

E-HEALTH FOR  
SUPPORT AND  
PSYCHOLOGICAL  
THERAPY AMONGST  
PEOPLE WITH  
INTELLECTUAL  
DISABILITIES

CHANCE AND CHALLENGE



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**eHealth for support and psychological therapy amongst  
people with intellectual disabilities: chance and challenge**

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# **eHealth for support and psychological therapy amongst people with intellectual disabilities: chance and challenge**

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*“Je kunt de mooiste, beste eHealth toepassingen in huis hebben. Mijn ervaring is dat het staat en valt bij de betrokkenheid van de medewerkers. Worden medewerkers niet meegenomen, tijd vrij gemaakt om, dan is het het paard achter de wagen spannen” –vrije veld citaat van een deelnemer onderzoek naar acceptatie eHealth in 2021*





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**CHAPTER 1**



# General Introduction



Digitalisation is increasingly becoming an integral part of everyday life and, similarly, has firmly established itself within the healthcare sector, offering opportunities for personalised, on-demand, and remote forms of care that are tailored towards individuals' needs (Van Gemert-Pijnen et al., 2011; Wangelin et al., 2016). This trend is also evident within healthcare organisations providing support to people with intellectual disabilities (Clifford Simpican et al., 2018; IGJ, 2023; Out et al., 2017; Tassé et al., 2020; Zaagsma et al., 2019). The Dutch Association of Healthcare Providers for People with Disabilities (VGN) and the Ministry of Health, Well-being, and Sports (VWS) published a policy report outlining key considerations for realising a sustainable future within healthcare for individuals with disabilities, with digital technology accorded a critical role in this process (VWS, 2021). Healthcare organisations providing support to people with intellectual disabilities are actively exploring the manifold opportunities afforded by digital technology, or eHealth as it is now commonly referred to, in order to address the needs of service users and integrate eHealth into the care and services provided to people with intellectual disabilities (VGN, 2021). This thesis examined the application of eHealth for people with intellectual disabilities who receive professional care, with a particular focus on the role played by healthcare professionals in applying eHealth within the context of support and psychological therapy.

## Healthcare for people with intellectual disabilities

People with intellectual disabilities have both lifelong and life-wide support needs centred on independence, social functioning, and well-being (Thompson et al., 2009; Verdugo et al., 2012). An intellectual disability is characterised by significant deficits in both intellectual (IQ score < 70) and adaptive functioning, with the onset occurring during the developmental period (Schalock et al., 2021). Four levels of intellectual functioning based on IQ scores can be distinguished: mild (IQ score 50-70), moderate (IQ score 35-50), severe (IQ score 20-35) and profound (IQ score < 20) (Carr et al., 2016). The intensity of the support needs required depends on someone's level of intellectual and adaptive functioning (Thompson et al., 2009). Adaptive functioning is expressed in conceptual, social, and practical skills that are essential to enhancing someone's daily functioning. People with intellectual disabilities are a heterogeneous population (e.g., Buckley et al., 2020; Maulik et al., 2011; Mazza et al., 2019). They receive healthcare from diverse healthcare domains, including community care support, general and specialised mental health institutions, and long-term residential care (Kroneman et al., 2016; Whittle et al., 2018). Organisations providing care and support for people with intellectual disabilities offer services across distinct domains, which encompass (psychological) assessment, (medical) care, support, paramedical, and psychological

therapy. This thesis specifically concentrates on two of these primary service domains: support and psychological therapy.

The nature of the support provided within these two aforementioned domains varies depending on the context, life stage, the presence of skills required to function in everyday life and mental health problems or challenging behaviour (e.g., Bowring et al., 2019; Munir, 2016). The level of support varies from either intermittent within specific situations (e.g., a transition or a crisis) to high-intensive and long-term across all domains of life (Carr et al., 2016). Support is defined here as ‘resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and enhance that person’s functioning’ (Thompson et al., 2009). Various meta-analyses and reviews provide supporting evidence for the effectiveness of psychosocial-behavioural interventions aimed towards teaching both general and specific adaptive behaviours that can in turn lead to improved cognitive and adaptive functioning within children as well as adults with intellectual disabilities (Ho et al., 2021; Sandjojo et al., 2020; Sturmey et al., 2014; Windsor et al., 2023). Research on support for people with intellectual disabilities predominately focusses on the delivery of in-person support, with considerably less emphasis being paid to forms of support that are delivered through digital technology, known as eHealth, which is the specific area of interest in this thesis.

Psychological therapy is defined as an ‘intervention using methods based on psychological theories and the understanding of persons and their context to make changes in people, their behaviour, their interpersonal relationships and systems around them’ (British Psychological Society, 2004). A systematic review of interventions targeting a reduction in challenging behaviour emphasises the importance of adopting a person-centred approach (O’Regan et al., 2022). Alongside this, cognitive-behavioural therapy, music, and art, microswitch technology, and illustrated stories were also shown to be applied in interventions for school-aged children with intellectual disabilities (O’Regan et al., 2022). Moreover, a systematic review and meta-analysis evaluating the efficacy of psychological therapy for people with intellectual disabilities found a moderate effect size for interventions focused on anger, and a small and non-significant effect size for those focused on anxiety and depression (Tapp et al., 2023). A review of the effectiveness of cognitive-behavioural therapy for anxiety amongst people with intellectual disabilities, including children and adolescents, reported positive results with respect to both its feasibility and its effect upon the participants’ anxiety levels (Fynn et al., 2023). Group-based interventions for mental health problems displayed a small and significant effect size, whereas the effect sizes for interventions delivered individually were found to be small and non-significant (Tapp et al., 2023). Osugo & Cooper (2016) also concluded that group cognitive-behavioural therapies have some

supporting evidence for their effectiveness, but that there were limited evidence-based interventions available for mental health problems for adults with mild intellectual disabilities. The aforementioned reviews also concluded that digital technology was only marginally applied within psychological interventions for people with intellectual disabilities, despite the ostensible opportunities afforded by these technologies to address the mental health needs of this group (Sheehan & Hassiotis, 2017). In this thesis, we explore the opportunities afforded by psychological eHealth interventions for this target group.

## **eHealth: definition and opportunities**

eHealth can be defined as ‘the use of the Internet or related technologies to support health, well-being, and healthcare delivery’ (Eysenbach, 2001; Van Gemert-Pijnen et al., 2018, Riper et al. 2010). Eysenbach (2001) concluded that eHealth not only focusses on the technical but also the psychological and social elements of healthcare practice. It is important to note that eHealth is an umbrella term and can be classified in different ways, namely: (a) how it is used within the healthcare process, (b) the users involved, (c) and the type of technology that is used (Riper et al., 2010; Van Lettow et al., 2019). Amongst general patient populations, eHealth is used in early identification and prevention, diagnostic assessment, monitoring, treatment/support, and relapse prevention for a broad range of (mental) health problems within the healthcare process (Akwa GGZ, 2022; Riper & Cuijpers 2016). Besides service users and healthcare professionals as eHealth users, eHealth can also facilitate the involvement of relatives as well as supporting greater collaboration between different healthcare professionals working across several healthcare domains, such as general mental health care and specialised care for people with intellectual disabilities (Akwa GGZ, 2022; Barak et al., 2008). The addition of digital technology can also positively impact upon the collaboration between service users and healthcare professionals. Specifically, eHealth facilitates greater self-management by service users, so that they can play a more active role in their own care. Roughly speaking, professional support in eHealth interventions can take three forms. First, the eHealth intervention can be unguided without the involvement of a healthcare professional. Here, the service user uses (digital) technology to search for information about a particular disease or mental health problem or follows an online self-help programme independently for depression, for example (Riper & Cuijpers, 2016). Second, an eHealth intervention can be guided with limited support from a healthcare professional combined with an online self-help programme. In this scenario, the service user might follow, for example, a brief online cognitive-behavioural therapy programme for depression and would be coached asynchronously by a healthcare professional in the event of mild to moderate complaints (5 to 6 modules, 5-6 weeks).

Finally, eHealth interventions can be guided via hybrid forms of support. In this case, face-to-face contact from a healthcare professional is alternated with digital contact or the service user themselves may work through an online programme (Kooistra et al., 2016). These eHealth interventions can be delivered via various digital tools such as personal digital devices, tablets, computers, mobile phones, video conferencing technology, web-based internet, etc. (Sucala et al., 2012; Timmer, 2015). The Ministry of VWS is of the belief that eHealth has notable potential and can contribute towards the improvement of healthcare quality, efficiency, accessibility, and expand the opportunities for personalised and tailor-made (remote) forms of care (Peeters et al., 2016; RIVM, 2022; Van Gemert-Pijnen et al., 2018). However, both the application of eHealth within care organisations providing support for individuals with intellectual disabilities and the resultant changes it brings about in this specific context remain relatively unexplored in extant literature.

## **The changes eHealth brings about in care organisations for people with intellectual disabilities**

In recent years, eHealth has become a more common part of support and therapy delivery within care organisations for people with intellectual disabilities (Vázquez et al., 2018; Inspection for Healthcare and Youth, 2023). Various studies have reported on the various opportunities afforded by digital technology to support people with intellectual disabilities (e.g., De Wit et al., 2015). Chadwick et al. (2013) emphasised that the internet provides a potential source of information, a way to express yourself and a means to get in contact with other people. In the field of intellectual disabilities, digital technology can provide a learning tool for developing practical or work-related skills (Ramdoss et al., 2012; Collins & Collett-Klingenberg, 2018), cognitive concepts like time (Den Brok & Sterkenburg, 2015), mentalising skills (Derks et al., 2022), as well as enabling people to practice these new skills within a safe environment (Hall et al., 2011; Standen et al., 2006). Furthermore, technology can potentially maintain the quality or improve the efficiency of care (De Wit et al., 2015; Perry et al., 2012), support the independent living of people with mild intellectual disabilities (Zaagsma et al., 2021), and enhance the self-determination of people with intellectual disabilities across various domains of life (e.g., selfcare, leisure time, work participation) (e.g., Van Dam et al., 2022; Van Delden et al., 2020; Wehmeyer et al., 2012). Today, eHealth is increasingly applied within care practice, in part, because of a significant rise in its usage during the COVID-19 pandemic (Chadwick et al., 2022). Like general healthcare, eHealth affects both the flexibility of service delivery and the ease of contact (Connolly et al., 2020; Henneman et al., 2017). First and foremost, remote forms of support via telecare or communicating by chat can facilitate low threshold contact independent of place and time (e.g., De Wit et al.,



2015; Zaagsma et al., 2020). Further, digital aids can help service users with intellectual disabilities to be less dependent upon professional support (Collins & Collet-Klingenberg, 2018; Den Brok & Sterkenburg, 2015). In addition, a study by Cooney et al. (2018) showed that people with mild intellectual disabilities attribute personal characteristics to digital characters (i.e., avatars) and, moreover, that they experience a personal and reciprocal connection with these avatars in a computerised form of cognitive-behavioural therapy for anxiety and depression.

Research indicates that internet-delivered Cognitive Behavioural Therapy (CBT) can be effective in terms of providing flexible, personalised psychological interventions for common mental health problems such as depression and anxiety (e.g., Carlberg et al., 2018; Riper & Cuijpers, 2016). Research has shown that mental health problems are more prevalent amongst people with intellectual disabilities compared to those without intellectual disabilities (Cooper et al., 2007; Hughes-McCormack et al., 2017; Pouls et al., 2023). Recent studies have reported on the feasibility of eHealth for delivering a mental health(-related) intervention for people with intellectual disabilities, such as pre-training for CBT skills (Vereenoghe et al., 2015; 2016), a computerised-CBT intervention for anxiety and depression (Cooney et al., 2017), and an interactive digital intervention promoting mental health (Vereenoghe and Westermann, 2019; Watfern et al., 2019).

Despite the increased focus upon eHealth within research, knowledge on its effectiveness for people with intellectual disabilities is less developed compared to other target populations (Sheenan & Hassiotis, 2017). Healthcare professionals in care organisations for people with intellectual disabilities continue to question both the feasibility and suitability of eHealth for people with intellectual disabilities and, as such, are reluctant on implementing eHealth within their work (Clifford Simplican et al., 2018). This attitude may hinder the potential application of eHealth within care organisations for people with intellectual disabilities (Parsons et al., 2008; Clifford Simplican et al., 2018). During the COVID-19 pandemic, healthcare professionals had to overcome their resistance to using digital technology rapidly, because of the governmental restrictions that forced them to find alternative – often digital – ways to keep in contact with their service users (Embregts et al., 2022). Although healthcare professionals' experiences with eHealth changed due to this crisis, their perception of the value of eHealth and how this leads to the adoption of eHealth with care practice remains underexposed. To the best of our knowledge, only one study, prior to the COVID-19 pandemic, reported on support staff exploring the opportunities of applying eHealth within their work in the Netherlands (Out et al., 2018). To implement eHealth successfully, it is essential that healthcare professionals know and acknowledge the potential of eHealth. Therefore, further research and knowledge development on the factors that bring about acceptance of eHealth amongst healthcare professionals is urgently needed.

## Acceptance of eHealth within care practice

Although the abovementioned studies explored the potential of eHealth to meet the support needs of people with intellectual disabilities, actual and long-term implementation of eHealth requires the involvement of all important stakeholders, including service users, relatives, healthcare professionals, and ICT departments (e.g., Van Gemert-Pijnen et al., 2018, Vis et al., 2018). Successful implementation of eHealth depends, in part, on the positive expectations and perceptions of service users as well as informal and formal network members. Besides members of the informal network (e.g., relatives, neighbours) who provide practical and emotional forms of support, formal network members such as healthcare professionals also play an important role (Giesbers et al., 2019; Van Asselt-Goverts et al., 2013). Therefore, it is important to be aware of how these people perceive the application of eHealth within the context of professional care. In this regard, Wennberg and Kjellberg (2010) discussed how the unwillingness of healthcare professionals served as a barrier to participants with intellectual disabilities using their cognitive assistive devices adequately. Moreover, Taber-Doughty et al. (2010) concluded that on-site support staff viewed their remote working colleagues as being less effective. However, people with intellectual disabilities themselves reported being satisfied with the telecare support they received, and, in fact, experienced this remote support as being equal to on-site support. Finally, De Wit et al., (2015) reported that support staff perceived that their communication with service users was facilitated by using a web-based programme. Overall, these studies found varying results concerning both the feasibility and suitability of eHealth for service users with intellectual disabilities as well as how the attitude of important others can either facilitate or hinder eHealth use in everyday practice. Gaining knowledge into the expectations and perceptions of stakeholders involved (i.e., service users, relatives as well as healthcare professionals) is essential given that implementation research indicates that acceptability is an important variable through which to evaluate the success of an implementation within research and clinical practice (e.g., Klaic et al., 2020; Proctor et al., 2011).

In particular, understanding the perceived opportunities and barriers of eHealth within care organisations for people with intellectual disabilities and their impact on acceptance is needed. The Unified Theory of Acceptance and Use of Technology (UTAUT) model is one of the most common theoretical models underpinning research on acceptance, intentions and actual use of technology by individual users (Venkatesh et al., 2003). Given that healthcare professionals play a pivotal role in the lives of service users with intellectual disabilities (e.g., Giesbers et al., 2019), one would expect that these professionals would also play an important role in eHealth implementation in care practice. Therefore, both their knowledge and careful consideration of eHealth being acceptable within support and therapy for people with intellectual disabilities

may be important drivers in eHealth implementation (Feijt et al., 2018; Skär and Söderberg, 2017). For this reason, in this thesis we focus on the acceptance of healthcare professionals – particularly support staff and therapists – working directly with service users with intellectual disabilities and their relatives.

Furthermore, the way healthcare professionals perceive eHealth as impacting upon the collaboration with service users could also play a role in terms of implementation (Berger, 2017; Davies et al., 2020). More specifically, healthcare professionals might feel reluctant to implement digital applications or remote therapy due to worries over the negative impact upon the quality of the collaborative relationship (Békés et al., 2021, Vis et al., 2018). Both within research literature and healthcare practice, this collaborative relationship is referred to as the working alliance, with several adjectives being used to characterise this alliance, such as ‘helping’ or ‘therapeutic,’ depending on the context of delivery (Flückiger et al., 2018). The working alliance is a common factor that has been found to be associated with positive outcomes, adherence, and satisfaction with an intervention irrespective of its theoretical underpinnings (Flückiger et al., 2018; Wampold, 2015). With respect to the development of a working alliance in interventions using digital technology amongst people with intellectual disabilities, mixed experiences have been reported in qualitative studies (Clyne et al., 2022; Cooney et al., 2018; Rawlings et al., 2021). These studies, on the one hand, have reported that service users felt supported by digital characters in computer programmes (Clyne et al., 2022; Cooney et al., 2018), whilst, on the other hand, service users failed to continue their therapy remotely during the COVID-19 pandemic (Rawlings et al., 2021). Although these studies discussed the development of a working alliance through digital characters and remote contact with professionals, this topic has thus far been explored on a limited scale in research. Moreover, an instrument through which to measure the working alliance in the context of support or therapy for people with intellectual disabilities, including digital forms of support or therapy, is currently lacking. These instruments are important insofar as they provide valuable insights into the effect of the working alliance upon intervention outcomes and the process of intervention delivery amongst general patient populations (e.g., Flückiger et al., 2018). Therefore, one would assume that applying these instruments can also shed light upon the role of the working alliance in interventions amongst people with intellectual disabilities. Furthermore, working alliance instruments can also be helpful for measuring the impact of digital technology upon the collaboration between service users and healthcare professionals. Finally, the need to compare interventions delivered in-person or digitally requires fitting instruments. Therefore, these needs can be met by the availability of suitable instruments for measuring the working alliance in-person and with eHealth tools, which is the focus of this thesis.

## Present thesis: aims and outline

The overall aim of this thesis was to explore opportunities for eHealth in daily support for people with mild intellectual disabilities and psychological interventions for mental health problems and/or challenging behaviour. eHealth studies underscore the importance of involving all relevant stakeholders for enabling successful eHealth applications within clinical practice (e.g., Van Gemert-Pijnen et al., 2018). Due to the significant role healthcare professionals play in implementing eHealth in delivering support and mental health services within clinical practice, we opted to focus on these specific stakeholders. Moreover, given the fact that the acceptance of eHealth by healthcare professionals working in primary care (i.e., support staff and therapists) may constitute one of the most relevant factors as to whether eHealth will ultimately be adopted within care organisations (Greenhalgh et al., 2017), it is critically important to investigate their role. The first aim of this thesis was to evaluate extant scientific knowledge on the usage of eHealth in support for daily functioning as well as psychological interventions for people with (mild) intellectual disabilities for mental health problems and/or challenging behaviour. These aims are addressed in the systematic review on eHealth for support for people with mild disabilities in daily life in **chapter 2** and a scoping review on eHealth in psychological interventions for people with intellectual disabilities in **chapter 3**. Implementation research emphasises the involvement of all relevant stakeholders (e.g., service users, relatives, and professionals) for implementing eHealth successfully within care practice, so gaining insight into their views on the application of eHealth within care practice is needed (Van Gemert-Pijnen et al., 2018). In **chapter 4**, the views of service users, relatives and professionals with respect to what eHealth is and what facilitates and hinders its usage within care practice are explored. The restrictive measurements imposed by governments, due to the COVID-19 pandemic, led to the increased use of telecare, such as videoconferencing technology, in order to continue clinical work (e.g., Békés et al., 2021; Wind et al., 2020). In particular, during the first lockdown period from March to May 2020, therapists working with people with mild intellectual disabilities were forced to replace their face-to-face diagnostic and therapeutical activities with remote digital alternatives. Their experiences of delivering diagnostic assessments and therapy via the use of video conferencing technology are described in **chapter 5**. Establishing a valuable and meaningful collaboration between people with mild intellectual disabilities and professionals is of paramount importance, and this is no different when eHealth is used. To enable future research into eHealth and investigate the collaboration in support and therapy, both with and without eHealth, requires psychometrically sound measurements. Therefore, two well-known and validated measurements of the working alliance, namely The Working Alliance Inventory Short Form version (WAI-SF) (Hatcher and Gillespy, 2006) and Technical Alliance Inventory Short Form (TAI-SF) (Herrero et

al., 2020; Kleiboer et al., 2016), were adapted to measure the perspectives of support staff and therapists working with people with mild intellectual disabilities on the (digital) working alliance. The adaptation procedure was carried out with a group of experienced healthcare professionals working with people with intellectual disabilities. Subsequently, a psychometric examination of both the adapted measurements was performed. The adaptation, factor structure and reliability of both measurements are reported in **chapter 6**. In **chapter 7**, we shed light on the factors that determine acceptance towards eHealth as well as the behavioural intentions of support staff and therapists to use eHealth for support and therapy amongst people with intellectual disabilities. The acceptance factors were derived from the Unified Theory of Acceptance and Use of Technology (UTAUT) model. In order to investigate the suitability of the UTAUT model, we consulted a group of healthcare professionals working in care organisations for people with intellectual disabilities and added relevant items to the survey. The extended UTAUT model was examined by confirmatory and exploratory factor analysis and led to a five-factor UTAUT. These factors were investigated in two cross-sectional studies in 2018, as well as during the COVID-19 pandemic in 2021. In **chapter 8**, first the main results from the studies are summarised, before then proceeding to discuss the strengths and limitations of the studies. Finally, the implications of the results for future research, clinical practice and policy are delineated.

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**CHAPTER 2**



# eHealth in the support of people with mild intellectual disability in daily life: A systematic review

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## **Abstract**

### **Background**

eHealth has recently made rapid progress in care, support, and treatment. However, studies on the use of eHealth to support people with a mild intellectual disability in daily life are limited. A systematic review was conducted to provide an overview of this use of eHealth.

### **Methods**

Seven databases were searched for relevant studies and assessed according to the PRISMA guidelines. Descriptive analyses were deployed using the Matching-Person-to-Technology model to evaluate the key areas contributing to successful eHealth use.

### **Results**

Most of the 46 studies included were small-scale case studies and focused on using eHealth to acquire daily living skills and vocational skills. In addition, several studies focused on eHealth use for self-support in daily living, and three studies focused on remote professional support.

### **Conclusions**

eHealth offers opportunities to support people with mild intellectual disabilities in various different contexts of daily life. Scientific research on this topic is in its early stage, and further high-quality research is needed.



## 1. Introduction

Around the world, increasing use is being made of health services and information delivered or enhanced over the Internet or related technologies, also referred to as eHealth (Eysenbach, 2001). This development may primarily be inspired by the potential of eHealth to improve the quality of the care provided while also upholding affordable care (Proudfoot et al., 2011). In addition, eHealth provides an opportunity for personalized, tailor-made, remote, and on-demand support and treatment (Oh, Rizo, Enkin, Jada, & Phil, 2005; Proudfoot et al., 2011; Van Gemert-Pijnen et al., 2011; Wangelin et al., 2016). Various systematic reviews and meta-analyses in general healthcare have indicated that the effectiveness of eHealth is promising in a broad range of settings, such as improving physical activity, facilitating independent living, promoting smoking cessation, preventing depression and anxiety, and reducing mental health and stress symptoms (e.g., Cotie et al., 2018; Deady, Choi, Calvo, Glozier, Christensen, & Harvey, 2017; Graham et al., 2016; Sapci & Sapci, 2019; Stratton, Lamput, Choi, Calvo, Harvey, & Glozier, 2017). Hence, eHealth has potential in promoting health, behaviour, and participation.

Just as in general healthcare, the use of eHealth within the care for people with intellectual disability has increased markedly (Deady et al., 2017; Statton et al., 2017). People with intellectual disabilities, in particular those with mild intellectual disabilities, have become more familiar with using the computer, the Internet and smartphones in the last decade (Chadwick, Wesson & Fullwood, 2013; Tanis, Palmer, Wehmeyer, Davis, Stock, Lobb & Bishop, 2012), resulting in more active and independent use of eHealth for various objectives compared to people with more severe levels of intellectual disabilities. Moreover, the use of eHealth among people with mild intellectual disability may contribute significantly to participation in the community, whereas the use of eHealth among people with more severe levels of intellectual disability is often focused on activating preferred stimuli. Due to these differences, these groups of people will use different sorts of eHealth for different purposes. Furthermore, developments such as the move from institutional to community care in the field of intellectual disability have led to a transformation in the location and manner in which support is delivered (Hall, 2011). Due to this transition, people with intellectual disability need support that is organised more flexibly, and targeted to the personal context (McConkey, Keogh, Bunting, Iriarte, & Watson, 2016). As such, eHealth may respond to these changing support needs (Perry, Beyer, & Hohn, 2009). Therefore, we have chosen to focus this review on the use of eHealth to support the daily life of people with mild intellectual disability, to improve their participation in the community.

Studies on the use of eHealth among people with mild intellectual disability range from a focus on treatment and therapy settings (e.g., Cooney et al., 2017; Vereenoghe et al., 2017) to studies focusing on support for daily life (e.g., Boot, Owuor, Dinsmore, & MacLachlan, 2018; Perry, Beyer, & Holm, 2016). Both support and treatment/therapy are important domains that contribute to a good life or decrease or resolve mental health problems among people with mild intellectual disability (Thompson et al., 2009; Watfern et al., 2019). Whereas eHealth interventions in treatment or therapy settings are primarily focused on mental health problems or challenging behaviour using an individual approach within a limited timeframe, support is often needed lifelong and is primarily focused on promoting personal functioning to enable participation. Hence, the difference between eHealth interventions focusing on support on the one hand and treatment/therapy on the other is likely to have consequences for the features of the eHealth interventions. For that reason, the data will result in two reviews, one focusing on the use of eHealth on supporting people with mild intellectual disability in daily life and another based on studies using eHealth in a treatment and therapy setting (Oudshoorn et al., 2021).

In order to use eHealth effectively in supporting people with mild intellectual disability in daily functioning, it is necessary to gain insight into the needs, preferences, and characteristics of people with mild intellectual disability, the environmental factors, and the functions and features of the eHealth applications (Scherer, Vanbiervliet, Cushman, & Scherer, 2005). Yardley and colleagues (2016) moreover state that the effective use of eHealth is strongly influenced by a person-based approach in which eHealth is tailored to users' abilities, needs, and level of language comprehension. Research into factors which influence effective eHealth use emphasizes the importance of involving all stakeholders and the interdependencies between human characteristics, technology, and the environment (Van Gemert-Pijnen et al., 2011). These factors are incorporated into the Matching Person and Technology (MPT) model (e.g., Scherer et al., 2005; Scherer & Craddock, 2002). MPT distinguishes three primary areas that need to be assessed for eHealth to be effective: 1) service users' characteristics, 2) environmental factors, and 3) functions and features of the eHealth application. The MPT model advocates for personalising the planning, design, and implication of eHealth applications so they are based on a service user's individual needs and preferences and aligned to the environment. There should be a match – from the standpoint of the service user – between the functions and features of the technology and the needs and preferences of the service user, as well as the environment in which the eHealth application will be used by the service user. When there is a match, the service user will be more inclined to use and benefit from the eHealth application, for example to be satisfied as well as to experience improved outcomes, such as quality of life. Hence, by distinguishing

these three areas, MPT is a practical as well as a research resource to identify significant aspects for effective eHealth use in people with an intellectual disability.

