reflecteerden de onderzoekers op hun ervaringen met het samenwerken binnen (en het samen uitvoeren van) onderzoek. Dit hoofdstuk beschrijft hoe zij ervoeren dat hun samenwerking het best vorm kon krijgen, de mogelijke voordelen van de samenwerking voor henzelf, en de ervaren impact op de kwaliteit van de uitgevoerde studies. Wat betreft hoe de

samenwerking het best vorm kon krijgen, werden verschillende aspecten benadrukt, zoals het belang van het werven van onderzoekers (met en zonder verstandelijke beperkingen) die geschikte en gemotiveerde partners zijn binnen inclusief onderzoek en het bieden van de juiste ondersteuning en facilitatie vanuit de werkgever (zo bleek het introduceren van een jobcoach een succesvolle strategie). Mogelijke voordelen voor de onderzoekers bestonden uit het krijgen van meer mogelijkheden om invloed uit te oefenen en om nieuwe vaardigheden en kennis te verwerven. Wat betreft de impact op de kwaliteit van de uitgevoerde studies, werd ervaren dat de samenwerking leidde tot het gebruik van andere (nieuwe) onderzoeksmethoden en een intensievere voorbereiding en uitvoering van alle onderzoeksstappen.

Algemene discussie

Hoofdstuk 9 bevat een algemene discussie over de bevindingen van dit proefschrift. Na een samenvatting van de belangrijkste bevindingen wordt gereflecteerd op de (potentiele) toegevoegde waarde van de DigiContact dienst. DigiContact maakt gespecialiseerde ondersteuning voor zelfstandig wonende mensen met verstandelijke beperkingen continu beschikbaar en op afroep inzetbaar. Hierdoor worden mensen in staat gesteld om ondersteuning te initiëren waar en wanneer zij dat nodig hebben of wenselijk achten. De bevindingen wijzen erop dat het opnemen van DigiContact in een breder aanbod van diensten op verschillende manieren waardevol kan zijn voor (de ondersteuning van) mensen met verstandelijke beperkingen die in een eigen huis in de samenleving wonen. Om te beginnen draagt DigiContact bij tot meer mogelijkheden om deze mensen te voorzien van professionele en gespecialiseerde ondersteuning die nauw aansluit bij hun persoonlijke behoeften en voorkeuren. DigiContact kan bijdragen aan professionele ondersteuning op maat door de ondersteuningsmogelijkheden te verbreden, door het mogelijk te maken om voldoende ondersteuning te krijgen en door de continuïteit in de levering van ondersteuning te vergroten. Daarnaast biedt DigiContact een unieke ingang om het functioneren en welbevinden van mensen te verbeteren: diens ondersteuning vergoot de mogelijkheden om keuzes te maken en beslissingen te nemen, kan bijdragen aan het voorkomen van (grotere) problemen en een opeenstapeling van stress, en kan een waardevolle rol spelen in het aanleren en versterken van adaptieve vaardigheden.

De bevindingen wijzen er ook op dat er beperkingen zitten aan wat de DigiContact dienst kan doen voor diens gebruikers en dat de ondersteuning niet voor elke persoon en iedere situatie even geschikt is. Het is daarom geen 'one size fits all' oplossing en wordt terecht gebruikt als onderdeel van een range aan ondersteuningsopties van waaruit per persoon een optimaal pakket samengesteld kan worden. De waarde van DigiContact ondersteuning lijkt te liggen in de combinatie met ondersteuning

thuis (en/of op de ontmoetingsplek), aangezien beide vormen van ondersteuning iets anders te bieden hebben. Zo bieden de meer reguliere diensten voor zelfstandig wonende mensen met verstandelijke beperkingen over het algemeen de mogelijkheid om ondersteund te worden door een min of meer vaste ondersteuner die fysiek aanwezig is in dezelfde ruimte, maar is hun ondersteuning over het algemeen niet continu en op afroep beschikbaar. DigiContact biedt juist ondersteuning die wel continu en op afroep beschikbaar is, maar deze ondersteuning vindt plaats op afstand. Door beide diensten te combineren in een 'blended care' vorm, worden mensen met verstandelijke beperkingen in staat gesteld beslissingen te nemen ten aanzien van welke ondersteuningsvorm het beste past bij hun behoeften en voorkeuren (in een bepaalde situatie). In dit opzicht kunnen ondersteuning thuis (en/of op een ontmoetingsplek) en DigiContact ondersteuning elkaar aanvullen en mensen de mogelijkheid bieden om te profiteren van de voordelen van beide vormen.