Various reviews (e.g., Collins & Collet-Klingenberg, 2018; Den Brok & Sterkenburg, 2015; Kagohara et al., 2013; Ramdoss et al., 2012) have already been conducted regarding the use of eHealth among people with intellectual disability, but this systematic review is the first to disassemble the key areas of client needs and preferences, environmental factors, and functions and features of eHealth applications. The central aim of this study is to gain insight into how eHealth is used to support people with mild intellectual disability in their daily life. In order to do this, a clear framework of relevant factors matching an individual with a specific eHealth application is required (Scherer et al., 2002). The MPT model provides such a framework of relevant factors and was therefore used as a guideline in describing the eHealth applications and related factors in the papers included in this review. Moreover, it provides the opportunity to identify potential knowledge gaps and formulate recommendations for future research regarding the needs and preferences of people with mild intellectual disability, the environmental factors, and the functions and features of the eHealth applications. The increasing use of eHealth to provide healthcare for people with mild intellectual disability underlines the urgency of this overview.

## 2. Method

### 2.1. Search strategy

Seven bibliographic databases (Embase, Medline (Ovid), Cochrane, Web of Science, PsycINFO (Ovid), CINAHL (EBSCO), and Google Scholar) were systematically searched on 5 September 2018, using a preset search string which was composed with the help of an experienced information specialist. Embase, Medline, Web of Science, and Google Scholar were chosen as they provide an optimal database combination for medically oriented systematic reviews (Bramer et al., 2017). In addition, PsycINFO and CINAHL were chosen as these databases focus primarily on studies in the field of behavioural sciences, mental health, nursing, and allied health. Finally, Cochrane was chosen as it contains high-quality studies with independent evidence to inform decision-making in healthcare. Hence, the combination of these seven databases includes medically oriented as well as psychologically oriented literature and was expected to contain all relevant studies. Studies had to have been published in English in peer-reviewed journals between January 1996 and September 2018. An updated search was conducted on 6 September 2019 to explore the most recent studies.

The PICO approach, specifying Population, Intervention, Comparison, and Outcome, was used to compose the search string and to determine the inclusion and exclusion criteria (Liberati et al., 2009). *Population* was specified as people with mild intellectual disability (IQ 50-69) (Carr, Linehan, O'Reilly, Noonan Walsh & McEvoy, 2016); people with more severe ID (IQ < 50) were excluded. Studies containing a mixed population of people with mild to moderate ID were included either when results were reported separately for both target populations or when no statistical differences were reported between the two target populations. Regarding the *Intervention*, studies should concern the use of eHealth in providing support for people with mild intellectual disability working closely together with a professional (e.g., healthcare provider). eHealth facilitating tasks of professionals (e.g., a digital scoring program for tests), communication between healthcare professionals themselves, surveillance technology, and specific communication (e.g., high-tech augmentative and alternative communication (AAC)), or assistive technology for motor problems (e.g., electronic wheelchair with eye tracking control) were not included in this review. Support was defined as "resources and strategies that aim to promote the development, education, interests, and the personal well-being of a person and that enhance personal functioning" (Thompson et al., 2009, p. 135). Initially, the *Comparison* and *Outcome* components were not specified in the search strategy as eHealth is a novel and emerging area in healthcare provision for people with mild intellectual disability and hence all information about eHealth in the context of professional support was considered to be of interest for this study. Similarly, study designs were not specified as various designs could provide relevant information for this review. However, given the substantial number of studies identified (see Figure 1), studies were only selected in the screening phase when the results focused on adaptive skills (except academic skills trained in an educational context) or aspects related to personal and emotional wellbeing. Because of the aim to provide an overview of how eHealth is used to support people with mild intellectual disability in their daily life, we focus on adaptive skills and personal and emotional well-being (Arvidsson & Granlund, 2016; Boot et al., 2018). Conceptual skills (e.g., mathematics, science) trained in an educational context were not included in this review. Furthermore, this selection increased the homogeneity of studies.

Table 1 provides an overview of the search terms and strategy applied in Embase using both Emtree and additional text words for "intellectual disability", "eHealth", and "support". Emtree is a controlled vocabulary thesaurus that Embase uses for indexing articles. Other databases have similar thesauri (e.g., PubMed uses Medical Subject Headings (MeSH)). As can be seen in Table 1, in order to optimize the search strategy, eHealth terms were embedded in support terms for more relevant results (Bramer et al., 2017) and combined with text words referring to "intellectual disability". It should also be noted that, in addition to the term "support", the terms "therapy", and "assessment"

were also included in the research strategy. These terms were included as we initially wanted to cover a broad range of concepts related to eHealth. However, given the large number of relevant studies remaining after the screening phase (see Figure 1), the decision was made to focus this review on eHealth in support of daily life (another review will focus on the use of eHealth in psychological interventions and therapy). With the help of an experienced information specialist, similar search strategies were used in the other databases.

**Table 1.** Search strategy Embase using MeSH Emtree and additional text words

EMBASE final search strategy
<p>(‘telehealth’/de OR ‘telemedicine’/de OR ‘teleconsultation’/de OR ‘telepsychiatry’/de OR ‘telerehabilitation’/de OR ‘teletherapy’/de OR ‘assistive technology’/de OR ‘computer assisted therapy’/de OR microcomputer/exp OR ‘e-mail’/de OR ‘Internet’/de OR ‘social media’/de OR ‘mobile phone’/exp OR ‘information technology’/de OR multimedia/de OR ‘educational technology’/exp OR ‘self-help device’/de OR ‘text messaging’/de OR (Telehealth* OR Telecare* OR telemedicine* OR teleconsultat* OR telepsychiatr* OR telemonitor* OR teletherap* OR telerehab* OR ((Tele OR telephone) NEXT/3 (health* OR medicine* OR consultat* OR psychiatr* OR therap* OR monitor* OR rehab*)) OR e-health OR ehealth OR mHealth OR (((assist* OR therap* OR aided OR treat* OR deliver* OR application* OR support* OR training OR education* OR learning OR surveillan* OR counsel* OR cbt OR intervent* OR rehabilitat* OR assessment* OR feedback OR support OR care OR help OR service OR assistance OR self-help) NEAR/3 (technolog* OR media OR computer* OR Web-based OR Website* OR web-interface* OR webinterface* OR web-page* OR web-resource* OR webpage* OR website* OR email OR online OR Internet OR computer*-program* OR software OR cyber* OR Remote OR virtual* OR device* OR ‘text messaging’ OR sms OR whatsapp OR skype)) NOT assist*-reproduct*-technol*) OR (((e OR electronic*) NEXT/1 (mail* OR health)) NOT electronic-health-record*) OR ‘social media’ OR ((mobile OR cell*) NEXT/1 phone*) OR smartphone* OR microcomputer OR ipad OR ipads OR (tablet* NEAR/3 (use OR usage)) OR ‘information technology’ OR multimedia OR domotic*);ab,ti)</p> <p>AND (‘intellectual impairment’/de OR ‘mental deficiency’/exp OR ‘learning disorder’/de OR ‘developmental disorder’/de OR (((mental* OR intellect* OR learning OR developmental* OR neurodevelopmental*) NEAR/3 (retard* OR impair* OR deficien* OR disab* OR handicap* OR difficult* OR limitation* OR delay*)) OR multipl*-disab* OR cognitive-disabilit* OR learning-disorder* OR (cognitive-impairment* NOT (dement* OR alzheimer* OR parkinson OR psychiatr* OR older OR aged OR elderly OR injur*)) OR development*-disorder* OR retarded OR (down* NEAR/3 (syndrome*));ab,ti) NOT ([animals]/lim NOT [humans]/lim) NOT ([Conference Abstract]/lim OR [Letter]/lim OR [Note]/lim OR [Editorial]/lim) AND [english]/lim</p>

## 2.2. Study selection

In line with the PRISMA guidelines (Liberati et al., 2009), the selection process consisted of four phases: (1) identification, (2) screening, (3) eligibility, and (4) inclusion (see Figure 1). First, in the identification phase, studies were identified in the seven different databases, returning 10,405 studies. Next, in the screening phase, 3,991 duplicates and 721 studies exceeding the publication date limit (< 1996) were removed, reducing the number of studies to 5,693. After this step, the titles and abstracts of the remaining studies were screened independently in two rounds by two reviewers (CO and NF) based on the inclusion criteria (see Table 2) in order to remove evidently unsuitable studies. Titles and abstracts were screened in two rounds. As eHealth is relatively uncharted

territory in the intellectual disability field, an initial screening was conducted with a broad focus to select all studies targeting people with intellectual disability and eHealth use in the most significant healthcare domains, namely assessment, support and treatment and therapy. In the second round, we focused on studies with participants with mild intellectual disability in which eHealth was used to support daily life. The data from the studies using eHealth in a treatment and therapy setting will be discussed in another review (Oudshoorn et al., 2020). Book chapters, duplicates, reviews, essays, and dissertation abstracts were excluded. This strategy resulted in 90% agreement between the two reviewers. Differences in judgment were discussed with a third reviewer (PE) until full consensus was reached.

**Table 2.** *Inclusion and exclusion criteria of identified studies*

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**Inclusion criteria**

- Studies focusing on people with mild intellectual disability (IQ 50-69).
  - Studies focusing on providing support using eHealth/ technology
  - Studies focusing on individual psychological or behavioral outcomes (e.g., participation, belonging, self-confidence, empowerment, self-determination, independency, emotional well-being, improvement personal skills in daily life)
- 

**Exclusion criteria**

Participants:

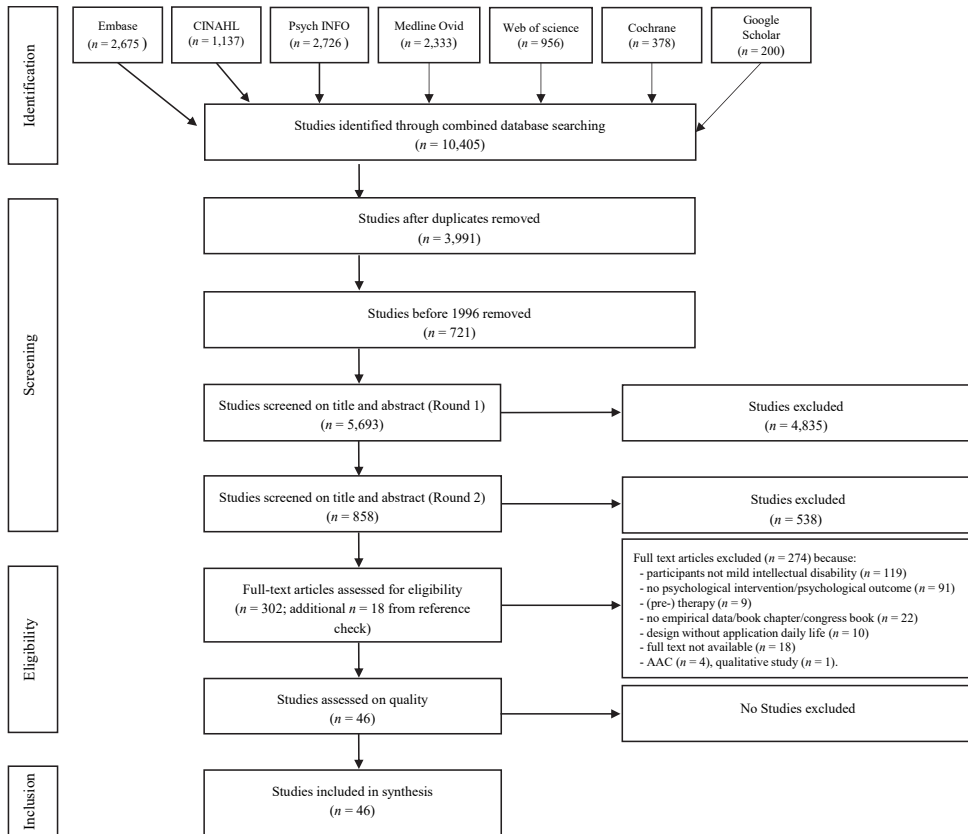
- Studies focusing on people with IQs below 50 and 70 and above
- Studies focusing on people with cognitive disabilities/impairments due to traumatic brain injury, stroke, cancer treatment or (early) dementia

Intervention:

- Studies focusing on using technology (e.g., online questionnaire or internet) to collect data for research without providing health care
  - Studies focusing on design of eHealth with results focusing on, among others, speed, accuracy, and accessibility without any application in real life situation
  - Studies focusing on training cognitive or neurocognitive skills (e.g., working memory, attention, visual spatial skill), training academic skills within an educational context (e.g., reading, mathematics, writing), or assistive technology in case of specific learning disorders (e.g., dyslexia, dyscalculia)
  - Studies focusing on learning to operate a (specific) technological application (e.g., learning to operate a mouse, training computer abilities, operate cognitive accessible mobile phone)
  - Studies focusing on using or learning to use high tech augmentative and alternative communication (AAC) applications or training motor skills with technology
  - Studies focusing on eHealth supporting workflow of professionals (e.g., electronic health records)
  - Studies focusing on using domotica/surveillance technology as standalone eHealth application
  - Studies not reporting psychological or behavioral outcomes.
  - Studies focusing on providing treatment / therapy using eHealth / technology
- 

General:

- Studies without empirical data (e.g., policy documents, conference papers, proposal clinical trial) or opinion papers
  - Studies presenting only psychometric data (i.e., validity and reliability of an instrument)
-



**Figure 1.** Flowchart of study selection for systematic review

Next, in the eligibility phase, the full texts of 302 studies were read by two reviewers (CO and NF) and two colleagues experienced in intellectual disability research. The full texts were assessed against the inclusion and exclusion criteria (see Table 2). In case of uncertainty about the criteria, the authors of the study were contacted for clarification. Differences in judgement were discussed with all reviewers, until full consensus was reached. At this stage, 274 studies were excluded for various reasons (see Figure 1), resulting in the inclusion of 28 eligible studies in this review. The reference lists of these studies were searched for potential eligible studies and led to an additional 18 eligible studies, giving a total of 46 studies included in the review.

The next step in the eligibility phase was to assess the quality of the studies included. As this review included studies with a mixture of single-case and group designs, a quality appraisal tool specifically designed to assess both designs was required. Therefore, in line with previous systematic reviews focusing on people with intellectual disability (e.g., NcNair, Woodrow, & Hare, 2017; Patterson, Williams, & Jones, 2019), the Evaluative

Method for Determining Evidence Based Practice (EMDEBP) (Reichow et al., 2008) was used. Although this tool uses different criteria for single-case and group designs, both types of studies are evaluated on primary quality indicators (e.g., participant characteristics and visual analysis) and secondary quality indicators (e.g., interobserver agreement and fidelity). Primary quality indicators were rated on an ordinal scale (i.e., unacceptable, acceptable, and high quality) whereas secondary quality indicators were rated on a dichotomous scale (Evidence or No Evidence of indicator). Using a codebook, the studies were scored on the quality indicators. The first author (CO) rated all studies; 11 studies (23.9%) were independently scored by a second reviewer (SN) to reduce reviewer bias (Mc Donagh, Peterson, Raina, Chang & Shekelle, 2013). The level of agreement between the two reviewers was 71%; disagreements were discussed until full consensus was reached and adaptations were made to the codebook to optimise the descriptions of items. Afterwards, the scoring was discussed with all authors. The ratings from the primary and secondary quality indicators were then combined to compute an overall research report strength: weak (i.e., high-quality and evidence ratings on less than half the primary and secondary indicators, respectively), adequate (i.e., high-quality ratings on most primary indicators and evidence ratings on about half the secondary indicators), or strong (i.e., high-quality ratings on all primary indicators and evidence ratings on most secondary indicators).

Table 3 provides an in-depth summary of the ratings on the primary and secondary quality indicators of the EMDEBP tool. Nine out of ten studies using a group design were rated as having weak research report strength; the study by Fage and colleagues (2018) was rated as having adequate research report strength. Regarding primary indicators, all received mainly acceptable ratings. This suggests that group design studies (a) provided sufficient demographic and clinical information about their participants, (b) chose appropriate outcome measures given their indicated goals, (c) employed control groups, (d) provided sufficient information regarding their intervention and outcome measures, and (e) applied appropriate statistical tests to measure the effectiveness of interventions. With respect to secondary indicators, group design studies consistently demonstrated evidence of effect size. However, there was little to no evidence of random assignment, interobserver agreement, blind raters, fidelity, attrition, generalization, and social validity. Indeed, as none of the group design studies used a randomized controlled trial (RCT) design, the expectation was that there would be no evidence of random assignment and blind raters. Without these measures, it becomes rather difficult to distinguish the true effect of an intervention from potential individual differences and biased scores on outcomes. It should be noted however that Fage and colleagues (2018) used a single-blind condition (i.e., the researchers were unfamiliar with the medical condition of the groups of participants during the intervention).



Out of the thirty-six studies using a single-case design, 10 studies were rated as having weak research report strength, 13 had acceptable research report strength, and 13 had strong research report strength. Overall, all primary indicators (i.e., participant characteristics, independent variable, dependent variable, baseline condition, visual analysis, and experimental control) received mainly acceptable to high ratings, suggesting that single-case design studies: (a) described their participants, their interventions and outcomes sufficiently, (b) were properly controlled, and (c) presented the required data visually. In terms of secondary indicators, there was no evidence of kappa or blind raters. In addition, there was evidence of fidelity in 26 studies and evidence of social validity in 19 studies. In 32 studies evidence was obtained for interobserver agreement and in 30 studies evidence was obtained for generalization.

Overall, as half of the included studies have adequate to strong research report strength, the evidence base for the use of eHealth in supporting people with mild intellectual disability in daily life functioning can be considered promising (Reichow et al., 2008).

### **2.3. Data extraction and analysis**

A narrative analysis was used based on qualitative descriptions regarding the use of eHealth in the studies included. A coding scheme was developed based on the MPT model to extract data about the participants and their living arrangements, the environment, and the eHealth application that was used in the intervention. In accordance with that scheme, we extracted the following data about the characteristics of service users: gender, age, comorbidity, and previous experience with technology. The data extracted about the environmental factors focused on where and by whom the intervention was delivered and whether the researchers worked closely together with relatives or other people who were significant to the person with mild intellectual disability. Finally, we extracted data about the features and functions of the eHealth application, for example: the kind of application, the goal it was used for, and opportunities for personal customization of the application.

**Table 3.** (a) Results critical appraisal group design studies. (b) Results of critical appraisal single-case design studies

<b>(a)</b>						
<b>Primary quality indicators</b>						
	<b>Participant characteristics</b>	<b>Independent variable</b>	<b>Comparison condition</b>	<b>Dependent variable</b>	<b>Link research question - data analysis</b>	<b>Use statistical analysis</b>
<b>Group research</b>						
1. Davies et al.(2002a)	H	A	A	A	A	A
2. Davies et al.(2002b)	A	H	H	H	U	A
3. Davies et al.(2003a)	A	A	H	U	H	H
4. Davies et al.(2003b)	U	A	H	H	A	H
5. Padgett et al.(2006)	A	A	A	A	A	U
6. Davies et al.(2010)	A	A	A	A	A	A
7. Stock et al.(2013)	A	A	U	A	A	H
8. De Wit et al. (2015)	A	A	A	H	H	A
9. Kerkhof et al.(2017)	A	A	H	U	A	U
10. Fage et al. (2018)	H	A	H	H	H	H
Total	U = 1	U = 0	U = 1	U = 2	U = 1	U = 2
	A = 7	A = 9	A = 4	A = 4	A = 6	A = 4
	H = 2	H = 1	H = 5	H = 4	H = 3	H = 4

<b>(a) Continued</b>								
<b>Secondary quality indicators</b>								
<b>Random assignment</b>	<b>Interobserver agreement</b>	<b>Blind raters</b>	<b>Fidelity</b>	<b>Attrition</b>	<b>Generalization and/or maintenance</b>	<b>Effect size</b>	<b>Social validity</b>	<b>Quality</b>
E	NE	NE	NE	E	NE	E	NE	W
NE	NE	NE	NE	NE	NE	E	NE	W
NE	NE	NE	NE	NE	NE	E	NE	W
E	NE	NE	NE	NE	NE	E	NE	W
NE	NE	NE	NE	NE	E	NE	NE	W
NE	E	NE	NE	E	NE	E	NE	W
NE	NE	NE	NE	NE	E	E	E	W
NE	NE	NE	NE	E	NE	NE	E	W
NE	NE	NE	NE	NE	NE	NE	E	W
NE	NE	E	NE	E	NE	E	E	A
NE = 8	NE = 9	NE = 9	NE = 10	NE = 6	NE = 8	NE = 3	NE = 6	A = 1
E = 2	E = 1	E = 1	E = 0	E = 4	E = 2	E = 7	E = 4	W = 9

Note. H = high quality, A = adequate quality, U = unacceptable quality. E = evidence of indicator, NE = no evidence of indicator. W = weak report strength and A = adequate report strength

<b>(b)</b>						
<b>Primary quality indicators</b>						
<b>Single subject research</b>	<b>Participant characteristics</b>	<b>Independent variable</b>	<b>Dependent variable</b>	<b>Baseline condition</b>	<b>Visual analysis</b>	<b>Experimental control</b>
11. Sigafos et al. (2005); USA	A	H	H	H	H	H
12. Cannella-Malone et al.(2006); USA	A	H	H	H	H	H
13. Van Laarhoven & Van Laarhoven-Myers (2006); USA	A	A	U	U	H	H
14. Sigafos et al. (2007); AUS	A	H	H	H	H	H
15. Cihak & Schrader (2008); USA	H	H	H	H	H	H
16. Hansen & Morgan (2008); USA	A	H	H	H	H	H
17. Mechling & Gustafson (2008); USA	U	H	H	H	H	H
18. Ayres et al.(2009); USA	H	H	H	H	H	H
19. Mechling et al.(2009); USA	A	H	H	H	H	H
20. Van Laarhoven et al.(2009); USA	H	H	H	H	H	H
21. Ayres & Cihak (2010); USA	H	H	H	A	U	H
22. Mechling & O'Brien (2010); USA	A	H	H	H	H	H
23. Taber-Doughty et al.(2010); USA	A	H	H	H	H	H
24. Van Laarhoven et al. (2010); USA	H	H	H	A	H	H
25. Mechling & Savidge (2011); USA	U	H	H	H	A	H
26. Taber-Doughty et al.(2011); USA	H	H	H	A	U	U
27. Bereznak et al.(2012); USA	H	H	H	H	H	H
28. Van Laarhoven et al.(2012); USA	A	A	U	U	U	U
29. Alexander et al.(2013); USA	H	H	H	H	H	H
30. Bouck et al.(2014); USA	A	H	H	H	H	H
31. Campillo et al. (2014); SPA	H	H	H	A	U	H
32. Burckley et al. (2015); USA	H	H	H	H	A	A
33. McMahon et al.(2015); USA	H	H	H	H	H	H

<b>(b) Continued</b>						
<b>Primary quality indicators</b>						
<b>Single subject research</b>	<b>Participant characteristics</b>	<b>Independent variable</b>	<b>Dependent variable</b>	<b>Baseline condition</b>	<b>Visual analysis</b>	<b>Experimental control</b>
34. Smith et al.(2015); USA	H	H	H	H	H	H
35. Spriggs et al.(2015); USA	H	H	H	H	H	H
36. Goo et al.(2016); USA	H	H	H	H	H	H
37. Smith et al.(2016); USA	H	A	H	H	H	H
38. Cavkaytar et al. (2017); TR	H	H	H	H	H	H
39. Cullen et al.(2017a); USA	A	H	H	H	H	H
40. Cullen et al. (2017b); USA	A	H	H	H	H	H
41. Douglas et al. (2018); USA	H	H	H	H	H	H
42. Golish et al. (2018); USA	A	H	U	A	A	H
43. Orum Çattik & Ergenekon (2018); TR	A	H	H	H	H	H
44. Price et al.(2018); USA	A	A	H	A	H	H
45. Shepley et al.(2018); USA	H	H	H	H	H	H
46. Van Laarhoven et al.(2018); USA	A	H	H	H	H	H
Total	U = 2 A = 16 H = 18	U = 0 A = 4 H = 32	U = 3 A = 0 H = 33	U = 2 A = 6 H = 28	U = 4 A = 3 H = 29	U = 2 A = 1 H = 33

<b>(b) Continued</b>						
<b>Secondary quality indicators</b>						
<b>Interobserver agreement</b>	<b>Kappa</b>	<b>Fidelity</b>	<b>Blind raters</b>	<b>Generalization and/or maintenance</b>	<b>Social validity</b>	<b>Quality</b>
E	NE	NE	NE	E	NE	<b>A</b>
E	NE	E	NE	NE	E	<b>A</b>
E	NE	E	NE	E	NE	<b>W</b>
E	NE	NE	NE	E	NE	<b>A</b>
E	NE	E	NE	E	E	<b>S</b>
NE	NE	NE	NE	E	NE	<b>W</b>
E	NE	E	NE	E	NE	<b>W</b>
E	NE	E	NE	E	E	<b>S</b>
E	NE	E	NE	E	NE	<b>A</b>

<b>(b) Continued</b>						
<b>Interobserver agreement</b>	<b>Secondary quality indicators</b>					<b>Quality</b>
	<b>Kappa</b>	<b>Fidelity</b>	<b>Blind raters</b>	<b>Generalization and/or maintenance</b>	<b>Social validity</b>	
E	NE	E	NE	E	E	<b>S</b>
E	NE	E	NE	E	NE	<b>W</b>
E	NE	E	NE	E	E	<b>A</b>
E	NE	E	NE	E	E	<b>A</b>
E	NE	E	NE	E	E	<b>A</b>
E	NE	E	NE	E	NE	<b>W</b>
E	NE	NE	NE	E	E	<b>W</b>
E	NE	E	NE	E	NE	<b>S</b>
E	NE	E	NE	NE	E	<b>W</b>
E	NE	E	NE	E	NE	<b>S</b>
E	NE	E	NE	E	E	<b>A</b>
E	NE	NE	E	NE	NE	<b>W</b>
E	NE	NE	NE	E	E	<b>A</b>
E	NE	E	E	NE	E	<b>S</b>
E	NE	E	NE	E	NE	<b>S</b>
E	NE	E	NE	E	E	<b>S</b>
E	NE	E	NE	E	E	<b>S</b>
E	NE	E	NE	E	NE	<b>S</b>
E	NE	E	NE	E	E	<b>A</b>
E	NE	E	NE	E	E	<b>S</b>
E	NE	E	NE	E	E	<b>A</b>
E	NE	E	NE	E	E	<b>A</b>
E	NE	E	NE	E	E	<b>S</b>
E	NE	E	NE	E	E	<b>S</b>
E	NE	E	NE	E	NE	<b>W</b>
E	NE	NE	E	E	NE	<b>W</b>
NE	NE	NE	NE	E	E	<b>A</b>
NE	NE	NE	NE	E	NE	<b>W</b>
E	NE	E	NE	E	NE	<b>S</b>
E	NE	E	NE	NE	E	<b>A</b>
NE = 3	NE = 36	NE = 9	NE = 33	NE = 5	NE = 16	S = 12
E = 33	E = 0	E = 27	E = 3	E = 31	E = 19	A = 14
						W = 10

Note. H = high quality, A = adequate quality, U = unacceptable quality. E = evidence of indicator,

NE = no evidence of indicator. W = weak report strength, A = adequate report strength, and S = strong report strength

### 3. Results

The characteristics of the 46 studies included in the review are presented in Table 4. After a brief description of the designs, the country of origin, the number of participants in the studies, and the function of eHealth, the studies will be examined with reference to the three key areas of MPT: service users' characteristics (i.e., personal and psychosocial

characteristics, needs, and preferences), environmental factors, and features of eHealth applications.

Regarding the design of the studies included, the vast majority of the studies applied a quantitative design ( $n = 44$ ); two studies used a mixed-method design. Ten studies applied a group design and 36 studies used a single-case design. The majority of the single-case design studies ( $n = 25$ ) used a multiple (probe) baseline design, nine studies used an (alternative) alternating treatment design (A-ATD), and two studies used an AB design. Six of the studies explicitly stated that the study was a feasibility study, a beta-study, or a pilot evaluation (Campillo et al., 2014; Davies et al., 2002b; Davies et al., 2003b; Fage et al., 2018; Kerkhof et al., 2017; De Wit et al., 2015).

The vast majority of the studies were conducted in the USA ( $n = 39$ ). The remaining studies were conducted in the Netherlands ( $n = 2$ ), Turkey ( $n = 2$ ), Australia ( $n = 1$ ), France ( $n = 1$ ), and Spain ( $n = 1$ ). Studies with six participants or fewer predominantly focused on eHealth for support in daily life ( $n = 38$ ); most studies were small-scale case studies with six participants or fewer.

The eHealth applications described in the studies can be divided into three distinct functions in the support of daily living (see Table 4). First, eHealth is primarily used as a temporary aid to facilitate training or learning a single daily living skill, a practical skill performed in the community, a vocational skill, or a combination of these skills, such as purchasing groceries (e.g., Ayres et al., 2009; Sigafos et al., 2005). Second, eHealth is used as a permanent support aid in a home situation or vocational context for people with mild intellectual disability themselves, for example to support independent task completion (e.g., Golish et al., 2018; Van Laarhoven et al., 2009). Third, eHealth is used as a facilitator for remote professional support to carry out daily activities, such as video calling to ask for help or remote coaching via a Bluetooth earpiece (e.g., Cavkaytar et al., 2017; Taber-Doughty et al., 2010).

### **3.1. Service users' characteristics**

#### ***3.1.1. Personal and psychosocial characteristics***

In total, the studies included in the review reported on 346 participants (197 male) of whom 210 had mild intellectual disability (IQ 50-70). This review therefore focuses on the outcomes related to these 210 people. Autism spectrum disorder was the most frequently-reported comorbidity in 24 studies. Although most participants were adults aged between 18 and 65 ( $n = 162$ ; 77%), half of the studies ( $n = 23$ ) specifically focused on children ( $n = 48$ ; 23%). Twelve studies reported on one or more participants with mild intellectual disability and challenging behaviour such as aggression and anxiety or

using psychotropic medication (Ayres et al., 2009; Ayres & Cihak, 2010; Bezernak et al., 2012; Bouck et al., 2014; Burckley et al., 2015; Campillo et al., 2014; Mechling et al., 2009; Mechling & O'Brien, 2010; Mechling & Savidge, 2010; Spriggs et al., 2015; Taber-Doughty et al., 2011; Van Laarhoven & Van Laarhoven-Myers, 2006).

### 3.1.2. Needs

Only one study specifically reported a systematic and methodical approach to determining the needs of participants *before* starting the intervention with eHealth. That is, Golish et al. (2018) used a participant-centred interview to inventory tasks in which the participants required assistance because they found independent completion difficult. In this study, support staff delivered information on task priorities first and then the participant decided which task to target for the intervention. Eight studies reported objectives in an Individual Education Plan (IEP), which could be considered as a systematic inventory of needs (Alexander et al., 2013; Ayres & Cihak, 2010; Bezernak et al., 2012; Bouck et al., 2014; Cavkaytar et al., 2017; Goo et al., 2016; Mechling et al., 2009; Smith et al., 2016).

### 3.1.3. Preferences

Three studies reported service users' preferences *before and after* the intervention, by asking participants about their preference for using an iPad or a pen or pencil (Bouck et al., 2014), about preferred strategies for successful task performance (Taber-Doughty et al., 2011), and about participants' preferences regarding onsite and remote support staff (Taber-Doughty et al., 2010). Motivation and preference related to the target skill were determined in four studies. In two studies this was done in order to add relevant reinforcers to the device (Burckley et al., 2015; Mechling & Savidge, 2011). In one study, the participant preferred to start with a given task because he perceived it as easy to complete (Golish et al., 2018), and in another study, the content of the applications was personalised (e.g., by adding personal photos and videos) to the preferences of the participants (Fage et al., 2018). Four studies reported the preferences of participants who were asked a simple preference question with respect to the instructional method on a device or the tool in the intervention (Cihak & Schrader, 2008; McMahon et al., 2015; Mechling et al., 2009; Mechling & Savidge, 2011).

Table 4. Characteristics of the included studies

Author (year), country	Design	Participants	Technology/features of applications	Type of support	Support function
<b>Group design studies</b>					
1. Davies et al. (2002a); USA	2 groups BSD	N = 12; IQ = mean 62.6 (range 45-90; all except 1 < 70 WAIS-R) 4 F/8 M Age 19-46	Automated multimedia Scheduling system designed to operate on the Windows CE palmtop computer platform	Task completion and Self-regulation in time-management	SS
2. Davies et al. (2002b); USA	Beta study; 2 groups WSD	N = 10; IQ = 54.8 (SD 10.37; range 39-72; WAIS-R) 2 F/8 M Age 18-70	Visual Assistant prototype	Complete vocational skills independently (pizza box assembly + software package)	SS
3. Davies et al. (2003a); USA	Pilot-study with a WSD	N = 9; IQ average 65.1 (range 56-72) 4 F/ 5 M Age 25-58	ATM-SIM is a multimedia training tool	Skill teaching by simulation (money ATM)	SLS
4. Davies et al. (2003b); USA	2 two-group, WSD design (beta-testing)	N = 40, mean IQ = 55.53 (SD 10.69, range 24-76) 17 F/ 23 M Age mean 29.38 (SD 10.97, range 18-54)	Pocket PC palmtop computer platform	Decision making in vocational tasks	SS
5. Padgett et al. (2006); USA	MPB	N = 5; FAS 4 > mild intellectual disability, 1 mild intellectual disability (mild: 55-69) 1 F/4 M Age 5-7	VR game	Skill teaching (fire safety skills)	SLS
6. Davies et al. (2010); USA	BSD two treatment conditions	N = 23; IQ = mean 54.32 (range 40-66). EG mean IQ = 52 (SD 8.39), CG mean IQ = 57.50 (SD 4.96). 14 F/ 9 M Age 18-49	Wayfinder (specially designed, cognitively accessible GPS based software prototype)	Facilitate independent bus traveling	SS
7. Stock et al. (2013); USA	n.r.	N = 26, average IQ = 56.1 (SD = 9.56; range 36-73) 14 F/ 12 M Age average 32.3 (SD 9.77; range 18-52);	Wayfinder (specialized GPS-based system) + Pharos 600e smartphone	Facilitate independent bus traveling	SS



Table 4. Continued

Author (year), country	Design	Participants	Technology/ features of applications	Type of support	Support function
8. De Wit <i>et al.</i> (2015); NL	Uncontrolled feasibility study	N = 39; 29 CPP and 10 mild intellectual disability; 4 F/6 M Age 47.6 (SD 8.4)	Web-based program MPC	Enabling professional support in daily functioning	FRCP
9. Kerkhof <i>et al.</i> (2017); NL	Participatory design and two pilots using pre- and post-test design	N = 7; 1 ASD no intellectual disability, 3 moderate intellectual disability, 3 mild intellectual disability; ASD, epilepsy	Memory application on individual touch screens	Structure and support daily activities	SS
10. Fage <i>et al.</i> (2018); FR	Co-design and pre- and post-intervention assessment	N = 48; 29 ASD and 19 intellectual disability, intellectual disability IQ = 60.53 (SD 4.50) WISC IV 10 F/ 9 M Age 14.23 (SD 0.29)	iPad + assistive applications and socio-cognitive remediation applications	Assisting to perform classroom routines in mainstream classrooms and providing exercises for socio-cognitive processes	SLS + SS
<b>Single-case designs</b>					
11. Sigafoos <i>et al.</i> (2005); USA	Delayed MPB across subjects	N = 3; 2 moderate intellectual disability, 1 mild intellectual disability (IQ = 50) 3 M Age 34-36	Portable Window XP-based Mercury MiniMerc TM computer + video	Skill teaching (popcorn in microwave)	SLS
12. Cannella-Malone <i>et al.</i> (2006); USA	MPB across subject with ATD	N = 6; 4 moderate intellectual disability, 2 mild intellectual disability (IQ = 51 and 69), ASD 1 F/5 M Age 27 and 36	Portable Window XP-based Mercury MiniMerc TM computer + instructional video	Skill teaching (setting table, putting away groceries)	SLS
13. Van Laarhoven & Van Laarhoven-Myers (2006); USA	within-subject adapted alternating treatment design	N = 3; 1 moderate intellectual disability, 2 mild intellectual disability (IQ = 51 and 52) 1 F/ 2 M Age 17 - 19	Laptop computer + video	Skill teaching (laundry, washing table and microwave pizza)	SLS
14. Sigafoos <i>et al.</i> (2007); AUS	MPB across subjects	N = 3; 2 moderate intellectual disability, 1 mild intellectual disability (IQ = 69), ASD 3 M Age 27	Portable Windows XP-based Mercury MiniMerc TM computer + video	Skill teaching (wash dishes)	SLS

Table 4. Continued

Author (year), country	Design	Participants	Technology/ features of applications	Type of support	Support function
15. Cihak & Schrader (2008); USA	ATD	N = 4; 2 SID, 1 moderate intellectual disability, 1 mild intellectual disability (IQ = 50), ASD 4 M Age 16	Laptop computer + video	Skill teaching (preparing family packs and first aid kits, making copies and sending fax)	SLS
16. Hansen & Morgan (2008); USA	MBD across participants	N = 3; 2 moderate intellectual disability, 1 mild intellectual disability (IQ = 55) 3 M Age 16-17	DVD and CD-ROM instruction + computer	Skill teaching (purchase in grocery store)	SLS
17. Mechling & Gustafson (2008); USA	AATD	N = 6; 4 moderate intellectual disability, 2 mild intellectual disability (IQ = 54 and 64), ASD 6 M Age 15 - 21	Portable DVD player	Task completion	SLS
18. Ayres et al.(2009); USA	MPB across behavior and replicated across participants	N = 3; 2 n.r., 1 mild intellectual disability (IQ = 53), ASD 1 F/ 2 M Age 7-9	I Can!- Daily Living and Community Skills (Sandbox Learning Company, n.d.) software + computer	Skill teaching (setting table, making soup and a sandwich)	SLS
19. Mechling et al.(2009); USA	MPB across three cooking recipes	N = 3; 1 BF, 1 moderate intellectual disability, 1 mild intellectual disability (IQ = 51), ASD 3 M Age 16 - 17	The Cyrano Communicator TM (Hewlett Packard iPAQ Pocket PC with pre-installed software)	Task completion by self-monitoring (cooking recipes)	SS
20. Van Laarhoven et al.(2009); USA	MPB across behaviors	N = 1; IQ = 52; 1p36 Deletion Syndrome 1 M Age 17	Video iPod TM	Skill teaching by self-instruction (cleaning bathroom, mopping floor and cleaning kennels)	SLS

Table 4. Continued

Author (year), country	Design	Participants	Technology/features of applications	Type of support	Support function
21. Ayres & Cihak (2010); USA	MPB across behaviors	N = 3; 1 TBI, 1 moderate intellectual disability, 1 mild intellectual disability (IQ = 51) 1 F/ 2 M Age 15	1 Cant! Daily Living and Community Skills software program + computer	Skill teaching (setting table, making soup and a sandwich)	SLS
22. Mechling & O'Brien (2010); USA	MPB across students and one bus route	N = 3; 1 moderate intellectual disability, 2 mild intellectual disability (IQ = 52 and 70); 1 PDD-NOS 2 F/ 1 M Age 19-20	Laptop computer + touchscreen	Skill teaching (public bus transportation)	SLS
23. Taber-Doughty <i>et al.</i> (2010); USA	ATD	N = 4; 2 moderate intellectual disability, 2 mild intellectual disability, 1 hearing impairment 1 F/3 M Age 42-47	computer contained within a secure box + single video camera. Sensors, speakers and microphones, two-way video monitor.	Task completion at home by support of telecare staff	FRCP
24. Van Laarhoven <i>et al.</i> (2010); USA	AATD	N = 2; 1 moderate intellectual disability, 1 mild intellectual disability (IQ = 52) WISC 2 M Age 13-14	laptop computer + video + Power Point presentation	Skill teaching (making microwave pasta and folding laundry)	SLS
25. Mechling & Savidge (2011); USA	MPB across three sets of novel structured work tasks	N = 3; 2 moderate intellectual disability, 1 mild intellectual disability (IQ = 54), ASD/ADHD 1 F/ 2 M Age 14	Cyrano Communicator TM (Pidion BM-150R with pre-installed software by One Write Company).	Task completion and transition (shoebbox tasks and navigation)	SS
26. Taber-Doughty <i>et al.</i> (2011); USA	ATD	N = 3; 2 mild intellectual disability (IQ = 61-72) 3 F Age 12-13	8-G iPad Nanos	Skill teaching (cooking)	SLS

Table 4. Continued

Author (year), country	Design	Participants	Technology/features of applications	Type of support	Support function
27. Bereznak et al.(2012); USA	MPB across behaviors replicated across participants	N = 3; 2 < IQ 40, 1 mild intellectual disability (IQ = 68), ASD 3 M Age 15-18	iPhone 3 G + iPhone app for instructional videos	Skill teaching by self-monitoring (using washing machine, making noodles and using copy machine)	SLS
28. Van Laarhoven et al.(2012); USA	modified pre- and posttest control group design	N = 6; 1 no intellectual disability, 1 BF, 3 moderate intellectual disability, 1 mild intellectual disability (IQ = 65), ASD 1 F/ 5 M Age 16	DVD	Maintenance vocational skill (food preparation)	SLS
29. Alexander et al.(2013); USA	MPB across participants	N = 7; 2 mild intellectual disability (IQ = 57 and 64), ASD 1 F/ 6 M Age 15 - 18	iPad 2	Skill teaching (sorting mail)	SLS
30. Bouck et al.(2014); USA	ATD	N = 3; 1 severe intellectual disability, 1 moderate intellectual disability, 1 mild intellectual disability (IQ = 57), ASD 2 F/ 1 M Age 13-15	iPad2 + Upad lite app to create recipes	Task completion (cooking)	SLS
31. Campillo et al. (2014); SPA	AB	N = 3; 1 SID, 1 n.r., 1 mild intellectual disability (IQ = 58) ASD 1 F/ 2 M Age 19-29	Samsung Q1 Ultra + Tic Tac software	Make time visual	SS
32. Burckley et al. (2015); USA	MPB across setting	N = 1; mild intellectual disability IQ = 54, PDD-NOS; 1 F Age 18	iPad 2 + Book Creator software	Skill teaching (shopping)	SLS
33. McMahon et al.(2015); USA	AATD	N = 6; 1 moderate intellectual disability, 5 mild intellectual disability (IQ = 51-65), 1 ASD 2 F/ 4 M Age 18 - 24	Google Maps on mobile device (iPhone/iPad) + Navigator Heads Up Display app on mobile device (= augmented reality navigation app)	Skill teaching + self-monitoring (traveling and navigation)	SS

Table 4. Continued

Author (year), country	Design	Participants	Technology/ features of applications	Type of support	Support function
34. Smith <i>et al.</i> (2015); USA	MPB across participants	N = 3; 1 n.r., 2 moderate intellectual disability, 1 mild intellectual disability, ASD 3 M Age 15-16	mobile device + iSkills app	Skill teaching + self-initiation (changing computer memory)	SLS
35. Spriggs <i>et al.</i> (2015); USA	MPB across participants	N = 4; 1 n.r., 3 mild intellectual disability (IQ = 50 - 67), ASD, PDD-NOS, ADHD 1 F/ 3 M Age 17 -19	iPad + My Pictures Talk TM application	Independent task transition	SLS
36. Goo <i>et al.</i> (2016); USA	MPB across students	N = 4; 2 moderate intellectual disability, 2 mild intellectual disability (IQ = 55) 4 M Age 18	HP Pavilion g series laptop	Skill teaching (purchasing)	SLS
37. Smith <i>et al.</i> (2016); USA	MPB across settings embedded in a MPB across participants	N = 4; 2 moderate intellectual disability, 1 mild intellectual disability (IQ = 62) BIF (IQ = 72, ASD, SLI) 4 M Age 15-19	iPhone 4s + 20 application icons + videos	Skill teaching by self-instruction (independent initiation self-instruction daily living and vocational tasks)	SLS
38. Cavkaytar <i>et al.</i> (2017); TR	MPB across participants	N = 3; 3 mild intellectual disability (IQ = 68) 3 F Age 19-32	Nokia BH-503 stereo Bluetooth headset + iPad I tablet computer	Skill teaching by combining remote professional and self-support	SLS + FRCP
39. Cullen <i>et al.</i> (2017a); USA	MPB across tasks; MPB across participants	N = 3; 1 no intellectual disability, 1 n.r., 1 mild intellectual disability (IQ = 74) 3 M Age 22	iPad + My Pics Talk app	Task completion by self-direction (tasks in integrated employment settings)	SS
40. Cullen <i>et al.</i> (2017b); USA	MPB across participants	N = 3; 2 no intellectual disability, 1 mild intellectual disability (IQ = 70) 3 M Age 20-24	iPad 4 + My Pics app	Task completion by self-direction (cleaning)	SLS

Table 4. Continued

Author (year), country	Design	Participants	Technology/features of applications	Type of support	Support function
41. Douglas et al.(2018); USA	MPB across participants and replicated across conditions	N = 4; 3 moderate intellectual disability, 1 mild intellectual disability (IQ = 56) WISC IV 4 M Age 11-14	iPad 2 + Photo Grocery List	Creating a shopping list (after determining low or almost empty items)	SLS
42. Gollish et al. (2018); USA	double baseline case study design	N = 3; 1 > mild intellectual disability and 1 moderate intellectual disability, 1 mild intellectual disability (IQ = 64) WAIS III 3 M Age 32-55	iPad + visual timer	Make time visual	SS
43. Orum Çattik & Ergenekon (2018); TR	MPB across participants	N = 3; 1 moderate intellectual disability, 2 mild intellectual disability 3 M Age 15-16	bug in ear/tablet computer target skills	Skill teaching (paying electric bill, using tram)	FRCP + SLS
44. Price et al.(2018); USA	MPB across participants and settings	N = 4; 1 ASD, 1 Down Syndrome, 2 mild intellectual disability 3 F/ 1 M Age 17-19	Smartphone + Google Maps app	Facilitate independent bus traveling	SS
45. Shepley et al.(2018); USA	MPB across participants	N = 4; 1 moderate intellectual disability, 3 mild intellectual disability (IQ = 51-57), ASD 2 F/ 2 M Age 12-14	iPod Touch + My Pictures Talk app	Task completion by self-instruction skills (set the table, cook receipt, make a cup of punch and snack task)	SLS
46. Van Laarhoven et al.(2018); USA	ATD	N = 4; 1 n.r., 1 no intellectual disability, 1 moderate intellectual disability, 1 mild intellectual disability (IQ = 62), seizure disorder 2 F/ 2 M Age 15-18	iPad + the Go Talk Now app by Attainment + the HP Slate Power Point	Skill teaching (prepare conference room)	SS

Note: Design (A) ATD, (adapted) alternating treatment design; BSD, between-subjects design; MBD/MPBD, multiple baseline/multiple probe baseline design; SSI, semi-structured interview; WSD, within-subjects design. Participants: ASD, autism spectrum disorder; CPP, chronic psychiatric patients; CG/EG, control group/experimental group; FAS, foetal alcohol syndrome; BIF, borderline intellectual functioning; SLI, speech language impairment; and TBI: traumatic brain injury. SS, self-support; SLS, support learning skill; FRCP, facilitate remote contact professional.

### **3.1.4. Expectations and perceptions of eHealth**

Cullen and colleagues (2017a) reported participants being asked about their perception and desired adjustments for the successful use of an iPad and an app in a vocational context in the near future. In addition, one study reported a participatory design using a memory application in real life, in which participants' expectations and perceptions of this application were used as input to optimize the application (Kerkhof et al., 2017). The other 44 studies did not report expectations and perceptions of eHealth.

### **3.1.5. Previous experience with eHealth and digital skills**

In various studies, the presence of digital skills is mentioned as an essential element of access to and actual use of eHealth (Hoppestad, 2013; Raspa et al., 2018; Tanis et al., 2012). For this reason, the previous digital experience of participants was extracted from the studies included in this review.

None of the studies reported a systematic assessment of the digital skills of participants before starting the intervention. However, 14 studies reported participants' previous experience with a digital device (Ayres & Cihak, 2010; Berezna et al., 2012; Burckley et al., 2015; Cannella-Mallone et al., 2006; Douglas et al., 2018; Mechling et al., 2009; Mechling & O'Brien, 2010; Shepley et al., 2018; Smith et al., 2015, 2016; Spriggs et al., 2015; Van Laarhoven et al., 2010; Van Laarhoven et al., 2012; De Wit et al., 2015). These experiences varied from playing online games to executing simple acts on a computer such as typing letters. Four studies stated that the participants did not have any digital experience prior to the intervention (Campillo et al., 2014; Cullen et al., 2017; Goo et al., 2016; Taber-Doughty et al., 2011). The majority of the studies included ( $n = 28$ ) were silent on participants' digital experience.

## **3.2. Environmental factors**

### **3.2.1. Context of service users' daily lives**

Although the vast majority of the studies ( $n = 43$ ) reported the context of the eHealth intervention, hardly any information was reported about the personal circumstances of the participants (e.g., living conditions, working conditions, and social network). Nine studies provided information about the personal context of participants: six of these studies described the personal context because the eHealth intervention was (partially) applied at their homes (Fage et al., 2018; Golish et al., 2018; Kerkhof et al., 2017; Taber-Doughty et al., 2010; De Wit et al., 2015; Van Laarhoven & Van Laarhoven-Myers, 2006). In the three remaining studies, with the intervention being applied in the educational context, it was stated that the participants lived in a community-group home, with family or friends, without further details (Cannella et al., 2006; Cullen et al., 2017b; Sigafos et al., 2005, 2010).

### 3.2.2. Context of eHealth interventions

The six studies which reported interventions taking place in the participant's home mostly focused on daily living skills such as cooking and everyday household tasks (Taber-Doughty et al., 2010; Golisz et al., 2018; Kerkhof et al., 2017; Van Laarhoven & Van Laarhoven-Myers, 2006; Van Laarhoven et al., 2012; De Wit et al., 2015). In addition, four interventions took place only in the community (Burckley et al., 2014; Davies et al., 2010; Orum Çattik & Ergenekon, 2018; Stock et al., 2013) and were, for example, focused on travelling on public transport and making purchases in a local grocery shop. Furthermore, in six studies, the interventions were applied in a vocational setting, targeting aspects such as independent task completion (Cannella-Malone et al., 2006; Cavkaytar et al., 2017; Cullen et al., 2017; Sigafos et al., 2005, 2007; Van Laarhoven et al., 2009). In two studies, a vocational setting was organized in the office of a software company (Davies et al., 2002a; 2003b). Notably, most eHealth interventions were performed in an educational context ( $n = 25$ ), of which five interventions even combined an educational and a societal context (Hansen & Morgan, 2008; Mechling & O'Brien, 2010; Goo et al. 2016; Price et al., 2018; McMahan et al., 2015) and one intervention combined an educational context with the home context (Fage et al., 2018). In one additional study, the intervention was applied in a day care centre (Campillo et al., 2014), targeted at making time visual in waiting situations. Four studies did not report a clear intervention context.

Interestingly, various studies mentioned examples where contextual barriers hindered optimal eHealth use, such as problems with the technological functioning of eHealth because of the low quality of the Internet connection (e.g., De Wit et al., 2015) and professionals' concerns about their lack of digital skills limiting their opportunities to support persons with an intellectual disability (e.g., Taber-Doughty et al., 2011).

### 3.2.3. Training in how to use the eHealth application

The majority of the studies included ( $n = 30$ ) reported device training before starting an intervention with an eHealth application. Eighteen of these studies used evidence-based instructional practices to teach participants to use the eHealth application, such as a system of least prompting, most-to-least and least-to-most prompting, constant and progressive time delay prompting, and model-lead test format (Ayres et al., 2009; Ayres & Cihak, 2010; Berezna et al., 2012; Cavkaytar et al., 2017; Cullen et al., 2017a; Cullen et al., 2017b; McMahan et al., 2015; Mechling & O'Brien, 2010; Mechling & Savidge, 2011; Price et al., 2018; Shepley et al., 2018; Smith et al., 2015; Smith et al., 2016; Spriggs et al., 2015; Stock et al., 2013; Van Laarhoven et al., 2009; Van Laarhoven et al., 2010; Van Laarhoven et al., 2018). In three of these studies, those providing the intervention worked closely with participants, using modelling and guiding them until independent use was achieved (Campillo et al., 2014; Fage et al., 2018; Padgett et al., 2006). In addition, two of these



studies used workshops with support staff to help participants become familiar with using the application (Kerkhof et al., 2017; De Wit et al., 2015). Furthermore, seven of these studies reported device training without giving additional details. The remaining 16 studies did not provide or report any device training.