Naast een reflectie op de belangrijkste bevindingen, bevat dit hoofdstuk een reflectie op methodologische aspecten van dit proefschrift. Er wordt specifiek aandacht besteed aan de inclusieve onderzoeksaanpak en de strategieën die gebruikt werden om de wetenschappelijke nauwkeurigheid en kwaliteit te verbeteren. Benadrukt wordt het belang van voorzichtigheid bij het toepassen van de huidige bevindingen op andere initiatieven voor ondersteuning op afstand, andere omstandigheden en andere groepen mensen.

Op basis van de bevindingen kunnen verschillende implicaties voor beleid, praktijk en onderzoek worden geformuleerd. Hoewel deze implicaties specifiek betrekking hebben op de DigiContact dienst, kunnen ze ook interessant zijn voor andere initiatieven op het gebied van ondersteuning op afstand en voor zorgorganisaties die van plan zijn (of overwegen) om ondersteuning op afstand aan te bieden. Met betrekking tot beleid en praktijk worden de implicaties besproken aan de hand van vier onderwerpen. Ten eerste is het belangrijk om bij het plannen en leveren van ondersteuning op afstand een persoonsgerichte benadering te hanteren waarbij de wensen, behoeften, mogelijkheden en doelen van de personen met een ondersteuningsbehoefte het uitgangspunt zijn bij alle beslissingen over of en hoe DigiContact ondersteuning wordt ingezet. Het is in dit opzicht van essentieel belang dat deze personen als actieve deelnemers worden betrokken bij alle plannings- en besluitvormingsprocessen. Ten tweede dienen ondersteuning op afstand en ondersteuning thuis (en/of op een ontmoetingsplek) goed op elkaar afgestemd te worden, waarbij beide diensten nauw samenwerken op basis van op elkaar afgestemde doelen, processen en methoden. Ten derde is het zinvol om te investeren in het toerusten van mensen met verstandelijke beperkingen met de

materialen en vaardigheden die zij nodig hebben om te kunnen profiteren van ondersteuning op afstand en op afroep. Zo is het bijvoorbeeld belangrijk om het gebruik van beeldbelgesprekken te stimuleren en faciliteren. Ook de vaardigheden om potentiële problemen tijdig te signaleren, contact op te nemen met de dienst en openlijk over problemen en gevoelens te praten kunnen voor sommige DigiContact gebruikers worden versterkt. Ten vierde is het belangrijk om aandacht te besteden aan hoe begeleiders beter toegerust kunnen worden om mensen met verstandelijke beperkingen op afstand te ondersteunen. Omdat gebleken is dat het werken bij DigiContact specifieke vaardigheden, kennis en affiniteiten vereist, is niet iedere begeleider (even) geschikt voor deze functie en is een gericht toegespitst wervings- en selectieproces aan te bevelen. Bovendien is het belangrijk om de begeleiders voldoende en passende ondersteuning en training te bieden.

Met het oog op toekomstig onderzoek lijkt het de moeite waard om nader onderzoek te doen naar het effect van DigiContact ondersteuning op kwaliteit van leven gerelateerde uitkomsten. Ook zou het zinvol zijn om te kijken naar de impact op andere betrokkenen, zoals of (en de mate waarin) DigiContact de werkdruk voor begeleiders kan verlagen en hun werkplezier kan verhogen, en of ook het natuurlijke steunnetwerk van mensen met verstandelijke beperkingen ondersteund kan worden. Aangezien de dienst steeds meer gebruikt wordt door andere groepen gebruikers (bv. mensen met verstandelijke beperkingen die begeleid wonen op een woongroep met begeleiding ter plaatse), is het ook belangrijk om de potentiële waarde van DigiContact voor deze groepen te onderzoeken. Tot slot zijn de ervaringen met een inclusieve onderzoeksaanpak reden om te pleiten voor het continueren van een inclusieve manier van werken in toekomstige onderzoeksprojecten. Op die manier zal ervaringskennis van mensen met verstandelijke beperkingen niet alleen deze projecten verrijken, maar kan ook de opgedane kennis en ervaring met betrekking tot inclusief onderzoek worden uitgebreid.