#### **3.2.4. Professionals providing the eHealth intervention**

In three studies, support staff performed the intervention without the involvement of the researchers (Campillo et al., 2014; De Wit et al., 2015; Taber-Doughty et al., 2010). In five other studies, the intervention was performed by a teacher without any involvement from the researchers (Cihak & Schrader, 2008; Douglas et al., 2018; Shepley et al., 2018; Spriggs et al., 2015; Van Laarhoven et al., 2012). Researchers collaborated closely with the teachers in three studies (Ayres & Cihak, 2010; Smith et al., 2015; Smith et al., 2016) and with support staff in only one study (Kerkhof et al., 2017). Parents were also involved in one study, guiding their children at home using training apps (Fage et al., 2018). Notably, in half of the studies, the eHealth intervention was performed by the researchers themselves ( $n = 21$ ).

In the remaining 12 studies, it was not clear who was performing the intervention, because of the use of general terms such as 'instructor' (Mechling et al., 2009; Mechling & Gustafson, 2008; Mechling & O'Brien, 2010; Mechling & Savidge, 2010), 'trainer' (Cannella-Malone et al., 2006; Sigafoos et al., 2005; Sigafoos et al., 2007), 'experimenter' (Cullen et al., 2017a; 2017b), 'project staff' (Davies et al., 2002b), 'others' (Golish et al., 2018), or 'staff, experimenter and a person who had experience working with adults with intellectual disability (Davies et al., 2003b).

### **3.3. Features of the eHealth applications**

In the studies included in this review, support was provided through a range of eHealth applications (see Table 4). In 13 studies, a portable application such as a smartphone or a personal digital device was deployed for support. In addition, an iPad/iPod tablet was used in 16 studies, frequently combined with an app, specific software, videos, a Bluetooth earpiece, and an e-book (Alexander et al., 2013; Burckley et al., 2015; Cavkaytar et al., 2017; Cullen et al., 2017a; Cullen et al., 2017b; Douglas et al., 2018; Fage et al., 2018; Golish et al., 2018; Van Laarhoven et al., 2009; Van Laarhoven et al., 2018; McMahon et al., 2015; Orum Çattik & Ergenekon, 2018; Shepley et al., 2018; Smith et al., 2015; Spriggs et al., 2014; Taber-Doughty et al., 2011). A computer or laptop was used in 11 studies, in combination with specific software, showing step-by-step pictures or videos of target skills. Virtual Reality (Padgett et al., 2006) and Augmented Reality (McMahon et al., 2015) were each applied in one study.

The applications used in the studies had different features: (a) monitoring the progress of task performance, time, sequence of activities during the day, and presence of professional staff ( $n = 7$ ) (Bouck et al., 2014; Campillo et al., 2014; Douglas et al., 2018; Golish et al., 2018; Kerkhof et al., 2017; Van Laarhoven et al., 2018; Spriggs et al., 2014), (b) prompting task or skill execution using pictures, videos and audio ( $n = 27$ ) (Ayres et al., 2009; Ayres & Cihak, 2010; Alexander et al., 2013; Bereznak et al., 2012; Burckley et al., 2015; Cannella-Malone et al., 2006; Cihak & Schrader, 2008; Cullen et al., 2017a; Cullen et al., 2017b; Davies et al., 2002a; Davies et al., 2002b; Davies et al., 2003; Goo et al., 2016; Hansen & Morgan, 2008; Van Laarhoven & Van Laarhoven-Myers, 2006; Van Laarhoven et al., 2009; Van Laarhoven et al., 2010; Van Laarhoven et al., 2012; Mechling & Gustafson, 2008; Mechling et al., 2009; Mechling & O'Brien, 2010; Mechling & Savidge, 2011; Sigafoos et al., 2005; Sigafoos et al., 2007; Smith et al., 2015; Smith et al., 2016; Taber-Doughty et al., 2011), (c) providing real-time information and feedback in the users' context (e.g., prompting during a trip on a public bus) ( $n = 7$ ) (Davies et al., 2010; Fage et al., 2018; McMahan et al., 2015; Orum Çattik et al., 2018; Price et al., 2018; Shepley et al., 2018; Stock et al., 2013), (d) providing a realistic and safe learning situation (e.g., virtual reality) ( $n = 2$ ) (Davies et al., 2003a; Padgett et al., 2006), and (e) facilitating remote contact and communication with professional care staff ( $n = 3$ ) (Cavkaytar et al., 2017; Taber-Doughty et al., 2010; De Wit et al., 2015).

## 4. Discussion

In line with general healthcare, the use of eHealth within the intellectual disability field has increased in recent years. Due to the transition from institutional to community care (Hall, 2011), there is a need for flexible support targeting the personal context of the person with an intellectual disability (McConkey et al., 2016). As such, eHealth may contribute to this changing support need (Perry et al., 2009). In this respect, the MPT model provides a valuable framework within which to consider the factors for effective eHealth for supporting people with mild intellectual disability. The MPT model emphasizes the importance of considering three key areas: (1) the characteristics of the person with a mild intellectual disability (e.g. personal and psychosocial characteristics, needs, and preferences of people with a mild intellectual disability), (2) environmental factors, and (3) functions and features of eHealth. Our study resulted in three main findings related to using eHealth to support people with mild intellectual disability in performing daily activities, discussed below.

The first main finding is that the majority of the studies do not inventory the personal needs and preferences of people with mild intellectual disability as a starting point to find the most appropriate eHealth application in a personal situation to meet the

subject's personal goals. Therefore, there seems to be little space for the voices of people with mild intellectual disability themselves or to explore how the opportunities of eHealth match their preferences. Studies reporting on how technology can help a person to fulfil personal needs underline the importance of a personalized, tailor-made approach in this matching process (Boot et al., 2018; Collins & Collet-Klingenberg, 2017; Frielink et al., 2019; Manzoor & Vimarlund, 2018; Scherer & Federici, 2015). With respect to personalized and tailor-made support, the absence of a needs assessment is not unique to the intellectual disability field. In the care of older people, too, only a few studies have explored aspects such as their needs and preferences for using the Internet and eHealth technologies in managing their health (e.g., Ware et al., 2017). The absence of a user-centred focus in developing and implementing eHealth technologies is postulated to contribute to usability problems and high attrition rates (Van Gemert-Pijnen et al., 2011).

The second main finding is that important persons in the informal and formal networks of people with mild intellectual disability (e.g., relatives, support staff, teachers) are rarely involved in the phase of selecting an appropriate eHealth application or in the phase of implementing the application, whether in daily practice or otherwise. In most eHealth interventions included in this review, the researcher delivered the intervention within an educational context. Although it is fairly common for researchers to introduce and train eHealth interventions, family members and support staff are important stakeholders who support people with an intellectual disability in using eHealth in daily life and they should be involved in the introduction and training phase (Tanis et al., 2012). In some studies included in this review, the researchers contacted support staff/teachers or family members, yet there was limited collaboration overall (e.g. teachers and parents were interviewed about the future possibilities of eHealth but did not take an active role during the intervention). Successful implementation and actual use of eHealth are commonly achieved in close collaboration with key stakeholders (Chadwick et al., 2013; Palmer, Wehmeyer, Davies, & Stock, 2012; Van Gemert-Pijnen et al., 2018) and require fine-tuning to the opportunities and challenges encountered in a daily living context (Beyer & Perry, 2013; Clifford Simpican, Shivers, Chen, & Leader, 2018; Parson, Daniels, Porter, & Robertson, 2008). As such, collaboration with staff and family members is essential, as people with mild intellectual disability have difficulty generalizing their learned skills to a new context, and their support needs are lifelong (Thompson et al., 2009). This means that they need repeated performance of tasks to maintain skills (De Wit, Moonen, & Douma, 2012). Future researchers are therefore encouraged to collaborate closely with support staff/teachers and family members of people with an intellectual disability in designing, introducing, and using eHealth.

The third main finding is that various eHealth applications can be successfully implemented following structured training using behavioural therapeutic principles for people with mild intellectual disability. Most eHealth tools offer opportunities to customize the tool to personal preferences. In this respect, it is important to take the aspects of Universal Design into account in designing eHealth tools (Hoppestad, 2013; Wehmeyer et al., 2004). Universal Design emphasises flexibility, a tailored approach, simplicity, and intuitive use as well as perceptible information (Damianidou et al., 2018; Wehmeyer et al., 2004; Wehmeyer et al., 2012). Developing eHealth applications while taking these aspects into account increases the likelihood of actual use in the daily life of people with mild intellectual disability, enabling them to benefit from eHealth in the same way as people in the general population (Raspa et al., 2018; Watfern, Heck, Rule, Baldwin, & Boydell, 2019; Wehmeyer et al., 2004). Although studies reported on the potential of eHealth, optimising the actual use of eHealth requires that attendance must be paid to the collaboration with service users and their personal network (informal and professional) from the very beginning of eHealth use.

The studies included in this review used a range of eHealth applications with different functions and features. The major function of eHealth in the studies included was as a temporary tool to support the learning process for practical daily living skills or vocational skills. This is in line with earlier systematic reviews, illustrating that technology could be useful in facilitating a learning process (e.g., Collins & Collet-Klingenberg, 2017; Damianidou et al., 2018; Kagohara et al., 2013; Ramdoss et al., 2012). In addition, although less frequently, eHealth was also used in other functions, for instance as a self-supportive tool and for the provision of remote professional contact. It would be beneficial for future eHealth applications to focus on these functions, too, especially because of their potential to empower people with mild intellectual disability and fine-tune their personal needs in their own environment (Den Brok & Sterkenburg, 2015; Wennberg & Kjellberg, 2014; Zaagsma et al., 2019). These eHealth applications could contribute to important issues in the lives of people with mild intellectual disability, such as making their own choices in various domains in life, enhanced independent functioning, and being an active member of society (Carey, Friedman, & Nelson Bryen, 2005; Haigh et al., 2013; Wehmeyer et al., 2012).

This literature review reveals various opportunities for future research. First, although the studies included showed promising results from using eHealth for different goals in various life domains, there were methodological weaknesses in these studies (i.e., most studies have a small sample size, lack of follow-up measurements, and weak study designs such as pilot, feasibility, and beta-studies). These weaknesses limit the generalisation of the findings. Future research should build out with well-executed studies. In addition to more large-scale studies, such as randomised control trials, single-

case studies can also contribute to the development and effective implementation of eHealth for people with mild intellectual disability to support them in daily living activities. A case study design performs well in providing insights into what will work for *this* person in *this* context, making it valuable for a better understanding of complex social contexts such as healthcare (Yin, 2014). An important requirement in this respect is to design good-quality case studies. Guidelines such as the What Works Clearinghouse single-case design technical documentation (Kratochwill, Hitchcock, Horner, Levin, Odom, Rindskopf, & Shadish, 2010) could help in this respect. Next, using models for the effective use of technology, such as the Matching Person to Technology model, could improve the process of matching the need of an individual with an intellectual disability to the best-fitting tool in the personal context (Scherer et al., 2005). Although many studies emphasise the importance of this matching process for successful eHealth use and underline the involvement of all stakeholders, including those with mild intellectual disability, it is remarkable that this process seems to be underestimated and hardly reported (Parsons et al., 2008; Lussier-Desrochers et al., 2017; Wennberg & Kjellberg, 2014). Third, and in addition to the focus on eHealth use for support in daily life, the domain of psychological interventions and therapy is also imperative. Therefore, a systematic inventory of available scientific knowledge of psychological interventions and therapy using eHealth among people with an intellectual disability is a necessary step in further research (Oudshoorn et al., 2021).

Some limitations of this systematic review need to be addressed as well. First, only studies in the English language were selected for inclusion in this review, so any studies published in other languages have been missed; potentially valuable knowledge published in other languages could help provide a more complete overview of studies about this topic. Second, different outcome measures limited the opportunities for a structured analysis of the outcomes, as is the case with a meta-analysis. It would have been interesting to investigate the link between using a well-defined plan and well-executed implementation of an eHealth tool (e.g., according to the three elements of MPT) and the effect on outcomes. Third, one of the main challenges of this review was to determine what is included in the concept 'eHealth', as it is often used as an umbrella term for different aspects of delivering and facilitating healthcare (Oh et al., 2005; Skär & Söderberg, 2017). A clear definition could decrease the risk of misinterpretation of what is intended by providing eHealth and stimulate the exchange of relevant knowledge about eHealth to support people with mild intellectual disability. It is therefore important for future research to focus on a more concrete definition and conceptualisation of what eHealth is.

To conclude, eHealth can contribute to the expansion of opportunities to support people with a mild intellectual disability in various domains of their daily lives and their

participation in the community. Studies about using eHealth to support people with mild intellectual disability show promising results; however, there is a need for a clear focus on the implementation of the eHealth tool before evaluating its effectiveness. With this focus, reliable insights can be obtained into the added value of eHealth for supporting the daily life of people with mild intellectual disability.

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The authors declare no conflicts of interest.

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This review does not involve any human participants.

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\*included publications in systematic review



**CHAPTER 3**

# 3



# Psychological eHealth interventions for people with intellectual disabilities: A scoping review

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## **Abstract**

### **Background**

The use of eHealth, which has accelerated in the wake of the COVID-19 pandemic, could contribute to the access to tailor-made psychological interventions for people with intellectual disabilities.

### **Method**

A scoping review was conducted on peer-reviewed studies between 1996-2019.

### **Results**

Thirty-three studies reported on the use of psychological eHealth interventions focused on mental health problems and/or challenging behaviour. The vast majority of these studies reported on interventions that were delivered at the individual level. The context in which these interventions were delivered varied, primarily ranging from the home setting to residential settings, as well as day or activity centres and schools. The studies described various types of interventions: telehealth interventions, computerized cognitive behavioural therapy, and interventions focused on (social) learning principles targeting challenging behaviour.

### **Conclusions**

eHealth provides new opportunities for both therapists and lay-therapists to deliver psychological interventions. Future studies should focus on the effectiveness of psychological eHealth intervention.

# 1. Introduction

In recent years, health services and information that is either wholly delivered or enhanced by the Internet or related technologies (i.e., eHealth; Eysenbach, 2001) are increasingly being used in the field of intellectual disabilities (e.g., Oudshoorn et al., 2020). The use of eHealth has accelerated even more rapidly in the wake of the current coronavirus (COVID-19) pandemic (Courtenay & Perera, 2020). In an attempt to prevent the proliferation of COVID-19, manifold preventive measures have been adopted by countries across the globe, such as enjoining their citizens to stay at home and engage in social distancing, closing public places (e.g., restaurants, schools, and sport facilities), and significantly reducing the use of public transport. In addition to these measures, work and day services for people with intellectual disabilities have been closed. Moreover, mainstream health care facilities, community care and specialized mental health organizations providing services to people with intellectual disabilities have introduced strict measures for on-site support, face-to-face therapy, and face-to-face mental health provision (VGN, 2020; World Health Organization, 2020). This means that, in most cases, mental health support for people with intellectual disabilities was not in operation during the initial stage of the COVID-19 pandemic. People with intellectual disabilities are more vulnerable to develop mental health problems and expose challenging behaviour compared to the general population (Cooper, Smiley, Finlayson, et al., 2007). Prevalence studies show a large number of people with intellectual disabilities suffering from mental health problems (30-50%; Einfeld et al., 2011) and/or exposing challenging behaviour (5.5%–18.1%; Bowring et al., 2017; Lowe et al., 2007). They experience more challenging life events, trauma, stigmatizing and discrimination, lack of meaningful relationships and have to deal with less abilities to cope with stressful situations effectively (Taylor et al., 2013). Given their vulnerability for mental health problems and reduced capacity to cope with stress, which may have increased during the pandemic and resulting lockdowns (Courtenay, 2020; Embregts et al., 2020), ensuring the continuation of mental health support for people with intellectual disabilities is of paramount importance (Cooper, Smiley, Finlayson, et al., 2007; Taylor et al., 2013). In this respect, eHealth may represent a valuable alternative. eMental Health interventions in the general population demonstrated positive effects for depression, anxiety, substance use of alcohol, and unspecified mental health disorders compared to a waiting list condition (Bennett et al., 2020). Research among the general population has reported on the feasibility of delivering effective psychological interventions via video conferencing with individuals, dyads, and groups, and found similar outcomes to interventions delivered on-site (Banbury et al., 2018). In light of the various governmental measures introduced to stop the proliferation of the COVID-19 virus, telehealth, such as video conferencing, represents therefore an interesting adjunct to in-person services

(Torous et al., 2020). Hence, it might be possible that people with intellectual disabilities may also profit from remote and digital interventions to support mental health.

Mental health support or psychological interventions can be defined as ‘attempts to make changes in people, their behaviour, the systems around them or their interpersonal relationships, using methods derived from a psychological knowledge and understanding of individuals and their world’ (British Psychological Society, 2004, p. 69). Numerous studies have examined the opportunities and benefits of psychological interventions for people with intellectual disabilities (e.g., Brown et al., 2011; Kok et al., 2016; Koslowski et al., 2016; Osugo & Cooper, 2016; Ramsden et al., 2016), for example, based on their meta-analysis of psychological interventions for adults with various levels of intellectual disabilities. Depression and anger in adults with mild to moderate intellectual disabilities could effectively be treated through cognitive behavioural therapy (CBT) or variants of CBT that have been adapted for working with people with intellectual disabilities (Vereenooghe & Langdon, 2013) and challenging behaviour through behavioural and psychological interventions for people with mild intellectual disabilities (Didden et al., 2006). Moreover, in their systematic review of interventions targeted towards people with severe intellectual disabilities who also had mental health problems, Vereenooghe et al. (2018) also included several studies about psychological interventions. Specifically, they proposed that, while the urgency for mental health intervention programmes with this target group appears to be underestimated (cf. Poppes et al., 2014), psychological interventions may also be beneficial for people with more severe intellectual disabilities.

Historically, psychological interventions have predominantly been provided on-site, and, in this respect, eHealth significantly expands the opportunities (Wangelin et al., 2016) by, for example, allowing the provision of psychological interventions to continue remotely during the current COVID-19 pandemic. As well as being expedient during a pandemic, in ordinary circumstances eHealth can potentially lower the threshold for participating in a psychological intervention (e.g., by eliminating the travel time and costs of public transport), while, simultaneously, reducing the fear of stigmatization and shame due to the fact that service users can receive the psychological intervention at home as opposed to visiting mental health services (Proudfoot et al., 2011). In addition, eHealth can contribute towards the designing of bespoke interventions more closely attuned to the personal abilities, wishes, needs, and personal contexts of the target group (Van Gemert-Pijnen et al., 2018). Although eHealth interventions among people with intellectual disabilities are routinely used in daily practice, psychological eHealth interventions specifically focused on mental health have hitherto not been extensively studied. The current COVID-19 pandemic accelerates the urgency for a review of extent knowledge on this topic, which can contribute towards research as well as

clinical practice (Wind et al., 2020). The present authors therefore conducted a scoping review specifically focused on psychological eHealth interventions among people with intellectual disabilities. The scoping review was underpinned by the following research question: What are the characteristics of the interventions, participants, and persons delivering the intervention, and the content of the studies reporting about psychological eHealth interventions for people with intellectual disabilities?

## 2. Method

To answer the above research question, we conducted a scoping review (Arksey & O'Malley, 2005). For the current review, it was imperative to adopt an iterative approach as psychological eHealth interventions for people with intellectual disabilities is an area of inquiry that is as yet not well-defined and relatively new. Hence, if a rigid, a priori design was used, then relevant literature might have been omitted. As a result, while we developed a search strategy and inclusion and exclusion criteria at the initial stages of the scoping review, we continually adapted them as the study proceeded.

### 2.1. Search strategy

A systematic search was conducted within seven bibliographic databases (CINAHL (EBSCO), Cochrane, Embase, Google Scholar, Medline (Ovid), PsycINFO (Ovid), and Web of Science) with the help of an experienced information specialist. These databases, which include both medical and psychologically-oriented databases, were selected for their specialism on research in the fields of behavioural sciences, mental health, allied health, and nursing. Using this combination of databases maximized the number of relevant studies found on this topic. Studies had to have been published in peer-reviewed journals in English from January 1996 until 6 September 2019. The 1996-2019 period was chosen on the grounds that the Internet was first introduced in 1995 within health care practice, thus increasing the likelihood of including relevant studies (Kelders & Howard, 2018).

The PICO approach was used, which comprises Population, Intervention/exposure, Comparison, and Outcome (Liberati et al., 2009), in order to compose the search string and define the inclusion and exclusion criteria. The *Population* was specified as people with intellectual disabilities, irrespective of their level of intellectual functioning (i.e., people with all levels of intellectual disabilities were included in this review). According to the American Association of Intellectual and Developmental Disabilities (AAIDD, 2012), an intellectual disability originates prior to the age of 18 and is often characterized by significant limitations in both intellectual functioning and adaptive behaviour, which encompasses a wide variety of everyday social and practical skills.

Regarding the *Intervention*, the studies needed to include a psychological intervention that corresponded to the definition of the British Psychological Society (2004), include an eHealth application (e.g., tablet, wearables, sensor technology or videoconferencing technology), and be carried out under the responsibility of a qualified professional (e.g., clinical psychologist, therapist or a trained research assistant). Next, the *Comparison* component was not specified as eHealth was regarded as being in its embryonic stages with respect to health care provision for people with intellectual disabilities, and, as such, all information about eHealth in the context of psychological interventions was considered to be of interest for the current study. The *Outcome* component was also not specified in the initial search strategy, in order to ensure that no relevant study in this novel and emerging research area was overlooked.

Table 1 provides an overview of the search terms and strategy that were employed in the Medline (Ovid) database, using MeSH terms (i.e., a controlled vocabulary thesaurus used for indexing papers) and additional text words for “intellectual disability”, “eHealth”, and “psychological intervention”. The other databases use similar thesauri systems (e.g. Embase uses Emtree terms). The “eHealth” terms and synonyms were embedded in “psychological intervention” terms used in the search strategy, as we were interested in sourcing all of the studies that applied eHealth in psychological interventions, and were combined with search words related to “intellectual disability” (Bramer et al., 2017).

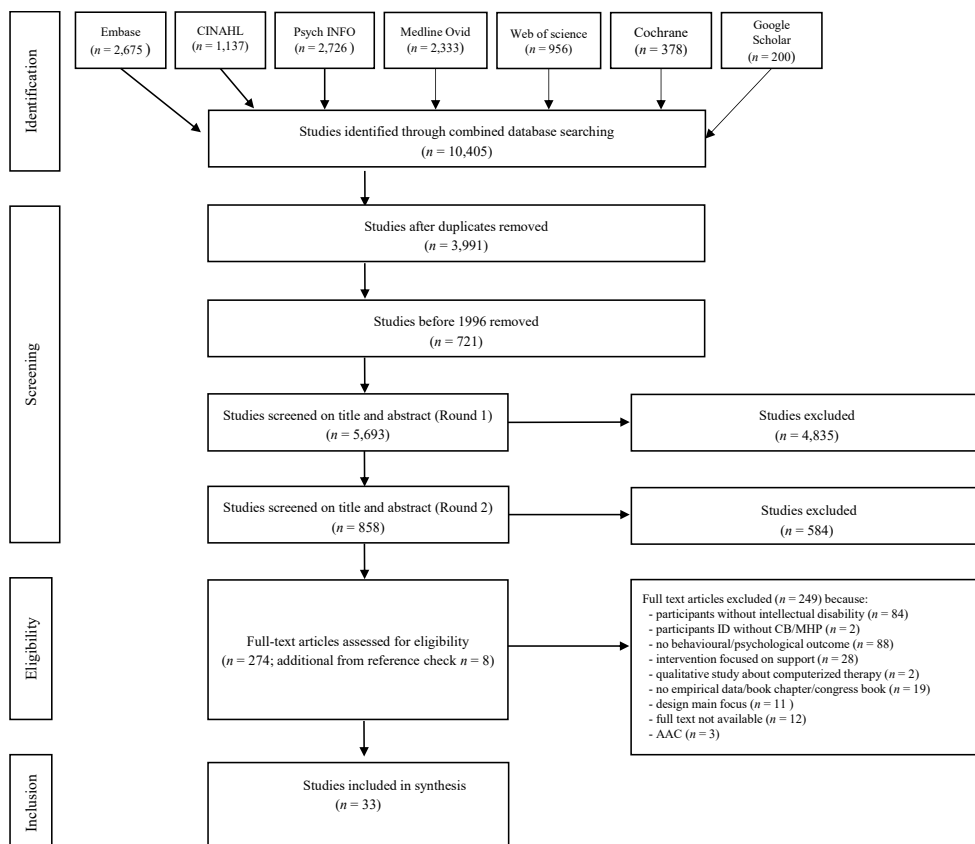
The initial search was deliberately broad so as to cover as many relevant studies as possible related to eHealth, including not only those studies on psychological interventions, but also those studies that used eHealth in support. The use of eHealth in supporting people with mild intellectual disabilities in daily life is reported in a systematic review (Oudshoorn et al., 2020). This scoping review instead focused on eHealth within the context of psychological interventions. Moreover, given the iterative nature of this scoping review, subsequent to the initial search strategy and prior to the second screening step (see *Study selection* for more information), mental health problems and challenging behaviours were ultimately chosen as the outcome measures due to the large number of studies. These outcome measures were also chosen because people with intellectual disabilities are more likely to both present symptoms of mental health disorders and exhibit challenging behaviour, which has a negative impact on the quality of life for people with intellectual disabilities, and, in turn, serves as a burden for themselves, relatives, and support staff (Campbell et al., 2014; Cooper, Smiley, Finlayson, et al., 2007; Cooper et al., 2007). In addition, mental health problems and challenging behaviour are often the primary reason for being referred to specialized help and psychological interventions (Carr et al., 2016).

**Table 1.** Search strategy for Medline (Ovid) database

Medline (Ovid) final search strategy
(exp "Telemedicine"/ OR "Self-Help Devices"/ OR "Therapy, Computer-Assisted"/ OR Microcomputers/ OR "Electronic Mail"/ OR "Internet"/ OR "Social Media"/ OR exp "Cell Phones"/ OR Multimedia/ OR "Educational Technology"/ OR "Computer-Assisted Instruction"/ OR (Telehealth* OR Telecare* OR telemedicine* OR teleconsultat* OR telepsychiatr* OR telemonitor* OR teletherap* OR telerehab* OR ((Tele OR telephone) ADJ3 (health* OR medicine* OR consultat* OR psychiatr* OR therap* OR rehab* OR monitor*)) OR e-health OR ehealth OR mHealth OR (((assist* OR therap* OR aided OR treat* OR deliver* OR application* OR support* OR training OR education* OR learning OR surveillan* OR counsel* OR cbt OR intervent* OR rehabilitat* OR assessment* OR feedback OR support OR care OR help OR service OR assistance OR self-help ) ADJ3 (technolog* OR media OR computer* OR Web-based OR Web-site* OR web-interface* OR webinterface* OR web-page* OR web-resource* OR webpage* OR website* OR email OR online OR Internet OR computer*-program* OR software OR cyber* OR Remote OR virtual* OR device* OR "text messaging" OR sms OR whatsapp OR skype)) NOT assist*-reproduct*-technol*) OR (((e OR electronic*) ADJ (mail* OR health)) NOT electronic-health-record*) OR "social media" OR ((mobile OR cell*) ADJ phone*) OR smartphone* OR microcomputer OR ipad OR ipads OR (tablet* ADJ3 ("use" OR usage)) OR "information technology" OR multimedia OR domotic*).ab,ti) AND ("Mentally Disabled Persons"/ OR exp "Intellectual Disability"/ OR "Learning Disorders"/ OR "Developmental Disabilities"/ OR "Neurodevelopmental Disorders"/ OR ((mental* OR intellect* OR learning OR developmental* OR neurodevelopmental*) ADJ3 (retard* OR impair* OR deficien* OR disab* OR handicap* OR difficult* OR limitation* OR delay*)) OR multipl*-disab* OR cognitive-disabilit* OR learning-disorder* OR (cognitive-impairment* NOT (dement* OR alzheimer* OR parkinson OR psychiatr* OR older OR aged OR elderly OR injur*)) OR development*-disorder* OR retarded OR (down* ADJ3 (syndrome*)))ab,ti) NOT (exp animals/ NOT humans/) NOT (letter OR news OR comment OR editorial OR congresses OR abstracts).pt. AND english.la.

## 2.2. Study selection

In accordance with the PRISMA guidelines (Liberati et al., 2009), the selection process contained four stages: (1) identification, (2) screening title and abstract, (3) eligibility, and (4) inclusion (see Figure 1). First, in the identification phase, peer-reviewed studies were identified in the aforementioned databases, which resulted in 10,405 studies. Second, the screening of the records based on title and abstract was performed in two steps due to the broad focus on eHealth within the core domains of health care: assessment, support, and psychological interventions. In the first step of the screening phase, 5,693 studies remained after removing 3,991 duplicates and 721 studies that were conducted prior to the publication date limit (1996). Title and abstract selection was carried out by two independent reviewers (CO and NF) based on the inclusion and exclusion criteria (Table 2). Reviews, dissertations, essays, and book chapters were excluded. In the second screening step, studies containing results of eHealth within a psychological intervention targeted at people with intellectual disabilities and focused on mental health problems and challenging behaviours were selected. The two reviewers were in agreement over 90% of their respective decisions; disagreements were discussed with the last author (PE). After discussion, the in- or exclusion of a study was made by a shared decision of all reviewers.



**Figure 1.** Flowchart of study selection for scoping review



**Table 2.** *Inclusion and exclusion criteria*

<b>Inclusion criteria</b>
<ul style="list-style-type: none"> <li>· Participants of the study were people with an intellectual disability (IQ &lt; 70, deficits in adaptive functioning resulting in support needs to meet developmental and sociocultural standards for personal independence and social responsibility, and the onset of deficits occur during the developmental period).</li> <li>· Participants of the study were reported to have challenging behaviour or a mental health disorder.</li> <li>· Studies about a psychological intervention or therapy intended to improve emotional, or psychological well-being, or behavioural change provided or supervised by a professional (e.g., psychologist, therapist, certificated interventionist).</li> <li>· Studies focusing on using technology for the (remote) provision of therapy, or psychological, or behavioral intervention.</li> <li>· Studies focusing on individual, psychological or behavioral outcomes (e.g., emotional and psychological well-being, challenging behavior, mental health problems, or specific behavior due to psychiatric disorder such as for example anxiety, depression).</li> </ul>
<b>Exclusion criteria</b>
<p>Participants:</p> <ul style="list-style-type: none"> <li>· Studies focusing on people with cognitive disabilities/impairments due to traumatic brain injury, stroke, cancer treatment or (early) dementia<sup>a</sup>.</li> </ul> <p>Intervention:</p> <ul style="list-style-type: none"> <li>· Studies focusing on design of eHealth without application in a psychological or behavioral treatment or a therapy context.</li> <li>· Studies focusing only on physical health outcomes (e.g., weight management, drinking, smoking, physical fitness).</li> <li>· Studies focusing on parents of children with intellectual disabilities and outcomes on parental behavior only.</li> </ul> <p>General:</p> <p>Studies without empirical data (e.g., policy documents, conference papers, proposal clinical trial) or opinion papers, qualitative studies and grey literature) .</p> <p>Studies presenting only psychometric data (i.e., validity and reliability of a specific instrument).</p>

*Note:*<sup>a</sup>several studies reporting about eHealth and mild cognitive impairment to detect early dementia. Because a few studies used the term 'mild cognitive impairment' also for people with mild intellectual disabilities, we decided to include '(early) dementia' as an exclusion criteria

Third, in the eligibility phase, the 274 full texts were read by the first author (CO), with a particular focus on the presence of the inclusion and exclusion criteria (see Table 2). This step led to the exclusion of 249 studies, and the retainment of 25 eligible studies. In the case of doubt, a second researcher (SN) was consulted. In addition, the reference lists of these 25 studies were screened for eligible studies, resulting in the identification of eight additional studies. As the objective of a scoping review is to provide an overview of relevant studies about a specific topic, rather than assessing the quality of the studies included, no quality appraisal was conducted (Arksey & O'Malley, 2005).

### 2.3. Charting data and analysis

Information on the following items was extracted from the included studies in the present review: the country of origin, the period of publication, the general characteristics of the participants and the design of the included studies. In addition, we extracted data

pertaining to the characteristics of the psychological interventions, the participants, the people delivering the intervention and the content of the studies reporting on psychological eHealth interventions for people with intellectual disabilities. The characteristics of the 33 studies included in the scoping review are presented in Table 3.

In line with scoping review recommendations (Levac et al., 2010), two reviewers (CO and SN) independently piloted the utility of the developed coding scheme, by randomly selecting and reviewing five of the 33 studies (18.2%). The first author selected five studies manually by using the Excel number table and pointed studies randomly. Disagreements stemming from ambiguity in the description of the codes were discussed and refined by both reviewers. Next, one reviewer (CO) extracted the data from the remaining 28 studies and any ambiguities were discussed with the second reviewer (SN) until an overall consensus was reached. The final content of the coding scheme was discussed with all authors.

### 3. Results

After a brief description of the country of origin, the period of publication, the general characteristics of the participants and the designs of the 33 included studies, the data from the studies will be mapped, charted and described in narrative form on: 1) the characteristics of the psychological eHealth interventions, 2) the characteristics of the participants with intellectual disabilities, 3) the characteristics of the people delivering the psychological eHealth intervention, and 4) the content of the studies reporting on psychological eHealth interventions for people with intellectual disabilities. The vast majority of the studies were conducted by two research groups from Italy ( $n = 22$ ), while the remainder of the studies were conducted in the United States ( $n = 4$ ), Australia ( $n = 2$ ), the Netherlands ( $n = 2$ ), Israel ( $n = 1$ ), Korea ( $n = 1$ ), and the United Kingdom ( $n = 1$ ). Most of the studies were published in the last decade ( $n = 24$ ); the remaining studies were published between 1997 and 2010. In 29 studies, a single case design was used (Dunphy & Hens, 2018; Gaskin et al., 2012; Hetzroni & Banin, 2017; Hronis et al., 2018; Kim et al., 2014; Lancioni et al. 1997; 1998; 1999; 2006abc; 2007; 2008ab; 2011; 2013ab; 2014ab; Perilli et al., 2019; Simacek et al., 2017; Singh et al., 2017; Stasolla et al., 2013ab; 2014ab; 2015; 2017ab). In addition, two studies used a pre-experimental design (Hoffman et al., 2017; Jonker et al., 2015) and one study used a randomized control trial (Cooney et al., 2017), while one study did not report about the study design (Monlux et al., 2019). Further details of the included studies are reported in Table 3.

**Table 3.** Characteristics of the studies included

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
<b>Individual interventions</b>									
1. Lancioni <i>et al.</i> (1997), IT	ABABAB (I), ABABABAB (II)	N=2, 1F 1M, Age 24 and 60		I. activity center; II. community home	Not explicated, but BT principles	sessions 30 min (I), 40 min (II). I. 2-4 times a day, 2 hrs a day device available, 3a4 dys a week. II. 2-4 times a week, device available 1-3 hrs a day, sessions 3-5 d/p/wk	battery-powered electronic unit worn at the chest and connected to an earpiece. The electronic unit consisted of a miniature electret microphone and a two-stage low frequency amplifier, with dials for setting the loudness limit	Observation (momentary time interval sampling)	Vocal loudness
2. Lancioni <i>et al.</i> (1998), IT	ABABABAB	N = 1, M Age 20	autistic-like behavior	activity center	prompts, reminders; rewards, positive comments are mentioned, but no theoretical framework	30 min per session, 5.5 months duration study	portable wearable device at the wrist providing visual and auditory feedback	Observation (6 moments during therapy program)	Vocal loudness
3. Lancioni <i>et al.</i> (1999), IT	ABABAB	N = 1, 1 F Age 56		activity centre	Not explicated, but BT principles	5 months of 30-min sessions, no further details	battery-powered electronic unit worn at the chest and connected to an earpiece. The electronic unit consisted of a miniature electret microphone and a two-stage low frequency amplifier, with dials for setting the loudness limit	Recording of talking and vocal loudness (momentary time interval sampling)	Vocal loudness

Table 3. Continued

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
4. Lancioni <i>et al.</i> (2006a), IT	multiple probe across responses design. Postintervention checks 1,2 and 3 months after intervention	N = 1, 1 M Age 12.5 yrs	congenital cerebropathy with spasticity, minimal residual vision, epilepsy	n.r.	Not explicated, but BT principles	n.r.	microswitch clusters	Microswitch recorded data movement, sensor monitoring finger mouthing.	Foot and head movements and finger mouthing
5. Lancioni <i>et al.</i> (2006b), IT	ABAB1B2	N = 7, 1 F 6 M Age 7,9-20.7 (M = 14.3)	sensory impairments, 5 diagnosed with epilepsy	home or educational context	Not explicated, but BT principles	5-10 min (advice parents/professionals) with a microswitch-based and a stimulation programme (separated and alternating condition) in a variable amount of sessions	microswitches (pressure device) were linked to an electronic control system. This was a portable, battery-powered case connected to a variety of preferred stimuli selected for the study	Microswitch activation responses were recorded directly during the sessions. Observation (partial interval system) of indices of happiness from videotapes	Microswitch activation responses and indices of happiness
6. Lancioni <i>et al.</i> (2006c), IT	ABB1AB1	N = 1, 1 F Age 41	DS, passive and sedentary	quiet activity room	Not explicated, but BT principles	5 min, 3-9 times a day	microswitch clusters (pressure and mercury devices)	Microswitch activation responses were recorded	Hand-pushing and face hiding
7. Lancioni <i>et al.</i> (2007), IT	ABB1AB1 design	N = 1, M Age 12.8	congenital cerebropathy with spastic tetraparesis, minimal residual vision, seizure disorder	quiet room in a educational context	Not explicated, but BT principles	5 min sessions 3-9 times a day on participant's availability. Intervention sessions 1,2, 44 and 50 sessions respectively. Post-intervention check 15 sessions	microswitch cluster (optical), light wires attached to a headband	Microswitch activation responses were recorded and target behaviour was measured by activation of sensor	Hand mouthing, eye poking and foot movements

Table 3. Continued

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
8. Lancioni <i>et al.</i> (2008a), IT	ABAB with 3 month post-intervention	N = 1, 1 M Age 29	congenital encephalopathy, seizure disorder	n.r.	not explicated, but BT principles	5 min, 3-7 times a day; 47-104 sessions	microswitch cluster	Microswitch activation responses were recorded and target behaviour was measured by activation of sensor	Object-contact responses without hand stereotype behaviour
9. Lancioni <i>et al.</i> (2008b), IT	ABAB with 3 month post-intervention	N = 1, 1 F Age 12.2	seizure disorder (Lennox Gastaut), visual impairment, MD	n.r.	A section about case conceptualization	10 min a day, 3-8 times a day. Treatment phases included 86 and 105 sessions	microswitch cluster	microswitch + optic and minitilt sensors and recorded data + observation of indices of happiness (partial interval) on videotapes	Object manipulation and hand mouthing
10. Lancioni <i>et al.</i> (2011), IT	non-concurrent multiple baseline design across participants	N = 2, congenital encephalopathy 1 F, 1 M Age 34 and 31	motor, sensory disabilities	care and rehabilitation center		304 and 129 sessions	microswitch (pressure) + computersystem for stimuli	computer system automatically recorded responses + observation of indices of happiness on videotapes	Microswitch activation responses and indices of happiness

Table 3. Continued

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
11. Gaskin et al. (2012); USA	Multiple probe design across skills	N = 1; IQ 66 verbal and 72 performance (WALS); 1 F 23 yrs		at home	PII module (parent-infant interaction); part of SafeCare® intervention. Social learning is assumed, but not reported explicitly	Visits home visitor (certified trainer) weekly at home. Five training sessions with a structured approach towards how physical and non physical skills were trained. A booster session was delivered (2 month FU) focused on underutilized skills	digital picture frame	Observation of PII skills by the Planned Activities Training checklist, infant version (PAT-VI) recording demonstration of PII skills + consumer satisfaction by a 10-question survey	Physical and nonphysical PII target skills
12. Lancioni et al. (2013a), IT	ABB1/AB1 design	N = 2, 1 F, 1 M. Age 19 and 20	visual impairment, non-ambulatory, one had epilepsy,	quiet room in the attended center the persons attended	Not explicated, but BT principles	1. 5 min, 2-6 times a day II. 30 m, once a day.	microswitch (optical) detected I. hand mouthing and an optical-touch screen computer monitor activated by the touch responds II. Napkin with sensors/microswitches, microprocessor and MP3 device	Observation of frequencies of touch responses, total amount of session time with the presence of hand mouthing were automatically recorded via the computer system	Touch responses, wiping/cleaning and hand-mouthing

**Table 3. Continued**

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
13. Lancioni <i>et al.</i> (2013b), IT	I. ABB1/AB1 design, II. ABB1/AB1B2 design	N = 3, 1 F 2 M, Age 10*, 27 and 64 * included	congenital encephalopathy with spastic tetraparesis	n.r.	Not explicated, but BT principles	I. 10 min, 3 to 6/7 times a day. (Intervention sessions 46, 28 sessions and 84 sessions). II. 15 min, 2-4 times a day	I. a) tilt and optic microswitches connected with the objects react by touching b) microswitch (optic) attached to the wheelchair + headrest was activated with head c) computer control system for preferred stimuli activation	Observation target responses automatically recorded by computer system, and observation by RA	I. adaptive behaviour (touching objects) and posture. II. adaptive behaviour (mouth-cleaning + object assembling) and drooling
14. Stasolla <i>et al.</i> (2013a), IT	multiple probe design across behaviors for each participant	N = 2, 2 F Age 12 and 17	Rett's syndrome, withdrawal, stereotyped behaviors, motor problems and epilepsy	at home	Not explicated, but BT principles	5 min 3-4 times a day, 4 days a wk. The intervention program lasted approximately 6 months. (Intervention I = 50 sessions, Intervention II = 50 sessions)	a wobble microswitch in the first phase, adopted microswitch = two optic sensors (photocells fixed to the lateral panels of the walker device)	Frequencies of responses of object manipulation (automatically count by device) + observation (partial interval and event) of indices of happiness and stereotype behaviour	Hand-washing, body rocking (stereo-types), access to preferred stimuli and step responses
15. Stasolla <i>et al.</i> (2013b), IT	ABAB sequence with a post intervention check after 15 days	N = 3, 3 M Age 6-9	Cerebral palsy and MD	at home	based on learning principles	10 min sessions, 2-4 times a day, 3 days a week. The intervention program lasted approximately 6 months. (Intervention I 40 sessions, Intervention II 60 sessions)	laptop computer equipped with a Clicker 5 software package, microswitch (pressure) + a connecting interface + mouse (Intervention II)	Observation of happiness signs (partial interval) and number of requested item	Independent choice behaviour and mood

Table 3. Continued

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
16. Kim <i>et al.</i> (2014); KR	Multiple probe design across participants	N = 3; IQ < 55 (KISE-KIT) severe ID, adaptive scores 49-76 (KISE-SAB), 1 F; 2 M Age 17		separated room in school	ABA Antecedent-based intervention; providing alternative behavioral strategies by using Social Stories	Before school starts the teacher provided the intervention (7-17 sessions; varied to participant involved)	Galaxy Tap smart tablet with Social Story created on Prezi and accessed via QR	Observation of disruptive behavior and academic engagement	Disruptive behaviour and academic engagement
17. Lancioni <i>et al.</i> (2014a), IT	ABAB design	N = 2; MID/MoID, 2 M Age 43 (I) and 34 (II) only data II included, I focused on support	II. total blindness, severe hearing disability	living room of the center	Not explicated, but BT principles	sessions 20-30 min, 34 and 47 intervention sessions (3 introduction sessions before start of intervention)	battery-powered sound-detecting unit fixed at the chest and connected with a throat microphone, an airborne microphone, a vibration box fixed at the shoulder. Sound-detecting unit was triggered when signals conveyed at about 85 dB	Observation of speaking and vocal loudness by momentary time sampling procedure	Vocal loudness
18. Lancioni <i>et al.</i> (2014b), IT	ABAB design (MPD across settings was used for participant 1).	N = 2; MoID and SID, 2 M, Age 33 and 42	blind; and one participant suffered from epilepsy; both congenital encephalopathy	activity area and large dining room for participant 1 (MoID/SID); activity room, corridor and 2 small rooms for participant 2 (SID/PMID)	Not explicated, but BT principles	One or two sessions per day, 3-5 days a week and 10 practical sessions to introduce the technology	orientation technology included a sound source at each of the destinations, a mini radio-coded device worn by participants on the shirt or belt, and a portable control device to activate such source. Short sentences from the apparatus encourage orientation in the right direction	Observation of anxiety-related behaviour (partial-interval)	Anxiety related behaviour



Table 3. Continued

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
19. Stasolla <i>et al.</i> (2014a), IT	non-concurrent multiple baseline design across participants	N = 2, 2 M Age 8-9	FXS, motor and speech disabilities	at home	matching behavioural responses to environmental consequences, DRO + self-determination	10 min sessions, 2-4 sessions a day, 4 days per wk. Study lasted approximately 5 months	optic sensors connected with battery powered control system unit.	Observation of stereotypic behaviour + indices of happiness + control system unit counts of performance of target behaviour	Occupation and choice opportunities, stereotyped behaviour and happiness
20. Stasolla <i>et al.</i> (2014b), IT	ABBTAB1	N = 3, 3 M Age 8.4-10.2 (M = 9.36)	ASD, motor and speech disabilities	quiet room at home	Not explicated, but BT principles	5 min, 3-5 times a day, 4 days per week, 125 sessions. Duration study: 3 months	microswitch-clusters program	Recording adaptive response device, hand-mouthing was detected by activation of optic sensor fixed with an adapted frame on the chin. Observation of indices of happiness (video)	Object manipulation, hand mouthing and happiness

Table 3. Continued

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
21. Jonker et al. (2015); NL	pre-experimental, quantitative approach	N = 1; MoID IQ = 47; 1 M Age 27	visual impairment	residential group home in care for ID and VI	Safe haven and secure base attachment intervention	First phase automatic responses received from a computer on the emotion message send by participant, second phase caregiver' response on distance and conversation between person with ID and caregiver about the exchanged messages according a protocol based on the Circle of Security when reunited in person	iPhone with app	ABCL, BSI, frequency and intensity of behavior at work and at home. Frequency of messages. Social Validity questionnaire caregivers and client.	Separation anxiety and challenging behaviour
22. Stasolla et al. (2015), IT	multiple probe design across participant responses for each participant	N = 3, 3 F Age 9-12	Rett's syndrome, withdrawal, isolation, passivity, motor disabilities, stereotyped behaviors	at home	Not explicated, but BT principles	10 min. 2-4 times per day, 4 days per week. Duration study: approximately 6 months. 225 sessions for each participants	containers with photocells + laptop equipped with a Clicker 5 software package and a connecting interface	Observation of mood signs + percentage of interval stereotyped behaviour + computer counting inserted objects	choice strategies, stereotyped behaviour and happiness

**Table 3. Continued**

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
23. Singh et al. (2017); USA	multiple-baseline design across participants with a 12 month follow-up	N = 3 teachers and N = 3 students; mild intellectual disability no IQ scores reported 3 M, Age 10-11		school	Mindfulness	Week 1 daily 30 min recognize precursor of anger + aggression and use SoF procedure and use SoF to effectively control his anger, week 2 daily 15 min sessions reviewing SoF procedure. Week 3 reminding the student to use the SoF procedure. Teacher recorded the SoF instruction on an iPad for self-instruction at school and at home	iPad for recording mindfulness exercises for students. iPad and Google Hangout for treatment fidelity check. iPhone and iPad for recording target behaviour of participants	Observation of frequency of physical and verbal aggression tapped on iPhone by 2 teacher aides independently	Physical and verbal aggression
24. Cooney et al. (2017); UK	A 2 * 3 RCT	N = 24 (cCBTG); 12 MID, 12 MoID, 16 F 8 M Age 42 (12.85); N = 25 (TAU); 8 MID, 17 MoID, 14 F 11 M Age 39,24(9.14)	anxiety, depression, comorbid anxiety and depression, or recurring anxiety or depression (DSM IV)	MHID team, a specialist secondary care service for non-crisis mental health services for adults with ID and mental health needs	CBT	7 consecutive weekly sessions, therapist guided during sessions	<i>Pesky Gnats: The Feel Good Island</i> prototype CBT computer game	Primary: GAS-ID, GDS-LD. Secondary: CORE-LD	Mood (anxiety/depression)

**Table 3. Continued**

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
25. Hoffman et al.(2017); NL	pre-experimental within-group design with multiple baselines and staggered intervention start-points	N = 6; MID and MoID (IQ scores n.r)/with visual impairment, 1 F, 5 M; Age 27-56	Separation anxiety	group homes at an organization	Safe haven and secure base attachment intervention	Messages sent by automatic response of a computer. Messages by caregiver. Discussion about the exchanged message	iPhone with app	ABCL anxiety subscale, BSI, PIMRA, IDQOL, frequency of each type of message. Frequency and intensity of behavior at home and at work	Separation anxiety and challenging behaviour
26. Stasolla et al. (2017a), IT	ABCAC experimental sequence, 3 month FU	N = 6, 6 M, Age 6.4-10.5 (M = 8.2)	ASD (severe conditions due to CARS score), isolated, passive and with drawn, motor an communicative disabilities	at home	Results can be comparable to a procedure of differential reinforcement of incompatible behaviors	5 min, 5 sessions a day, 5 days a week. Duration of study: 5 months 205 sessions per participant	2 microswitches (optic sensors) connected to battery powered control unit system.	Recording of adaptive behaviour by sensors fixed within the containers + recording challenging behavior by sensor embedded in a specific frame fixed on the chin. Observation of indices of happiness (partial interval with 20 observation per session)	adaptive behaviour and hand/ object mouthing

**Table 3. Continued**

Author/year/country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
27. Stasolla et al. (2017b), IT	Single-subject reversal experimental design (included two BL and two intervention phases). Follow-up phase after 3 months	N = 3; 3 M Age 8-10	FXS, quite passive and isolated, exhibiting withdrawal and stereotyped behaviors (hand mouthing and flapping), motor and communicative disabilities	at home	Not explicated, but BT principles	sessions of 5 min, 4-6 sessions a day, 4 days a week. Study lasted approximately 5 months. 150 sessions per participant. Before start 6 familiarization sessions	Optic sensors connected with an interface, to a laptop. The laptop automatically record a behavioral response, automatically ignored hand a new behavioral response within the stimulation period and providing participants with positive stimulation during the intervention and follow-up	Adaptive response was recorded by the computer + Observation of stereotyped behaviour, hand mouthing and indices of happiness	adaptive response, hand mouthing and happiness
28. Perilli et al. (2019), IT	ABB1AB1 design	N = 6; 6 M, Age 13-19	FXS	individually at participants' homes	Not explicated, but BT principles	BL 5 sessions within 2 days; B 30 sessions within 3 wks; B1 30 session within 3 wks. BL2 5 sessions within 2 days. FU (after 1 yr) 30 sessions within 3 wks. Sessions lasted 10 min	micro switch cluster technology	computer-system automatically recorded responses + Observation of positive participation (video)	adaptive response, hand biting and positive participation

Note. ABCL = Adult behavior checklist; BSI = Brief Symptom Inventory; BT = behavioral therapeutic; CARS = Childhood Autism Rating Scale; CB = challenging behavior; cCBTG = computerized Cognitive Behavior Therapy Group; cg = care giver; CORE-LD = Clinical Outcomes in Routine Evaluation - Learning Disability; DMT = dance and movement therapy; DSM IV = Diagnostic and Statistical Manual of Mental Disorders; F = female; FXS = fragile X syndrome; GAS-ID = Glasgow Anxiety Scale for people with Intellectual Disability; GDS-LD = Glasgow Depression Scale for people with Learning Disability; ID = intellectual Disability; IDQOL = Intellectual Disability Quality of Life; IQ = intelligence quotient; KISE-KIT = Korea Institute for Special Education-Korea Intelligence Test for Children; KISE-SAB = Korea Institute for Special Education-Scales of Adaptive Behavior; M = male; MARA = Movement Assessment and Reporting App; MD = multiple disabilities; MHID = Mental Health of Intellectual Disability team; MoID = moderate intellectual disability; NC = not clear; n.r. = not reported; PII = parent-infant interactions; PIMRA = Psychopathology Instrument for Mentally Retarded Adults; PMID = profound multiple intellectual disability; OR = quick response; RA = research assistant; RA2 = second research assistant; RCT = randomized controlled trial; SD = standard deviation; SID = severe intellectual disability; SoF = Soles of Feet mindfulness training; TBI = traumatic brain injured; TAU = treatment as usual; WAIS = Wechsler Adult Intelligence Scale.