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PHD PORTFOLIO

Name PhD student: Miriam Zaagsma
PhD period: February 2016 – August 2022
PhD supervisor: prof.dr. Geert van Hove
PhD co-supervisors: prof.dr. Alice Schippers
dr. Karin Volkers

PhD training	Year	ECTS
General Courses		
Scientific integrity	2017	2
Presenting and pitching your research in English	2017	2
Writing a scientific article	2018	3
Analytic storytelling	2019	2,5
Self-presentation: focus, structure, interaction and visualisation	2020	2,5
Specific courses		
Kwalitatief onderzoek in de praktijk van de gezondheidszorg	2018	2
Praktische epidemiologie: het opzetten van onderzoek	2018	4
Kwalitatief onderzoek: verdieping en toepassing	2019	2
Kwalitatieve analyse: een fenomenologisch hermeneutische methode	2019	4
Mixed methods research: how to combine quantitative and qualitative methods	2020	2,5
Seminars, workshops and master classes		
Research meetings	2016-2020	2
Presentations		
Oral presentation international congress DSiN	2017	2
Oral presentation international congress IASSIDD Glasgow	2019	2
Poster presentation international congress IASSIDD Melbourne	2016	-
Poster presentation national conference ‘Kennismarkt gehandicaptenzorg’	2016	-
Oral presentation international congress MHID Luxembourg	2017	-
Oral presentation international congress IASSIDD Athens	2018	-
Oral presentation national congress ‘Focus op onderzoek’	2018	-
Poster presentation international conference of IASSIDD and University College Ghent	2018	-
Oral presentation (online) international conference EURECO	2020	-
Oral presentation (online) international conference EURECO	2021	-
TOTAL		**32,5**

Publications	Year	ECTS
Peer reviewed, included in thesis		
Zaagsma, M., Volkers, K. M., Schippers, A. P., Wilschut, J. A., & Van Hove, G. (2019). An exploratory study of the support needs in 24/7 online support for people with mild intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 16*(1), 78–87. https://doi.org/10.1111/jppi.12275d	2019	-
Zaagsma, M., Volkers, K.M., Koning,M. H.M., Van Hove, G., & Schippers, A. P. (2020). The usefulness of offering 24/7 online support within a wider mix of professional services for peoplewith intellectual and developmental disabilities living independently: A qualitative, multiple case study. *Inclusion, 8*(2), 138–154. https://doi.org/10.1352/2326-6988-8.2.138	2020	-
Zaagsma, M., Volkers, K. M., Swart, E. A., Schippers, A. P., & Van Hove, G. (2020). The use of online support by people with intellectual disabilities living independently during COVID-19. *Journal of Intellectual Disability Research, 64* (10), 750–756. https://doi.org/10.1111/jir.12770	2020	-
Zaagsma, M., Van de Velde, D., Koning, M.H. M., Volkers, K. M., Schippers, A. P., & Van Hove, G. (2021). When I need them, I call them and they will be there for me. Experiences of independently living people with intellectual disabilities with 24/7 available online support. *Disability and Society.* https://doi.org/10.1080/09687599.2021.1932756	2021	-
Zaagsma, M., Koning, M. H. M., Volkers, K. M., Schippers, A. P., & Van Hove, G. (2022). 'It really is quite a different ballgame'. A qualitative study into the work experiences of remote support professionals. *Journal of Applied Research in Intellectual Disabilities, 35*(5), 1153-1161. https://doi.org/10.1111/jar.13001	2022	-
Zaagsma, M., Koning, M. H. M., Volkers, K. M., Schippers, A. P., & Van Hove, G. (2022). Supporting independently living people with intellectual disabilities: a qualitative study into professional remote support practices. *British Journal of Learning Disabilities*. Advance online publication. https://doi.org/10.1111/bld.12488	2022	-
Zaagsma, M., Koning, M., Van Andel, C., Volkers, K., Schippers, A., & Van Hove, G. (2022). A Closer Look at the Quest for an Inclusive Research Project: 'I Had No Experience with Scientific Research, and then the Ball of Cooperation Started Rolling'. *Social Sciences, 11,* 186. https://doi.org/10.3390/socsci11050186	2022	-
Others, not in this thesis		
Zaagsma, M., Volkers, K. M., Swart, E. A., Schippers, A. P., & van Hove, G. (2020). Online begeleiding van zelfstandig wonende mensen met een verstandelijke beperking tijdens COVID-19. *Tijdschrift voor Artsen voor Verstandelijk Gehandicapten, 38*(4), 249-252.[16]	2020	-

16 This is a Dutch summary of the publication Zaagsma, M., Volkers, K. M., Swart, E. A. K., Schippers, A. P., & Van Hove, G. (2020). The use of online support by people with intellectual disabilities living independently during COVID-19. *Journal of Intellectual Disability Research, 64*(10), 750–756. https://doi.org/10.1111/jir.12770 (in thesis).