**Table 3. Continued**

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
<b>Group interventions (with individual elements)</b>									
29. Hetzroni & Banin (2017); IL	Single subject multiple baseline design across situations	N = 5; mild ID (IQ scores n.r.), 5 M Age 11-15	Axenfeld-Rieger syndrome, psycho-motor behavior disorder and epilepsy	school	Social information processing theory and social modelling and simulation	Small group activities (50 min): observation of video-clips (adequate and non-adequate behaviours), followed by discussions related to the demonstrated behaviours. Participation in simulations of the social skill learned. At the end of each session students played the educational computer games. Group sessions included one participant and 5-6 other school peers	Computer, video modelling clips	Observation of socially adequate behavior (before, during and after intervention in three situations). A observation form was developed with information about the participant, activity and what behavior was exposed in what situation	Action, verbal and non-verbal behaviour in three social situations

**Table 3.** *Continued*

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
30. Dunphy & Hens (2018); AUS	Mixed method: Observational data and interviews and focusgroups with participants; center staff, managers and parents	N = 12; MoID and MID, IQ scores, gender and age n.r.		day center for people with ID	Dance and movement therapy	16 weekly sessions	MARA app with iPad	Observation scores on behaviour linked to 2 objectives DMT in six sessions (beginning, mid and final sessions) + interviews participants on experiences DMT and reviewing video clips and therapist scores of DMT sessions	Exposing behaviour on objectives (physical domain and inter-personal domain)
31. Hronis <i>et al.</i> (2018); AUS	Feasibility study by case series design	N = 21: 2 groups Juniors N = 10 MoID/MID, 10 F Age 13-15; seniors N = 11 MoID/MID 11 F Age 14-18	SAS-TR school anxiety, SUDS and ID	all-girls school supporting children with special needs	CBT	10 face-to-face group sessions twice weekly and an online program	<i>Fearless Me!</i> Online program with exercises related to CBT	Scores on SUDS of participants, SAS-TR reported by teachers. Parents outcome measures were not reported due to low response rate	Anxiety

Note. CBT = Cognitive Behavior Therapy; MID = mild intellectual disability; MoID = moderate intellectual disability; SUDS = subjective units of distress score; SAS-TR = Social Anxiety Scale-Teacher Report

**Table 3. Continued**

Author#year#country	Study design	Participants	Diagnosis (DSM or ICD)	Treatment context	Model of change/therapeutic	Therapy conditions	eHealth application	Outcome measures	Target behaviour
<b>Dyad interventions</b>									
32. Simacek <i>et al.</i> (2017); USA	Single-case experimental designs; MPD and ABAB design embedded	N = 3; IQ n.r., low adaptive range VABS: 2 ASD and 1 Rett's syndrome. 3 F Age 3.5-4 yrs	ASD, Rett's disorder (severe neuro-developmental disability)	at home	ABA	Functional communication training delivered by parents up to 7 daily sessions with a 5 min/3 trial block with a prior functional assessment and psycho-education of parents supported a certified coach via telehealth	Screen-recording software on computer, headset, secure internet and storage of data. Videoconferencing software (Google Hangout) and webcam	Observation of idiographic responses and requests using PECS cards/microswitch for requests and problem behaviour. Treatment Acceptability Rating Scale-Revised parents	Adaptive request to parents and yelling, tantrum, and hitting object
33. Monlux <i>et al.</i> (2019); USA	not reported	N = 10 parent-child dyads with eight dyads completed the treatment; IQ n.r. mean adaptive behavior composite standard score 62.1 (SD=8.3, range=50-73). Age 3-10	FXS	at home	ABA	12-weeks 1-h telehealth-supported to implement a functional communication plus extinction training on a daily basis delivered by parent	Apple iPad Air® with a built-in webcam, a Bluetooth® earpiece and a HIPAA compliant videoconferencing program	Observation of the rate of problem behavior and functional communication response during 1 h telehealth session. Treatment Acceptability Rating Scale-Revised parents	problem behaviour and child demands

Note. ABA = Applied Behavior Analysis; ASD = autism spectrum disorder; BIF = borderline intellectual functioning; F = female; FXS = fragile X syndrome; HIPAA = Health Insurance Portability and Accountability Act; M = male; MID = mild intellectual disability; MoID = moderate intellectual disability; PECS = Picture Exchange Communication System; VABS = Vineland Adaptive Behavior Scale.



## Characteristics of the psychological eHealth interventions

The vast majority of the studies ( $n = 29$ ) reported on interventions that were delivered at the individual level (Cooney et al., 2017; Dunphy & Hens, 2018; Gaskin et al., 2012; Hoffman et al., 2017; Jonker et al., 2015; Kim et al., 2014; Lancioni 1997, 1998, 1999, 2006abc, 2007, 2008ab, 2011, 2013ab, 2014ab; Perilli et al., 2019; Singh et al., 2017; Stasolla et al., 2014ab, 2015, 2017ab). In addition, two interventions were delivered to a dyad comprising a child with an intellectual disability and his/her parent (Monlux et al., 2019; Simacek et al., 2017), while two studies reported on a combination of a group intervention with individual elements, such as a group discussion combined with playing video games individually (Hetzroni & Banin, 2017; Hronis et al., 2018).

### 3.1.1. *The types of interventions*

The types of interventions used within the studies varied. The majority of the studies ( $n = 24$ ) included applied behaviour analysis or behaviour therapeutic principles as the basis for the intervention (Lancioni et al., 1997; 1998; 1999; 2006a; 2006b; 2006c; 2007; 2008a; 2008b; 2011; 2013a; 2013b; 2014a; 2014b; Monlux et al., 2019; Perilli et al., 2019; Simacek et al., 2017; Stasolla et al., 2013a; 2013b; 2014a; 2014b; 2015; 2017a; 2017b), for example prompt fading, extinction, and differential reinforcement. In addition, two studies used a practice-based programme, which was originally developed for a specific centre or target group and subsequently adapted for the participants within the study (Gaskin et al., 2012; Kim et al., 2014). Moreover, two studies reported on using Cognitive Behavioural Therapy (CBT) in their interventions (Cooney et al., 2017; Hronis et al., 2018). CBT is a form of therapy helping people to reduce distress by becoming aware of and changing unhelpful thoughts, underlying thinking schemes and practicing other ways of thinking and applying new skills in daily life (Jahoda et al., 2017). Furthermore, the Circle of Security intervention for developing secure attachment with primary caregivers was used in two studies (Hoffman et al., 2017; Jonker et al., 2015). Finally, two studies reported on interventions that used a systemic approach (Dunphy & Hens, 2018; Hetzroni & Banin, 2017), while one study focused on mindfulness (Singh et al., 2017).

### 3.1.2. *Context of intervention delivery*

Eleven studies reported that the intervention was deployed at home (Gaskin et al., 2012; Monlux et al., 2019; Perilli et al., 2019; Simacek et al., 2017; Stasolla et al., 2013ab, 2014ab, 2015, 2017ab). In five studies, the intervention was delivered in a residential setting (Hoffman et al., 2017; Jonker et al., 2015; Lancioni et al., 1997, 2014ab). In addition, a day or activity centre served as the intervention context for five studies (Dunphy & Hens, 2018; Lancioni et al., 1997, 1998, 1999, 2013a), and a school context for four studies (Hetzroni & Banin, 2017; Kim et al., 2014; Lancioni et al., 2007; Singh et al., 2017). Furthermore, one study combined a school context with the use of online information and practicing of elements of CBT at home (Hronis et al., 2018), while one study delivered

the intervention in an educational context for some of the participants and at home for others (Lancioni et al., 2006b). A clinical mental health setting served as the context for one study, with a specialist team delivering secondary care service (Cooney et al., 2017), while another study was carried out in the context of a care and rehabilitation centre (Lancioni et al., 2011). Finally, four studies did not report the context in which the intervention occurred (Lancioni et al., 2006a, 2008ab, 2013b).

### **3.2. Characteristics of the participants with intellectual disabilities**

In total, the 33 studies contained 168 participants with intellectual disabilities (75 males, 68 females); two studies did not report about the gender of their 25 participants (Dunphy & Hens, 2018; Monlux et al., 2019). In 16 studies, the participants were children with intellectual disabilities aged between 3 and 18 years old (Hetzroni & Banin, 2017; Hronis et al., 2018; Kim et al., 2014; Lancioni et al., 2006a; 2007; 2008b; Monlux et al., 2019; Simacek et al., 2017; Singh et al., 2017; Stasolla et al., 2013ab; 2014ab; 2015; 2017ab). Adults with intellectual disabilities participated in 14 studies (Cooney et al., 2017; Dunphy & Hens, 2018; Gaskin et al., 2012; Hoffman et al., 2017; Jonker et al., 2015; Lancioni et al., 1997; 1998; 1999; 2006c; 2008a; 2011; 2013a; 2014ab), while in three studies, both a child and an adult with intellectual disabilities were included as participants (Lancioni et al., 2006b; 2013b; Perilli et al., 2019).

In 18 studies, people with severe and profound intellectual disabilities participated in psychological eHealth interventions (Kim et al., 2014; Lancioni et al., 2006abc; 2007; 2008ab; 2011; 2013ab; Stasolla et al., 2013a; Lancioni et al., 2014b; Perilli et al., 2019; Stasolla et al., 2014ab; 2015; 2017ab). In addition, people with moderate intellectual disabilities participated in five studies (Jonker et al., 2015; Lancioni et al., 1997; 1998; 1999; Stasolla et al., 2013b) and a mixed group of people with mild to moderate intellectual disabilities participated in five studies (Cooney et al., 2017; Dunphy & Hens, 2018; Hoffman et al., 2017; Hronis et al., 2018; Lancioni et al., 2014a), while three studies only reported the results for participants with mild intellectual disabilities (Gaskin et al., 2012; Hetzroni & Banin, 2017; Singh et al., 2017). Two studies did not report the level of intellectual functioning, but reported the results on the Vineland Adaptive Behaviour Scale with scores in the low adaptive range (Monlux et al., 2019; Simacek et al., 2017). It is noteworthy that only one study reported detailed information about IQ scores based on standardized testing of the participants (Gaskin et al., 2012); all other studies merely reported a description of the level of intellectual functioning of the participants.

#### ***3.1.2. Type of challenging behaviour and mental health problems***

In 23 studies, the rationale for the intervention was that the participants were exhibiting various types of challenging behaviour. First, self-injurious and stereotypic behaviour, such as finger biting and hand mouthing, eye poking and body rocking, were reported

in 15 studies (Lancioni et al., 2006ac, 2007, 2008ab, 2012, 2013ab; Perilli et al., 2019; Stasolla et al., 2013a, 2014ab, 2015, 2017ab). Next, vocal loudness was reported in four studies (Lancioni et al., 1997, 1998, 1999, 2014a), aggressive behaviour in two studies (Monlux et al., 2019; Singh et al., 2017), disruptive behaviour in one study (Kim et al., 2014), and tantrums, crying and whining in one study (Simacek et al., 2017), while one study reported on the harmful parental behaviour of a mother who had a mild intellectual disability (Gaskin et al., 2012).

Of the remaining studies, ten studies focused on the mental health problems of the participants; in five of these, the main mental health problem was a type of anxiety: general anxiety (Hronis et al., 2018), anxiety with comorbid depression (Cooney et al., 2017), separation anxiety (Hoffman et al., 2017; Jonker et al., 2015), and travel-related anxiety (Lancioni et al., 2014b). Five studies focused on the combination of mood problems and self-injurious behaviour (Stasolla et al., 2013; 2014ab; 2015; 2017ab).

### 3.3. Characteristics of the people delivering the psychological eHealth intervention

The interventions reported in the studies were delivered by a wide variety of people. Two interventions were delivered by parents at home who were being coached remotely by professionals qualified in Applied Behaviour Analysis and early interventions (Monlux et al., 2019; Simacek et al., 2017). Other interventions were delivered by support staff ( $n = 2$ ) (Hoffman et al., 2017; Jonker et al., 2015) or teachers ( $n = 3$ ) (Hetzroni & Banin, 2017; Kim et al., 2014; Singh et al., 2017). Therapists delivered the intervention in three studies: a clinical psychologist (Cooney et al., 2017), a dance and movement therapist supported by support staff from the day centre (Dunphy & Hens, 2018), and a psychologist working in collaboration with the class teacher and teaching assistant (Hronis et al., 2018). One study was delivered by a SafeCare® home visitor (Gaskin et al., 2012). Research assistants supported people with severe intellectual disabilities and motor disabilities during the intervention through a combination of verbal and physical prompting ( $n = 15$ ) (Lancioni et al., 1997, 1998, 1999, 2006abc, 2008b, 2013a, 2014ab; Stasolla et al., 2013ab, 2015, 2017ab). Parents and support staff were involved to provide information about the personal preferences of people with severe and profound intellectual disabilities. Seven studies failed to report who delivered the intervention (Lancioni et al., 2007, 2008a, 2011, 2013b; Perilli et al., 2019; Stasolla et al., 2014ab).

### 3.4. Content of the studies reporting on psychological eHealth interventions

Overall, the content of the included studies reporting on psychological eHealth intervention can be classified into four types, which are not mutually exclusive and combining different types of content (e.g., the use of a videoclip within a cognitive

behavioural therapy). First, five studies used pictures and video clips of the participants with intellectual disabilities or the person who delivered the intervention (e.g., the teacher) to enable communication about the target behaviour (e.g., discuss about objectives and therapy progress) and to facilitate learning the desired skills rather than exhibiting challenging behaviour (Dunphy & Hens, 2018; Gaskin et al., 2012; Hetzroni & Banin, 2017; Kim et al., 2014; Singh et al., 2017). With respect to the latter, the participants were for example stimulated to display the behaviour learned in the intervention through using the eHealth application. By showing pictures of the participants involved displaying the desired behaviour on a digital screen, the application works as a primer prior to the school day beginning (Kim et al., 2014) or as a reminder (Gaskin et al., 2012), ultimately helping a mother with a mild intellectual disability to repeat the positive parental behaviour she had learned in between the sessions with the home visitor. Three other studies used video modelling clips of the participants to show good examples or the process of therapy progress (Dunphy & Hens, 2018; Hetzroni & Banin, 2017; Singh et al., 2017). In an intervention designed to encourage self-management of aggression in three boys with mild intellectual disabilities, the boys learned to apply a mindfulness-based procedure (Soles of Feet). More specific, the teacher recorded the Soles of Feet exercises on an iPad, so that they could use the exercises as an alternative to regulate their stress at both school and home (Singh et al., 2017). Another study reported on a programme that used video-modelling clips of the participants themselves interacting with peers via a computer programme to recognize adequate and non-adequate social behaviours, in combination with group discussions held in a classroom which involved practicing social skills in pairs under the instruction of a teacher (Hetzroni & Banin, 2017). Finally, the study of Dunphy and Hens (2018) reported on the use of the MARA app as a tool for monitoring the progress of participants in Dance and Movement Therapy (DMT) in line with specific objectives (e.g., movement and interpersonal functioning). This intervention also used video clips of the participants from six different sessions at the beginning, halfway point, and end of the therapy to both discuss the progress of the therapy along with the participants and to share the results with relatives, staff, and managers.

Second, in order to enable communication about the target behaviour and facilitate learning the desired skills rather than exhibiting challenging behaviour, four studies used a remote, mediated approach (Hoffman et al., 2017; Jonker et al., 2015; Monlux et al., 2019; Simacek et al., 2017). Two of these studies reported on interventions delivered by parents at home who were simultaneously being coached remotely by professionals via video telecommunication. They conducted a functional analysis of the problem behaviour of the child displaying challenging behaviour. The functional analysis was deployed together with the parent and supported the application of a subsequent tailor-made behavioural programme. The parents received an instruction manual

prior to the intervention with information, tips, and supporting materials (e.g., red and green cards), and were given specific feedback via email after the session (Monlux et al., 2019; Simacek et al., 2017). In two other studies, support staff delivered a blended (i.e., combination of offline and online components) eHealth intervention for people with mild to moderate intellectual disabilities and visual impairments. Both studies reported on an intervention focused on separation anxiety which was based on the 'safe base, safe haven' principle. Once they were separated during the intervention, the 'safe base' consisted of a reply from the support staff member confirming the emotion that the client had shared in the text message sent from their mobile phone (an adapted iPhone touch was provided to the visually impaired person). After the person with an intellectual disability and the person with a visual impairment were reunited with support staff, they both discussed the content of the messages to encourage the person to dare to express emotions while the support staff provided 'a safe haven' (Hoffman et al., 2017; Jonker et al., 2015).

Third, a computerized CBT approach was used in two studies (Cooney et al., 2017; Hronis et al., 2018). In Hronis et al.'s (2018) study, a psychologist delivered a group CBT intervention focused on anxiety, in collaboration with the class teacher and teacher's assistant, to a group of adolescents with intellectual disabilities. These face-to-face sessions led by the psychologist and the teacher comprised group and individual activities combined with an online programme to practice relevant CBT skills. Another CBT intervention was delivered by a clinical psychologist, who sat next to the person with an intellectual disability during the session. The person followed a computer-based programme, which used social stories with avatars in a computer game to explain the cognitive mediated model. This computer-based programme was combined with digital mindfulness and relaxation exercises at the end of each session. In addition, a workbook was used between the sessions to support the transfer of the skills they had learned in therapy into their daily lives (Cooney et al., 2017).

Fourth, in 22 studies, sensor technology detected the exposure of the target behaviour, such as touching objects without hand mouthing, followed by activation of an aversive<sup>1</sup> or preferred stimulus (Lancioni et al., 1997; 1998; 1999; 2006abc; 2007; 2008ab, 2011; 2013ab; 2014ab; Perilli et al., 2019; Stasolla et al., 2013ab; 2015; 2017ab). The vast majority of these studies included people with severe to profound intellectual disabilities with additional disabilities (e.g., motor and sensor disability), and used principles of behaviour modification that involved reinforcement schedules without any explicit prior functional assessment to identify the variables causing or maintaining the challenging behaviour. The conclusion of the researchers involved in these studies, nevertheless, was that the

1 The use of aversive stimuli is less widely used in contemporary psychological interventions and could be considered as an unacceptable procedure of punishment

behaviour was not socially reinforced or related to specific events without providing any further details. A small number of the studies ( $n = 5$ ) (Lancioni et al., 1997; 1998; 1999; 2014a; Stasolla et al., 2013b) investigated the use of sensor technology which provided verbal feedback among people with mild to moderate intellectual disabilities. For example, in one study, a participant with an estimated moderate intellectual disability and severe motor and communication disabilities found sensor technology to be helpful for expressing his preferences, which, in turn, contributed to happiness (Stasolla et al., 2013b).

## 4. Discussion

In recent years, eHealth has increasingly been used in the field of intellectual disabilities, a shift which has been accelerated even more rapidly over the last few months due to the COVID-19 pandemic. Although psychological eHealth interventions for people with intellectual disabilities are routinely being applied in daily practice, there is a relative dearth of knowledge in this area to inform both research and clinical practice. To address this scarcity of knowledge, this scoping review identified and summarized literature about psychological eHealth interventions among people with intellectual disabilities who also have mental health problems and/or exhibit challenging behaviour. The authors explored the characteristics of interventions, the participants, the people delivering the intervention, as well as the content of 33 studies reporting on psychological eHealth interventions for people with intellectual disabilities.

With respect to the characteristics of the psychological eHealth interventions, the vast majority of the studies reported on interventions that were delivered at the individual level and within the individual's living environment or home of the person with intellectual disabilities. In so doing, such psychological interventions can overcome often cited physical and logistical barriers that hinders the access to mental health care and solve the challenge of transferring learned skill to personal life (Taylor et al., 2013; Whittle et al., 2018). More specifically, the transfer of learned skills from an intervention in the therapist's room to daily life and the recall of relevant situations to discuss in a session are often mentioned as significant barriers for people with an intellectual disability (Taylor et al., 2013). eHealth could overcome those barriers by delivering a psychological intervention in an individual's living environment or home, so a person with intellectual disabilities could benefit optimally from the intervention. An additional advantage of eHealth is that psychological eHealth interventions can be tailored (e.g., use of personal video clips, preferred stimuli as motivators, online homework assignments). Literature about the adaptations of psychological interventions among people with intellectual disabilities emphasizes the importance of adaptation within the provision

of psychological therapies, such as using visual tools and the application of technology for monitoring target behaviour and progress (Jahoda et al., 2018; Whitehouse et al., 2006).

A notable finding of the scoping review is that only two studies reported about parents of young children exhibiting challenging behaviour being coached via telecare (i.e., delivering a psychological intervention through the use of video conferencing technology); no studies reported using telecare applications to deliver psychological interventions directly to people with intellectual disabilities. Research among the general population has reported on the feasibility of delivering effective psychological interventions via video conferencing with individuals, dyads, and groups, and, in fact, have reported similar outcomes to interventions delivered on-site (Banbury, et al., 2018; Shaffer et al., 2020). The pilot or feasibility nature of studies fits into the early stage of developing effective eHealth interventions. That is, evaluation of the effectiveness of interventions (e.g., Thornicroft et al., 2011), and in particular eHealth interventions (e.g., Bonten et al., 2020) often starts with an initial phase in which the opportunities of eHealth interventions are explored in feasibility/pilot studies. Within those studies, the aim is to provide insight into the possibilities of psychological eHealth interventions rather than conducting these interventions to explore its effectiveness. When more evidence-based knowledge is available with respect to psychological eHealth interventions, it is likely that other studies will be conducted as well, such as studies focusing on the effectiveness of a psychological eHealth intervention delivered directly to people with intellectual disabilities. Further, potential barriers for delivering psychological interventions directly may be the lack of access to digital devices (e.g., computer, laptop) and internet, sensory and motor abilities to handle a device, digital literacy and cognitive burden (Lussiers-Desrochers et al., 2017). Perceived barriers depend on the attitude of professionals, for example by assuming that delivering a psychological intervention to people with intellectual disabilities directly might be too difficult (Parsons et al., 2008). The COVID-19 pandemic forced therapists to deliver psychological interventions to their clients directly, because onsite support staff or relatives were not allowed to visit group homes. So, the current situation provides valuable insights into relevant aspects for delivering eHealth interventions to people with intellectual disabilities directly. In a review of telepsychiatry among people with intellectual disabilities in a psychiatric setting, Madhavan (2019) concluded that it constituted an effective means through which to empower people with intellectual disabilities, while, simultaneously, reducing costs.

Regarding the participants that were involved in the psychological eHealth interventions, both children and adults were included in the studies. More than half of the studies included participants with severe to profound intellectual disabilities who were engaged in self-injurious and stereotypic behaviour and the interventions were focused primarily

on learning adaptive behaviour and unlearning challenging behaviour. One-third of the studies reported on psychological eHealth interventions among people with mild to moderate intellectual disabilities that were focused on anxiety and mood disorders. This latter focus is in accordance with psychological eHealth interventions among the general population suffering from mental health problems, which predominantly address anxiety and depression (Carlbring et al., 2018; Grist et al., 2019). However, psychological eHealth interventions among the general population serve a broader range of mental health problems that also happen to be especially prevalent among people with mild intellectual disabilities (e.g., anger, body dissatisfaction, PTSD, and substance abuse). Both the broader range of mental health problems affecting people with intellectual disabilities besides anxiety and depression and the wealth of opportunities afforded by eHealth require further attention from researchers (Berryhill et al., 2019; Carlbring et al., 2018; Mevissen & De Jongh, 2010; Schützwohl et al., 2016). There is a scarcity of studies specifically focusing on psychological eHealth interventions for mental health problems among people with mild intellectual disabilities ( $n = 3$ ), despite their increased risk of mental health problems (Bowring et al., 2019; Munir, 2016).

Regarding the characteristics of the people delivering psychological eHealth interventions, various persons were identified in this scoping review. All psychological eHealth interventions were either guided or therapist-led interventions, with only a few interventions delivered by a therapist (e.g., clinical therapist). Support staff and teachers, were often involved as lay therapists along with non-professionals, such as parents in the delivery of a psychological eHealth intervention. They were supervised by a clinical expert and provided with an instruction manual to increase the reliability of the treatment and the materials. Indeed, the participation of lay therapists is often used as a feasible method through which to deliver psychological interventions among people with intellectual disabilities (Jahoda et al., 2013). Within psychological eHealth interventions among the general population, non-clinicians often function as lay therapists under the supervision of a psychologist as well (Titov et al., 2010). In general, the addition of human support leads to enhanced adherence to eHealth interventions (Mohr et al., 2011). The applicability and role of lay therapists within psychological eHealth interventions among people with intellectual disabilities requires further exploration. In contrast to a substantial number of eHealth interventions among the general population (Deady et al., 2017), this scoping review did only contain studies that used a guided approach.

There are some limitations of the scoping review that need to be addressed. First, only studies written in English were included, which means that relevant studies published in other languages have potentially been overlooked. Second, the quality of the evidence was not formally evaluated within this scoping review. More than 20% of the studies



reported that their intervention was a pilot, trial, or feasibility study, with researchers openly acknowledging that they failed to meet the high-quality research standards found, for example, in RCT's (e.g., Hronis et al., 2018). Given that the aim of this scoping review was to provide an overview of studies reporting on psychological eHealth interventions rather than assessing the quality of these studies, a quality appraisal was not carried out (Arksey & O'Malley, 2005). Third, similar to our previous systematic review (Oudshoorn et al., 2020), a notable challenge of this scoping review was to determine the concept of 'eHealth' itself, as it is regularly used as an umbrella term for a multitude of different ways of delivering and facilitating health care (Oh et al., 2005; Skär & Söderberg, 2017). Hence, it would be beneficial to formulate a clear definition of eHealth, which, in turn, would reduce the risk of misinterpreting what precisely eHealth is. Future research should therefore focus on developing a more concrete definition and rigorous conceptualization of the concept of eHealth.

This scoping review identified various psychological eHealth interventions, and reported on their specific characteristics. Although the current COVID-19 pandemic has accelerated the use of eHealth with people with intellectual disabilities, unfortunately they have hitherto often been excluded from studies about psychological eHealth interventions targeted at the mainstream population, and in this respect scientific knowledge in this areas has not kept pace with knowledge development of psychological eHealth interventions among the general population (Brown et al., 2011). Hence, further research is needed to contribute to knowledge building about effective psychological eHealth interventions among people with intellectual disabilities who suffer from mental health problems and challenging behaviour. While some recent qualitative studies have shown that people with intellectual disabilities are, in general, interested in and open to eHealth, many obstacles still need to be overcome, including limited access to digital devices or lacking the necessary digital skills to participate in eHealth interventions (Cooney et al., 2018; Frielink et al., 2020; Vereenooghe et al., 2017). Moreover, it would be interesting for future research to explore the value of a blended format, combining face-to-face sessions with online sessions, which is now commonly utilized with the general population (Wentzel et al., 2016).

To conclude, this scoping review has demonstrated that eHealth provides an opportunity for therapists and lay therapists to deliver psychological eHealth interventions, which could range from a small component of a multimodal intervention up to a completely computerized, therapist-led intervention. The inherent variety and flexibility of eHealth provides opportunities to overcome obstacles which are commonly encountered during face-to-face psychological interventions, especially as face-to-face sessions are impossible because of the COVID-19 measures. eHealth enables the delivery of different forms of psychological eHealth interventions (e.g., CBT, mindfulness, Circle of

Security) which may be helpful to people with intellectual disabilities, but also to their relatives and direct support staff, during the COVID-19 pandemic (Courtenay & Perera, 2020). eHealth may solve access barriers and bring a therapist and the psychological intervention in the personal situation. The loss of professional care at home is a huge problem and increases anxiety and mental health problems in individuals previously receiving support (Embregts et al., 2020; Willner et al., 2020). The current situation requires patience and is a long-term process in which eHealth could be 'the digital bridge' connecting people with intellectual disabilities who need mental health support and those who could deliver it.

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The authors declare no conflicts of interest.

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This review does not involve any human participants.

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\*included studies in the scoping review.



**CHAPTER 4**



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

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## **Abstract**

### **Background**

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

### **Method**

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

### **Results**

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

### **Conclusions**

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

## 1. Introduction

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

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

Despite the progressive use of eHealth in support for daily functioning of people with ID, few studies focused on its feasibility or effectiveness. De Wit and colleagues (2015) examined the feasibility of a web-based program facilitating professional support for service users with chronic conditions, including ten people with mild ID, in their daily

functioning. Their results showed that the use of this web-based program was accepted by both the professionals and the service users. Moreover, the online support did not reduce service users' satisfaction with the received support, empowerment, and quality of life compared to face-to-face support as usual. In addition, in a pilot study, Taber-Doughty and colleagues (2010) compared remote telecare support with face-to-face support as usual on independent performance of four adults with moderate-to-mild ID in completing household tasks. Results indicated that service users who were supported by telecare had a higher degree of independent performance compared to face-to-face support as usual. Hence, these initial results are promising and may justify further research on the effectiveness of the use of eHealth in support for daily functioning for service users with ID.

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

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



impeding factors for the use of eHealth in support for daily functioning. Understanding these aspects from the perspective of service users, relatives, and professionals may contribute to the successful use of eHealth in support for daily functioning.

## 2. Method

### 2.1. Research design

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

### 2.2. Participants

After ethical approval was provided by the Ethics Review Board of Tilburg University (EC-2015.04), the study was conducted in an ID service in the southern part of the Netherlands which offered residential homes, 24-hour community residences, ambulant support at clients' own homes, and day care facilities. To recruit service users (people with mild to borderline ID; IQ 50-85) and relatives of people with ID to participate in this study, the authors contacted the coach of the central client council of the ID service. The coach supports the members of this council, consisting of both service users and relatives, in various manners (e.g., jointly drawing up the agenda, preparing their meetings as well as meetings with for example the board of directors, and being present for any assistance possible). After the coach was informed about the study, she selected eight service users and four relatives (three parents, one brother) based on their experiences and knowledge of eHealth. Next, the authors contacted the service users and the relatives (who were not related to each other) by phone and fully informed them about the study; all voluntarily agreed to participate and provided informed consent. The service users (five men), who had a mean age of 35.6 years (range: 24-53), were equally divided over two focus groups (i.e., four service users for each focus group). According to the clinical judgment of the psychologist, all service users had a mild to borderline ID. All received support within a residential care setting. The relatives, all men, had a mean age of 49.0 years (range: 36-69). One father had a son with a mild ID, one father had a

son with a severe ID, and one father a daughter with a severe ID; the brother was the relative of a man with a severe ID. All relatives attended one focus group.

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

### **2.3. The interview and materials**

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

Each focus group and the individual interview started with a brief introduction of the interviewers and the participants, followed by an explanation of the current study. Next, the participants agreed to audiotape the focus groups and the interview; participants' informed consent was audiotaped. Subsequent, the interviewers posed questions associated with the topics in a semi-structured interview guide developed for the purpose of the current study. That is, participants were first asked: What comes to your mind when you think of defining eHealth in support for daily functioning? In addition, participants were asked to illustrate examples of eHealth applications they knew. Next, by means of a PowerPoint® presentation, the interviewers provided the most-cited definition of eHealth, by Eysenbach (2001)<sup>2</sup>, and outlined a clustering of eHealth applications based on Timmer (2014) to provide input for the participants in the case they were not familiar with the term eHealth. While doing so, the interviewers emphasized that although

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

the eHealth definition of Eysenbach and the clustering of Timmer is broad, this study focuses only on eHealth in support for daily functioning. Then, in the second part of the focus groups and the interview, the participants were asked about advantages and disadvantages of eHealth in support for daily functioning and, in the third and last part of the focus groups and the interview, what facilitating and impeding factors for the use of eHealth in support for daily functioning they faced. Hence, the interview guide consisted of three parts: (1) familiarity with eHealth in support for daily functioning, (2) advantages and disadvantages of eHealth in support for daily functioning, and (3) related facilitating and impeding factors, each operationalized with numerous open-ended questions. The interview guide for professionals and relatives was identical; the open-ended questions within the interview guide for service users were simplified, but the scope of the questions was nevertheless similar. In addition, the eHealth definition provided to the service users was also simplified (i.e., eHealth was defined as the use of the Internet, a computer, or smartphone in support for daily living).

## 2.4. Analysis

A standard content analysis on the basis of a general inductive approach (Thomas, 2006) was conducted. This approach was chosen as the aim of the current study was to gain insight into the level of knowledge regarding eHealth in support for daily functioning and to identify advantages and disadvantages as well as facilitating and impeding factors for the use of eHealth in support for daily functioning, without theories or prior assumptions directing the exploration. The general inductive approach aims to abbreviate the text data into a brief summary, make clear associations between the research goals and the summary findings, and to present the underlying structure of experiences and perceptions of participants as originated from the text data (Thomas, 2006). In the first step of this general inductive approach, one of the researchers read the verbatim transcriptions in detail to ensure he is acquainted with the content (i.e., in our case, the first author). Next, phrases of clear importance for the study (i.e., in our case, related to one of three topics of this study: (1) familiarity with eHealth in support for daily functioning, (2) advantages and disadvantages of eHealth in support for daily functioning, and (3) related facilitating and impeding factors) were assigned a code based on the data itself. Subsequent, a second level of coding was conducted to identify themes associated with the topics of the interview guide. Finally, the identified themes, subthemes, and codes were discussed by the authors and two other researchers within our research group and adapted when required.

## 2.5. Rigor of the methodology

To improve the quality of the study, a number of trustworthiness and credibility checks were conducted. First, a second coder performed a coding check to ascertain clarity and consistency of the codes. Second, different stakeholders (i.e., service users, relatives,

and professionals) were interviewed to ensure that the account reported is as rich and comprehensive as possible. Finally, extensive discussions about the codes and proposed themes and subthemes were held between the authors and two other researchers to ensure that the themes and subthemes took into account a variety of perspectives, and hence, were as rich as possible.

### 3. Results

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

#### 3.1. Familiarity with eHealth in support for daily functioning

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

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

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

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

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

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

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

Furthermore, professionals noted that eHealth is a broad term. According to a professional:

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

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

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

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

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

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

### **3.2.1. Advantages**

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

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

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

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

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

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

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

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

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

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

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

*You can bet that once an online health platform is brought into use, mom and dad will log in regularly just to see how things are going. Not to check up on support staff, but just because they want to see how their son is doing. And if you can be part of that process, then that's a big plus. [Relative 2]*

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

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

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

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

### 3.2.2. Disadvantages

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

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

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

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

Moreover, service users, relatives as well as professionals indicated that by using eHealth-applications, social contacts with other people might change, and its use should therefore be considered carefully. In the words of a professional:



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

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

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

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

#### **3.3.1. Facilitating factors**

Regarding the facilitating factors for the use of eHealth in support for daily functioning, service users, relatives as well as professionals indicated that it is important to recognize that there is a distinction between people who are open-minded towards eHealth and people who are not (see Table 3). That is, not everyone want or is able to use eHealth applications, for example through lack of interest or aging. In the words of a service user:

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

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

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

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

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

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

*As soon as you've found the right app, you should share this with others. You need to avoid having lots of small islands where some people discover this and others discover that, but nobody knows what other people are discovering. [Professional 4]*

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

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

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

### 3.3.2. Impeding factors

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

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

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

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

## 4. Discussion

In this study, eight service users with mild to borderline ID, four relatives, and four professionals participated in four focus groups and one semi-structured qualitative interview to identify 1) the level of familiarity, 2) the advantages and disadvantages, and 3) facilitating and impeding factors for the use of eHealth in support for daily functioning. In order to do so, a general inductive approach was used to cluster the responses of the participants.

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

Regarding the advantages and disadvantages of eHealth in support for daily functioning, participants indicated benefits directly related to service users (e.g., increased independency and more opportunities for communication) and benefits which were more related to relatives and professionals (e.g., providing more efficient support and being able to stay in contact with the service user remotely). These benefits are consistent with previous ID research (e.g., Gutiérrez & Martorell, 2011; Clifford Simplican et al., 2018), indicating that engaging in social contacts and more control over one's own life are important benefits of eHealth. Although participants in the current study suggested that the use of eHealth in support for daily functioning of people with ID may result in more time for face-to-face contact with the service user, they also mentioned

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

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

did not seem to apply to the use of surveillance technology, as participants merely expressed positive sentiments about surveillance (i.e., improved and more effective health care). This contradicts previous findings showing that the application and use of surveillance technology in residential care for vulnerable populations raises substantial ethical concerns (Niemeijer et al., 2010). However, these concerns do not necessarily focus on the effects of surveillance technology, but rather on the moral acceptability of those effects. Niemeijer and colleagues (2010) found in their study this is particularly the case when there is a discrepancy between the interests of the service user and the interests of the health care organization. Future research should pay more attention to this important yet complex privacy issue in the ID field.

A strength of the current study was that we collected data directly from people with ID rather than via proxy. Although proxy reports can be useful and informative, studies reported perception gaps between people with ID on the one hand and support staff or family members on the other hand (e.g., van Oorsouw, Theeven, Leenders, Vermeulen, & Embregts, 2019; Scott & Havercamp, 2018). Especially in the case of people with mild ID, much information can be obtained by asking service users themselves, in particular when it concerns their views or experiences. With this in mind, we encourage researchers to take steps to broaden the involvement of service users in studies that directly concern topics that affect them. The present results should nevertheless be interpreted in light of the limitations of the study. Firstly, although a qualitative research design with focus group method was chosen, one semi-structured interview was conducted in this study with a professional. It was intended that this professional participated in the focus group with the three other professionals, but due to an emergency he was not able to attend. Given his particular expertise with eHealth in support for daily functioning as clinical psychologist working with people with ID, we have decided to include his views and experiences on the basis of a semi-structured interview. Secondly, all participants of the current study were related to one ID service in the Netherlands. Given that the policy of organizations and their vision towards eHealth influence the views of individuals related to that organization (Parsons, Daniels, Porter, & Robertson, 2008), it would be recommendable to extend this exploratory study to multiple ID services. Thirdly, the level of ability of the service users was based on the clinical judgment of the psychologist rather than on actual IQ-scores or scores on the level of adaptive functioning derived from psychometrically sound tests. Fourthly, all relatives in the current study were male. Although this may suggest that eHealth seems to be of more interests to fathers and other male relatives, this suggestion cannot be supported by eHealth literature (e.g., Cho, Park, & Lee, 2014; Wang, Wu, & Wang, 2009). Hence, the preponderance of men in this study is likely to be due to the convenience sample. In addition, in line with research in the general population (e.g., Hardiker & Grant, 2011), age might be an important variable in understanding or familiarity with various eHealth applications as well. To

overcome these issues in future research, research on a larger scale is needed with specific attention to the distribution of age and gender. Fifthly, although participants in several cases explicitly stated to what specific eHealth application they were referring to when mentioning an advantage or disadvantage about eHealth, this was not always the case. Therefore, some statements are linked to a specific eHealth application and some statements are rather general. Nevertheless, in all cases participants referred to eHealth applications in support for daily functioning and therefore, providing significant insights for the current study. It would be interesting for future research to explore the views of people with ID, their relatives, and their professionals regarding specific eHealth applications in order to determine areas of agreement as well as areas of disagreement.

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

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### **Conflict of interest**

None

### **Author Note**

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**CHAPTER 5**



# Experiences of therapists conducting psychological assessments and video conferencing therapy sessions with people with mild intellectual disabilities during the COVID-19 pandemic

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## Abstract

### Background

Due to the restrictive measures introduced to tackle the COVID-19 pandemic, therapists working with people with mild intellectual disabilities have had to use video conferencing to continue to conduct their psychological assessments and therapy sessions. This qualitative study explored therapists' experiences of using video conferencing during the initial lockdown period in the Netherlands.

### Method

In total, seven therapists working at a service organisation supporting people with intellectual disabilities participated in this qualitative study ( $M = 34.4$  years;  $SD = 6.0$ , range: 26-42). The therapists documented their experiences via audio recordings, which were subsequently analysed using thematic analysis.

### Results

Five themes emerged: (1) An immediate transition to virtual working; (2) Developing virtual ways to support service users in both coping with COVID-19 related stress and with continuing therapy; (3) Lacking the appropriate equipment; (4) Limitations in virtually attuning to people with mild intellectual disabilities; and (5) Unforeseen opportunities for distance-based psychological assessments and therapy.

### Conclusion

This study provides valuable insights into the experiences of therapists using video conferencing to support people with mild intellectual disabilities during the COVID-19 pandemic. These insights can help inform clinical practice with respect to the use of video conferencing for psychological assessment and therapy with people with mild intellectual disabilities.

## 1. Introduction

Healthcare professionals across the globe are increasingly using eHealth within the field of intellectual disabilities (Oudshoorn et al., 2020), a trend which has been accelerated even further by the ongoing COVID-19 pandemic (Courtenay & Perera, 2020). On March 11 2020, the World Health Organisation declared the COVID-19 outbreak, a coronavirus causing infections of respiratory with serious risks for people with a vulnerable health status and older people, a pandemic (Moreno et al., 2020; Rose et al., 2020; World Health Organisation, 2020a). Governments worldwide took manifold preventive measures in an attempt to reduce the risk of infection based on the announcements of the WHO, such as to keep social distance, the closure of public places (e.g., schools, restaurants, churches/mosques, museums, and theatres), and the instruction to leave the house only for essential necessities (e.g., food and medication) (World Health Organisation, 2020b). In response to the pandemic, a series of restrictions were also introduced by the Dutch government, including maintaining physical and social distance, staying and working at home as much as possible as well as the closure of public facilities such as schools. These measurements had a profound impact on the daily lives of many citizens, particularly older people, people with intellectual disabilities and people with mental health problems (Dutch Government, 2020; Embregts et al., 2020). Some of the common negative consequences of social isolation reported by people with mild intellectual disabilities include, amongst other things, loneliness, difficulty in maintaining structure in daily life and increased stress as a result of the closure of day and work services, the loss of formal and informal support and misunderstanding of information about the COVID-19 virus (Embregts et al., 2020).

Service organisations for people with intellectual disabilities have introduced strict measures regarding engaging in face-to-face contact with relatives and healthcare professionals other than the direct support staff working in residential group settings. Professionals working in the community had to either postpone or move their face-to-face contact with service users with intellectual disabilities online within a very short space of time. In order to continue to conduct psychological assessments and therapy sessions, health care professionals, and therapists in particular, have begun to use video conferencing (Békés & Aafjes-van Doorn, 2020; Embregts et al., 2021a). Studies evaluating the effectiveness of video conferencing for conducting psychological assessments and therapy amongst the general population have reported promising results, concluding that video conferencing is feasible for both neuropsychological assessment (Marra et al., 2020) and diagnosing an autism spectrum disorder (Alfuraydan et al., 2020). Furthermore, video conferencing has been found to produce similar outcomes as in-person interventions for anxiety, depression and post-traumatic stress disorder, achieving sufficient to good user-satisfaction (Backhaus et al., 2012; Blake Berryhill

et al., 2019a; Blake Berryhill et al., 2019b; Turgoose et al., 2017). Conversely, technical problems, lack of on-site support as well as the severity and complexity of a person's problems prior to therapy have been found to negatively impact the effectiveness of video conferencing (e.g. Poletti et al., 2020). However, there is a relative dearth of research assessing the feasibility and effectiveness of video conferencing amongst people with mild intellectual disabilities (Oudshoorn et al., 2021). Recently, in a small-scale mixed-methods study, Rawlings et al. (2020) explored the accessibility and acceptability of using video conferencing for psychological interventions for anxiety, low mood and anger amongst people with intellectual disabilities, and found that only a minority of service users accepted therapy being conducted in this way. Given that professionals play a key role in the acceptance and implementation of interventions delivered by a broad range of eHealth applications, such as video conferencing (Henneman et al., 2017), it is important to also explore their perspectives. To the best of our knowledge, the perspective of professionals providing psychological interventions to people with intellectual disabilities via video conferencing has hitherto not been explored. Although people with intellectual disabilities are a very heterogeneous group with a wide variety of support needs, this study reported on the experiences of therapists working with people with mild intellectual disabilities (IQ 50-70 and significant deficits in adaptive functioning) and high support needs due to mental health problems (Schalock et al., 2021).

Recently, Embregts et al. (2021b) explored the general experiences of five psychologists working online with people with intellectual disabilities during the initial lockdown in the Netherlands. These psychologists reported difficulties with picking up non-verbal cues and discussing sensitive topics, alongside technical difficulties associated with the lack of secure internet connections and devices at group homes, which undermined the ability of service users and staff to use video conferencing. Although Embregts et al.'s (2021b) study provides interesting insights into video conferencing from the perspective of psychologists, who experienced challenges in terms of both discussing sensitive topics with service users and keeping in contact with support staff in group homes, it would be noteworthy to specifically explore the experiences of therapists using video conferencing to conduct psychological assessments and therapy amongst people with mild intellectual disabilities. This is because therapists play a key role in terms of both the acceptance and implementation of a broad range of eHealth applications, including video conferencing (Henneman et al., 2017). Moreover, their attitude towards using video conferencing is a strong predictor of its actual use (e.g. Békés & Aafjes-van Doorn 2020; Feijt et al., 2018). Therefore, the rationale for the present study is that exploring their perspectives will enhance knowledge concerning the role of therapists working with people with mild intellectual disabilities. Hence, the present exploratory qualitative study is underpinned by the following research question: what



are the experiences of therapists conducting psychological assessments and video conferencing therapy sessions with people with mild intellectual disabilities during the initial COVID-19 lockdown?

## 2. Methods

### 2.1. Study design

A phenomenological qualitative study design was adopted in order to capture the experiences of therapists conducting psychological assessments and video conferencing therapy sessions with people with mild intellectual disabilities during the initial COVID-19 lockdown in the Netherlands. Phenomenological studies are qualitative studies focusing on the lived experiences of a specific group sharing common features with a phenomenon or context (Creswell, 2014; Neubauer et al., 2019; Yarimkaya & Töman 2021). To capture the experiences of a group of therapists, they were invited to self-record their experiences on their smartphone. This form of data collection has been used effectively more often during the COVID-19 pandemic (e.g., Embregts et al., 2021a, 2021b; Nind et al., 2020). Some brief topics (e.g., positive and negative experiences, factors that either facilitated or served as barriers to using video conferencing, and what went well and what problems they encountered when using video conferencing), based on their clinical expertise, served as a guideline for the therapists to reflect upon. This method of data collection was deemed to be convenient for this group of participants who were already exceptionally busy during the COVID-19 pandemic, as they were able to determine for themselves when to record their audio messages. Although posing follow-up questions was not possible due to the use of audio recordings, the participating therapists were clearly instructed in advance to describe as many details and feelings as possible in their audio messages.

### 2.2. Participants

This study was conducted in a large service organisation in the Netherlands that provides support and treatment from more than 5,000 professionals to nearly 6,000 people with intellectual disabilities. In total, seven therapists (all female) participated in the study. The mean age of the therapists (five psychologists, one art-based therapist, and one psychomotor therapist) was 34.4 years ( $SD = 6.0$ , range: 26-42). On average, they had worked with people with intellectual disabilities for 10.7 years ( $SD = 6.4$  years; range: 1-17), and had 3.7 years ( $SD = 2.2$ ; range: 1-8) of experience in their current position. Both additional demographic features of the participants and a brief description of the specific support needs of service users are presented in Table 1. They conducted individual psychological assessments ( $n = 7$ ) and provided psychological therapy ( $n = 6$ ) to both children and adults with mild intellectual disabilities, mental

health problems (e.g., anxiety, attachment, depression, trauma) and/or who exhibited challenging behaviour (e.g., aggressive or sexually deviant behaviour), who were either living independently in the community and receiving outpatient support or living in residential care facilities. The therapists delivered individual psychological therapy, systemic therapy, experience-based therapy, and applied Eye Movement Desensitisation Reprocessing (EMDR) therapy, in conjunction with different elements from Cognitive Behavioural Therapy (CBT), Competitive Memory Training (COMET), and Solution-Focused therapy (SFT). The experience-based therapists (i.e., art and psychomotor) provided psychological therapies in tandem with a psychologist. The psychological assessments focused on diagnosing an intellectual disability, attachment disorder and autism spectrum disorder. The service organisation provided the therapists with an account for the simple and safe video conferencing apps Vicasa™ and Microsoft Teams™. None of the therapists were trained beforehand in how to use video conferencing to conduct psychological assessments and therapy.

### **2.3. Procedures**

The participants were recruited via convenience sampling. We used this particular sampling method because these participants were both easy to contact and willing to participate during the lockdown period. A team manager in the service organisation was contacted by the first author. Eligible therapists had to be working with people with mild intellectual disabilities with extensive support needs as well as conducting individual psychological assessments and/or providing psychological therapy. With their consent, the team manager provided the names of seven therapists to the first author, who subsequently contacted these potential participants by phone. After outlining the purpose and nature of the study, all seven therapists voluntarily agreed to participate in the study and provided written informed consent. The Ethics Review Board of Tilburg University approved this study (RP179).

### **2.4. Materials**

The therapists were asked to reflect upon their experiences of conducting assessments and providing therapy through video conferencing during the first two months of the initial lockdown period in the Netherlands, which lasted from 16th March to 15th May, 2020. Similar to Embregts et al.'s (2021a; 2021b) study, the participants self-recorded their experiences on their smartphone and sent the audio recording (mean duration for each participant: 12.8 minutes;  $SD = 5.3$ ; range: 6.12-16.32) to the first author. When recording the audio message, the participants were offered the following topics to reflect on: 1) positive and negative experiences of using video conferencing, 2) factors that either facilitated or served as barriers to using video conferencing, and 3) what

went well and what problems they encountered when using video conferencing. Two therapists preferred to share their experiences in written form, simply because they felt more comfortable expressing themselves in this way than talking to a device.

## **2.5. Data analysis**

Themes were identified by deploying an inductive thematic analysis method (Braun & Clarke, 2006). Given of the novelty of the topic being studied, the analytic process was undertaken without prior theories or assumptions. The analytic process followed the six-phases delineated by Braun and Clarke (2006). First, the first author transcribed verbatim the verbal data from the recorded audio files into written data. The verbatim texts were read carefully at length together with the second author for the purpose of familiarisation with the content of the data. Second, the first author inductively generated codes based on phrases of clear relevance to the present study. The second author checked all codes, which were subsequently discussed with the first author until a consensus was established. Third, all codes were clustered into potential themes.

To both ensure consistency within each theme and maintain the differences between themes, the potential themes were then discussed by all the authors in the fourth phase. As the original verbatim texts were in Dutch, the coding and clustering was also conducted in Dutch, while the findings were subsequently translated into English by a professional native speaker. Finally, the themes were defined and named by the first two authors in the fifth phase, before a narrative structure with accompanying descriptions was then established by all authors in the final stage. Two checks of trustworthiness and credibility were carried out in order to ensure the quality of the study. First, the second coder checked the coding to ascertain the consistency and clarity of the codes identified by the first coder. Second, extensive discussions of the codes and purposed themes took place between the coders and all of the authors to ensure both the coherence of the codes within each theme and that there was a clear distinction between themes.

**Table 1.** Demographical characteristics of the participants (all female)

Pseudonym	Age	Position	Working experience with people with intellectual disabilities	Working in current position	Content of work	Support needs of service users*	eHealth use before March 2020
Eleonor	42	psychologist, systemic therapist	17 years	8 years	psychological and systemic assessment, individual and family therapy	<b>Assessment:</b> emotional functioning, intellectual and adaptive functioning, needs assessment <b>Therapy:</b> family dysfunctioning and crisis, complex trauma	Incidental
Irene	26	art-based therapist	3 years	2 years	individual and group (forensic) therapy and observation in individual assessment	<b>Assessment:</b> observation differential diagnosis ASD, attachment and trauma <b>Therapy:</b> trauma, self-esteem problems, emotion regulation problems, unsafety and risk of domestic violence	Incidental
Lisa	27	psycho-motor therapist	1 year	1 year	individual and group therapy and observation in individual assessment	<b>Therapy:</b> anxiety and stress management problems, emotion recognition and management problems, self-esteem problems, anxiety disorder	Regular base (chat, online assignment)
Nathalie	38	psychologist	11 years	4 years	psychological and systemic assessment, individual and family therapy	<b>Assessment:</b> ASD, emotional functioning, sexual development, sexual trauma, complex trauma <b>Therapy:</b> anxiety and panic, problematic partner-relationship and domestic violence, obsessive compulsive disorder, psychosis, resilience empowerment	Regular base (chat, online assignment, video modeling), incidental/Virtual Reality
Tessa	34	psychologist	16 years	4 years	individual assessment	<b>Assessment:</b> sexuality and defiant sexual behaviour, personal and developmental history interviews, attachment, ADHD, ASD	Incidental

Table 1. Continued

Pseudonym	Age	Position	Working experience with people with intellectual disabilities	Working in current position	Content of work	Support needs of service users*	eHealth use before March 2020
Susan	37	psychologist	16 years	4 years	psychological and systemic assessment; individual therapy	<b>Assessment:</b> personal and developmental history interviews, social-emotional functioning. <b>Therapy:</b> complex trauma, mood disorder, obsessive-compulsive disorder	Incidental
Wilma	37	psychologist	11 years	3 years	psychological and systemic assessment and individual and family therapy	<b>Assessment:</b> intellectual and adaptive functioning, attachment, trauma, ASD, ADHD. <b>Therapy:</b> depression, suicidal thoughts, families with children with challenging behaviour and high risk of maltreatment	Incidental

Note. ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; PWID = people with intellectual disabilities. \* Features of assessment/therapies in period March-May 2020.

### 3. Results

Based on a total of 317 codes, the thematic analysis identified five main themes: (1) An immediate transition to virtual working (65 codes; 7 therapists); (2) Developing virtual ways to support service users in both coping with COVID-19 related stress and with continuing therapy (41 codes; 5 therapists); (3) Lacking the appropriate equipment (61 codes; 7 therapists); (4) Limitations in virtually attuning to people with mild intellectual disabilities (71 codes; 6 therapists); and (5) Unforeseen opportunities for distance-based psychological assessments and therapy (73 codes; 7 therapists). Six codes were assigned to a miscellaneous category as these codes were very general and broad (e.g., lack of safety at home). Table 2 presents an overview of the identified themes and corresponding description.

**Table 2.** *Overview of the identified themes and descriptions*

Themes	Description
An immediate transition to virtual working	Flexibility and new skills needed due to an adapted workflow of using video conferencing within a very short space of time
Developing virtual ways to support service users in both coping with COVID-19 related stress and with continuing therapy	Adapting to supporting service users who were overwhelmed by feelings of stress because of the impact of COVID-19 on their daily lives at a distance by video conferencing as well as continuing to provide current therapies despite the restrictive measures in place
Lacking the appropriate equipment	The importance of the availability of proper equipment for all users involved in video conferencing sessions
Limitations in virtually attuning to people with intellectual disabilities	The impression of how video conferencing affected both people with mild intellectual disabilities and the therapist as well as missing the support of members of the formal and informal network of a service user who were usually involved in person
Unforeseen opportunities for distance-based psychological assessments and therapy	The surprise advantages of video conferencing experienced by therapists that allowed them to continue their work (assessment and therapy) with service users and gain a better picture of their personal circumstances

#### 3.1. An immediate transition to virtual working

Due to the restrictive measures introduced in the initial lockdown period, therapists were not allowed to conduct psychological assessments and therapy in-person. The therapists experienced this situation as unreal and strange, insofar as they had to immediately transition to remote contact by telephone and video conferencing in order to continue with their work.

*...that very first day was kind of surreal due to the fact that I was not actually allowed to see service users. ...so I began to quickly arrange all requests for Vicasa™ [name of video conferencing application] in the first week... [Nathalie]*

At the beginning of the lockdown, therapists experienced their own digital skills as insufficient, and thus had to spend time and effort learning the necessary skills. Moreover, they were confronted with various new tasks, such as arranging a working account for service users, and instructing both them and their relatives how to install and activate the secure video conferencing app and to create a password. For example, they had to search for personal data in the electronic health records system, where they occasionally found that the up-to-date data on service users that was needed to create a working account was missing. The sudden change and rapid adaptation necessitated by the pandemic proved to be demanding for all of the therapists and tested their flexibility.

### **3.2. Developing virtual ways to support service users in both coping with COVID-19 related stress and continuing with therapy**

During the initial weeks of the lockdown, therapists primarily helped service users to cope with stress that stemmed from both difficulties in understanding the measures and a fear that they or their loved ones would contract the COVID-19 virus. Therapists had to pay attention to the profound impact of the measures on service users and focus on how to cope with the stressful situation, by, for example, guiding them through relaxation exercises and pointing towards finding helpful ways of thinking and performing activities at home. In so doing, the therapists were exploring methods to convert their normal work into the virtual realm. For example, some therapists noticed that it was helpful to send materials (e.g., workbooks, questionnaires, paints, or clay) to service users prior to a session. In addition, therapists were hesitant to use video conferencing for therapy with complex families, due to difficulties in observing the interpersonal interactions between family members on the same screen, which left therapists feeling unable to intervene adequately. In the case of emotionally unstable people, therapists experienced difficulties in helping these people to deal with and channel their overwhelming feelings at a distance.

*[I] have to explain and clarify things more and question what is actually happening to someone else. ... a man began to cry very loudly and actually disappeared out of sight [moved away from the screen]. Urgh, that felt very unpleasant because [I] couldn't do anything at that moment, I didn't know where the other person was and [I was] really at a distance. [Eleonor]*

Not being in the same room as the service user, forced the therapists to consider the feasibility of video conferencing for a particular session with a sensitive topic to discuss or making appointments with service users beforehand on how to cope with stress or a crisis situation during a video conferencing session. So therapists had to prepare a video conferencing session more intentionally compared to a face-to-face session.

### **3.3. Lacking the appropriate equipment**

Therapists were also confronted with technical challenges that hampered their ability to do their work. Specifically, unstable internet connections, overly small screens that resulted in uncomfortable sitting positions, and a dependency on third parties to restart interrupted sessions were routinely cited as barriers.

*...a verbal consultation in which the connection is broken off... those kinds of things are not very pleasant at all, and then [!] you miss [!] simply miss the ability to restart the session quickly...when someone gets emotional and the connection is broken, yes, it is more difficult to engage in a good conversation. [Tessa]*

In the case of video conferencing via a smartphone, a broken connection was often the consequence of an incoming call. In addition, therapists reported that inappropriate equipment (e.g., as a result of organisational policy only smartphones or private equipment could be used) made it difficult for them to provide adequate psychological therapy, because nonverbal cues were barely visible on small screens, which, in turn, had a negative effect on the session. Further, both therapists and service users lacked the appropriate tools to engage in therapy via video conferencing, which caused difficulties in terms of contact and communication. These experiences underscore the importance of the availability of proper devices for both therapists and service users.

### **3.4. Limitations in virtually attuning to people with mild intellectual disabilities**

The therapists reported on the difficulties that service users experienced with planning and attending their sessions. Service users were often too late or took part in the session while they were driving or at the shops. Hence, therapists had to support service users by speaking to them specifically about their attendance. Explaining the objectives and expectations was found to lead to improvements in the video conferencing therapy sessions. In comparison to face-to-face therapy, therapists reported that several service users were less serious during therapy via video conferencing. For example, therapists routinely observed service users checking their smartphones instead of actively participating in the session. Moreover, service users were more likely to request to reschedule the therapy session at the last moment, often when the session was about to start. In addition, therapists cited difficulties in remotely contacting service users with



complex needs, such as service users who were in a crisis situation, who either avoided questions or simply did not answer when a therapist attempted to call them.

Therapists reported that conducting assessments or therapy without the presence of important stakeholders (e.g., partners, parents, support staff) led them to take on a different inflection. Participants experienced notable differences when comparing working with and without the support of staff or parents during assessments and therapy sessions. Specifically, they reported that meetings without the help of stakeholders were more difficult. They felt inconvenienced and missed the regular support of stakeholders, who provide either technical or practical on-site support (e.g., practicing exercises at home or organising a private space), and instead had to support service users at a distance.

*... they could not find the e-mail [to activate the video conferencing app] and actually had little help from [persons in] the environment to support them. This was because both outpatient and family support were less present because of Corona, so it was hard to rely on them for support with service users. [Lisa]*

Finally, the therapists indicated that solely working online meant that they were unable to illustrate relevant themes for service users, either by drawing or showing pictures or using tangible materials (e.g., little dolls). This is problematic, because they reported that video conferencing is heavily reliant on verbal communication skills, which they judged to be difficult for people with mild intellectual disabilities.

*.. a lot of people had difficulties with engaging in long conversations, as well as difficulties with expressing what they felt and experienced. [Lisa]*

These experiences clearly testify to the fact that therapists were largely unaware of the possibilities presented by video conferencing tools, and, as such, were actively searching for the best ways to optimise their sessions and attune them to the specific needs of service users, such as, for example, by providing support in the case of stress or through visualising.

### **3.5. Unforeseen opportunities for distance-based psychological assessments and therapy**

Despite the fact that some therapists felt insecure about delivering certain types of therapy (e.g., Psycho Motor Therapy, EMDR for complex trauma) and reported that it was too complex to establish a therapeutic alliance with service users with more complex problems, they also recounted positive experiences of using video conferencing and noted that it produced comparable results to face-to-face sessions for the majority

of service users, particularly with regard to reduced tension and enhanced ability to cope with stress, improved self-awareness, higher self-esteem and less problems with marital partners. Over time, therapists felt more adept at using video conferencing and reported greater satisfaction with their efforts.

*My experience of online treatment is that I came to the conclusion that there were far more possibilities than I had originally expected. I do not think that I will go back to exclusively working face-to-face [with service users]. [Susan]*

In the case of psychological assessments, for example, relatives were found to be useful in terms of both making it easier to arrange interviews in the first place and for helping service users when they joined interviews virtually. Prior to the COVID-19 pandemic, relatives had less opportunity to support their family members in person because of other responsibilities and duties. In particular, the fact that relatives were home due to the restrictive measures created positive opportunities for therapists to invite relatives to engage in the online therapy sessions. The use of video conferencing thus enabled virtual insight into the personal lives of service users. Another unforeseen advantage of online sessions was that some service users were more relaxed at home, which, in turn, resulted in an increased frankness in their discussions. At the same time, therapists cited that they needed to pay greater attention to observations about unsafe environments now that they were virtually present in the living situation of service users. Another unforeseen positive finding was the opportunity to immediately be able to implement the content of the therapy session into service users' personal context, due to the fact that exercises could be completed in the targeted context (e.g., controlling compulsive behaviour). Finally, reduced travel time and greater opportunity to engage in quick online consultations with other professionals were also cited as saving time. Hence, one can conclude that the therapists were surprised by the opportunities, and sometimes advantages, associated with conducting assessments and providing therapy via video conferencing, which, in turn, resulted in them gaining a more nuanced picture of how video conferencing could be used in their work.

## 4. Discussion

The restrictive measures introduced during the initial lockdown period in the Netherlands led to a pronounced transition in terms of how therapists conduct diagnostic assessments and provide psychological therapy to people with mild intellectual disabilities. Conducting a thematic analysis of their experiences led to the identification of five themes: (1) An immediate transition to virtual working; (2) Developing virtual ways to support service users in both coping with COVID-19 related stress and with

continuing therapy; (3) Lacking the appropriate equipment; (4) Limitations in virtually attuning to people with mild intellectual disabilities; and (5) Unforeseen opportunities for distance-based psychological assessments and therapy.

The lockdown period forced therapists to immediately have to engage in a series of new tasks, such as instructing service users at a distance how to use video conferencing and developing virtual ways to continue to carry out their work. Therapists were able to provide mental health support to service users who were trying to cope with the restrictive measures. The period of lockdown from March to May 2020 was a stressful time for both service users and therapists (Embregts et al., 2020; 2021b). Anxiety levels increased due to the fear of infection, the loss of loved ones and the prevailing feeling of uncertainty. Changes in daily life routines and the loss of informal and formal support caused increased levels of stress for service users, but also for families of people with intellectual disabilities (Embregts et al., 2021a; Zaagsma et al., 2020). The COVID-19 pandemic signalled a profound turning point for the virtual delivery of mental health services with therapists rushing to implement remote care. Over time, the therapists adapted to video conferencing and came to experience it as both positive and as adding value to their work. Specifically, therapists cited time efficiency, easier access to service users and important stakeholders, and working directly in service users' living environment as key benefits of working online. Barriers such as technological problems, lack of proper equipment, insecurity and worries over their digital competence as well as the lack of on-site support for service users were also cited. Therapists missed the option of visualising things for their clients, such as by drawing a picture as part of psycho-education, and worried about the level of verbal communication required in video conferencing. This derived from a lack of awareness about the various possibilities offered by video conferencing programs. These results underline the importance of training professionals to both feel more skilled in using all of the options provided by a tool such as Microsoft Teams™ and to become more self-confident in using video conferencing for diagnostic and therapeutic objectives. Therapists noted service users' difficulties in both organising their attendance and maintaining their focus during video conferencing sessions. Moreover, the present study clarified the important role played by relatives and support staff as practical and emotional resources, both during and in between the online sessions. This finding is in line with previous recommendations positing that face-to-face therapy for people with intellectual disabilities should seek to involve relatives or support staff (e.g., Jahoda et al., 2017; Scott et al., 2019).

To the best of our knowledge, this study is the first to have explored the experiences of therapists using video conferencing for conducting psychological assessments and therapy amongst service users with mild intellectual disabilities. Although the evidence on the use of video conferencing to conduct psychological assessments and therapy

amongst the general population is promising (Alfuraydan et al., 2020; Marra et al., 2020), studies involving people with mild intellectual disabilities are scarce. Temple *et al.* (2010) concluded that administering both the Wechsler Adults Intelligence Scale and the Beery-Buktenica Test of Visual-Motor Integration for adults with mild intellectual disabilities is possible via video conferencing, provided there is on-site support from staff, while Zaagsma *et al.* (2019) reported promising results for the use of video conferencing in remote support. Despite these aforesaid studies, video conferencing remains an underdeveloped opportunity vis-à-vis providing mental health support to people with intellectual disabilities (e.g., Rose et al., 2020; Sheenan et al., 2020).

There are several limitations of this study that need to be discussed. First, only seven participants from one service organisation shared their personal experiences of using video conferencing to continue their work, which prevents us from generalising these findings to all people with mild intellectual disabilities. Second, as a consequence of convenience sampling, only female participants were included in the study. Consequently, further research is required with a larger group of therapists, including male therapists. Moreover, given the small number of participants, it is possible that other themes or subthemes might have emerged if there had been additional participants. Based on the data of the participating therapists, we are unable to draw conclusions about the differences between adults and children or the specific issues these two groups face. This could be a relevant topic for future research. The method used for data collection also had some limitations in terms of gaining more in-depth experiences from therapists, but was convenient during such a demanding lockdown period.

Despite these aforementioned limitations, a notable strength of this study is that it provides important insights into how therapists experience the use of video conferencing to conduct assessments and therapy amongst people with mild intellectual disabilities. Gaining insights from a larger group of therapists inspired by the results of the present exploratory study is thus important, especially given that remote care and support is expected to remain in the near future (Wind et al., 2020). In this study, we specifically focused on the experiences of therapists. However, the experiences of service users are also important to explore. Understanding their views on being interviewed in the context of receiving either a psychological assessment or therapy via video conferencing is of paramount importance for gaining a more nuanced picture of the opportunities presented by eHealth.

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**CHAPTER 6**



# Measuring working alliance and technical alliance from the perspective of healthcare professionals working with people with mild intellectual disabilities: Adaptation, factor structure and reliability

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## Abstract

### Background

The establishment of a valuable and meaningful working alliance between people with mild intellectual disabilities (IDs) and healthcare professionals is critically important for improving both the quality of life and impact of therapy for people with mild IDs. Measuring the working alliance as a treatment or support component is therefore of utmost relevance. In light of the increased use of eHealth tools, it is also essential to measure the alliance using these tools, which is referred to as technical alliance. There was a lack of validation of these two measurements for healthcare professionals working with people with mild IDs, which this study sought to address.

### Method

Both the validated Working Alliance Inventory – Short Form – (WAI-SF-MID) and Technical Alliance Inventory – Short Form – (TAI-SF-MID) for general patient populations were adapted for healthcare professionals working with people with mild IDs. A two-step approach was conducted to systematically adapt both measurements with an expert group of healthcare professionals. Confirmatory factor analysis was conducted to test a three-factor structure for both the WAI-SF-MID ( $N = 199$ ) and the TAI-SF-MID ( $N = 139$ ), and internal consistency was determined for both scales.

### Results

An acceptable-to-good model fit was found for both the WAI-SF-MID and the TAI-SF-MID; confirmatory factor analysis confirmed a three-factor model for both measurements. Cronbach's alpha and McDonald's omega were excellent for both total scales ( $\geq 0.90$ ) and acceptable to good for sub-scales of both versions.

### Conclusion

Both the WAI-SF-MID and TAI-SF-MID are promising measurements for determining healthcare professionals' perspective on the (digital) working alliance with people with mild ID.

## 1. Introduction

The importance of positive interpersonal relationships between people with mild intellectual disabilities – who are characterised by significant limitations in intellectual functioning (IQ score between 50-70) as well as in adaptive functioning with evident effects on practical, social and conceptual functioning in daily life (Schalock et al., 2010) – and healthcare professionals providing them with support and therapy has been widely acknowledged (e.g., Van Asselt-Goverts et al., 2013; Robinson et al., 2020). This results in the need for practical, informational and emotional support (Vaucher et al., 2021). Healthcare professionals refer to people who provide care services in a professional context (Granja et al., 2018). Alongside the informal support of relatives and family members, healthcare professionals such as support staff and therapists have a key role to play in the lives of people with mild IDs (Giesbers et al., 2019). Further, professional help is often needed for people with mild intellectual disabilities who are known to be vulnerable to develop mental health problems associated with general health problems (Hughes-McCormack et al., 2017). People with mild intellectual disabilities receive support and treatment from various types of services, such as intellectual disability services, community social care, mainstream mental health services, non-acute and acute psychiatric services, emergency departments. (Standen et al., 2016; Whittle et al., 2018). Forming a valuable and meaningful relationship with a professional contributes greatly to both the quality of life and support for people with mild intellectual disabilities and therapeutic outcomes (Embregts et al., 2020; Evans & Randle-Phillips 2021; Smith et al., 2020). In general client populations, this sense of alignment between healthcare professionals and clients is commonly referred to as the working alliance. Besides the emotional bond as experienced by a healthcare professional and a client, a working alliance also refers to the collaboration in performing activities to achieve goals that they set together (Hatcher & Barends, 2006). Gelso (2014) distinguishes three elements of a relationship in his tripartite model: (1) the real relationship (genuine personal relationship between client and professional as valued by both); (2) the transference (the projection of feelings, wishes and expectations to a professional or a client based on former relationships) (Hafkenschied, 2021); and (3) the working alliance. The latter is about the active part of working together within the collaborative relationship between client and professional.

In research and health practice, the construct ‘alliance’, has been used with various exchangeable adjectives such as ‘working’, ‘helping’ and ‘therapeutic’, depending on the setting where the health care is delivered (Flückiger et al., 2018). Alliance can be defined as ‘a proactive collaboration of clients and therapists across sessions and in moment-to-moment interactions’ (Flückiger et al., 2018, p. 330). The concept is often studied in-depth and is traditionally used within the context of psychotherapy (Barber

et al., 2013). Alliance is considered as a common factor contributing to the effectiveness of psychotherapy regardless of theoretical background such as psychoanalytical or cognitive behavioural therapy (Wampold, 2015). Nowadays, the construct of working alliance is used in a broader context and is the focus of this study. Horvath (2018) concluded that working alliance is related to all kinds of relationships between a client and a professional and could be studied as part of the effectiveness of an intervention. A positive working alliance is associated with positive treatment outcomes, client satisfaction with professional contact and lower early withdrawal or drop-out (Barber et al., 2013; Flückiger et al., 2018; O’Keeffe et al., 2020). The working alliance in support and therapy for people with mild intellectual disabilities, also when eHealth tools are included, seems to be an unexplored area yet and, hence, is the central focus of this study.

Studies exploring the experiences of clients with mild intellectual disabilities in collaborating with their direct support staff or therapists have produced consistent results (e.g., Pert et al., 2013; Evans & Randle-Phillips, 2020; Fish & Morgan, 2021). Specifically, these studies indicate that being listened to, the need for trust and confidence, feeling respect for one’s personal choices, and experiencing personal attention and time are vital factors for a good collaboration. In contemporary professional support, person-centered care based on the personal needs, preferences and self-determination are the central elements in the collaboration between clients with mild intellectual disabilities and healthcare professionals (Bigby et al., 2017). Although some studies amongst healthcare professionals working with people with mild intellectual disabilities have highlighted the importance of the working alliance, little is known about how these professionals view the emotional bond and collaborative relationship with clients and which factors are relevant to them in this collaboration (e.g., Jones, 2013; Fish & Morgan, 2021).

Besides face-to-face contact, eHealth is increasingly being used in the context of supportive or therapeutic relationships (Riper et al., 2010; Oudshoorn et al., 2021). Examples are the aid of avatars in digital stories within a computerised cognitive behavioural therapy session (Cooney et al., 2018), receiving practical and emotional professional support by telecare (Zaagsma et al., 2021), and working with a tablet that visualises a task to support task completion independently (Shepley et al., 2018). This trend was accelerated by the COVID-19 pandemic (Chadwick et al., 2022; Embregts et al., 2022). In line with the limited knowledge on working alliance in face-to-face contact, even less is known about these factors when the supportive or therapeutic contact is facilitated by an eHealth tool. eHealth complemented supportive relationships to reinforce newly acquired daily living skills, provide practical information to people with mild intellectual disabilities and facilitate remote professional support (Oudshoorn et

al., 2020). In order to better understand how healthcare professionals working with people with mild intellectual disabilities perceive the working alliance, including when using eHealth tools, a psychometrically sound measurement is required to investigate the working alliance within this target group.

To assess the quality of the working alliance within the general client population, Horvath & Greenberg (1989) developed the widely used and extensively validated Working Alliance Inventory (WAI), which distinguishes between three factors: bond, tasks and goals. This instrument was based on Bordin's theory, which considered working alliance with three interconnected components: (1) bond, the personal bond between a health care professional and the client; (2) the mutual agreement on goals; and (3) the tasks contributing to reaching the agreed goals (Bordin, 1979). The WAI measurement is used for various purposes: to assess satisfaction, adherence, quality of collaboration from the perspective of clients and therapists and client centredness (Sturgiss et al., 2019). Alongside the original scale that consists of 36 items, Hatcher & Gillaspay (2006) also developed a short form comprising 12 items (WAI-SF). The WAI-SF has been applied in various contexts (e.g., for general practice, general mental healthcare, addiction treatment centres and youth care) to assess the emotional relationship and mutual collaboration (e.g., Lakke & Meerman 2016; Sturgiss et al., 2019). Besides a self-reported version for clients, a version for professionals is available. In general, higher scores on working alliance measures reflect a better working alliance between client and professional as perceived by the person who fills in the measurement. The WAI-SF has good psychometric properties with reliability scores reflecting a satisfying internal consistency (Cronbach's alpha's range between 0.81 and 0.91) (Flückiger et al., 2018; Paap et al., 2018). In addition, the goodness of fit for a three-factor model has been demonstrated by various studies (e.g., Hatcher & Gillaspay 2006; Munder et al., 2010; Lamers et al., 2015). Within the field of mental healthcare for people with IDs, Meppelder-de Jong et al. (2014) focused on the working alliance between parents with mild intellectual disabilities and their experiences with family support staff (WAI-SF  $\alpha = 0.86$ ). However, to the best of our knowledge, no specific, psychometrically sound instrument has hitherto been used to examine healthcare professionals' perceptions of how the clients they are working with experience the working alliance, both within face-to-face contact and via the use of an eHealth tool.

The choice to focus on the perspective of professionals was driven by the fact that working alliance instruments are rarely included in intellectual disability research or clinical practice. Although the importance of the quality of the professional relationship is generally acknowledged, measuring alliance via well-studied/developed instruments adapted to the context of intellectual disability care organisations is understudied. Hartmann et al. (2015) concluded that the professionals' experiences on working alliance

are less investigated than clients' views, despite these experiences being highly relevant because of their significant contribution to the development of the alliance (e.g., Berger 2014; Nissen-Lie et al., 2015; Flückiger et al., 2018). The perspective of professionals is important, as their attitudes and choices impact the quality of care (Pelleboer-Gunnink et al., 2021). Hackett et al. (2020) used the therapist-version of the WAI-SF within a small exploratory study that sought to determine the feasibility of interpersonal art therapy for adults with mild intellectual disabilities and anger problems, without further exploring the psychometric properties of this measurement.

Consequently, in the present study, both the factor structure and the reliability of the two versions of the WAI for healthcare professionals were described and could be considered as a first step to pave the way for measuring working alliance in the context of care organisations for people with intellectual disabilities. First, the original WAI-SF (Hatcher & Gillespie 2006) was adapted for administration by healthcare professionals working with people with mild intellectual disabilities. Second, the recently developed Working Alliance Inventory for online interventions – short form, also briefly referred to as the Technical Alliance Inventory – Short Form (TAI-SF; Herrero et al., 2020; Kleiboer et al., 2016), which focuses on the working alliance within eHealth interventions, was also adapted for the previously referred healthcare professionals. Because of the lack of a uniform definition, we describe technical alliance as the perception of technology (e.g., app, computer program, video conferencing program and social robot) in terms of how it affects someone's experience with the applied technology's contribution to person-centered care, how it helps attain the client's personal goals and how the client develops confidence when using this applied technology in a professional relationship. Hence, the aim of this study was to investigate the factor structure and reliability of the adapted Working Alliance Inventory – Short Form – MID (WAI-SF-MID) and Technical Alliance Inventory – Short Form – MID (TAI-SF-MID) from the healthcare professional's perspective.

## **2. Participants and methods**

### **2.1. Design**

After being granted ethical approval by the Ethics Review Board of Tilburg University (EC-2016.71), this study used a convenient sample and a cross-sectional design to validate both the WAI-SF-MID and TAI-SF-MID by investigating the factor structure and reliability. For this study, eligible participants were recruited from five care organisations for people with IDs in the Netherlands. These organisations are affiliated with the Academic Collaborative Centre Living with an intellectual disability, Tranzo, Tilburg University. This study was part of a larger study aimed at exploring the attitude of

support staff and therapists towards eHealth usage in providing support and therapy for people with intellectual disabilities, including the impact on working alliance. To explore the opportunity of the WAI-SF and TAI-SF instruments for the context of care organisations for people with IDs, both instruments were adapted for administration by healthcare professionals.

## 2.2. Participants

The inclusion criteria for this study were working with people with mild intellectual disabilities as a support staff member, psychologist or experience-based therapist (e.g., a drama or psychomotor therapist). Direct support staff members are professionals 'who had regular contact with a person with mild intellectual disabilities and were responsible for supporting and/or facilitating their access to health care' (Whitehead et al., 2016, p. 391). These professionals provide support to clients in community-care settings several hours a week as well as 24/7 in residential care. The inclusion of these professional groups ensured that both support and therapy were covered in the study. The WAI-SF-MID professionals' version was presented to support staff members, psychologists and experience-based therapists who reported working with people with mild IDs. Conversely, the TAI-SF-MID was only presented to those working with people with mild IDs who indicated they were using at least one eHealth tool in either a support or therapeutic setting at the time of completing the online survey. The WAI-SF-MID professionals' version was filled out by 199 participants, while the TAI-SF-MID was completed by 139 participants. Table 1 contains more detailed information on the work domain, education level, years of working experience and demographic characteristics of the participants.

**Table 1.** Demographic characteristics of the participants in the present study, differentiated between both scales

Demographic attribute	WAI-SF-MID professionals N = 199		TAI-SF-MID professionals N = 139	
	n	%	n	%
Gender				
Male	37	18.6	15	10.8
Female	161	80.9	123	88.5
Other	1	0.5	1	0.7
Age*				
< 20 years	1	0.5	1	0.7
20-29 years	28	14.1	20	14.4
30-39 years	64	32.2	50	36.0
40-49 years	62	31.2	42	30.2
50-59 years	34	17.1	18	12.9
> 60 years	9	4.5	7	5.0
Education <sup>1</sup>				
Low	2	1.0	-	-
Mid	61	30.8	30	21.6
High	134	67.6	108	77.7
Other	1	0.5	1	0.7
Profession*				
Support staff	144	72.4	88	63.3
Psychologist	44	22.1	42	30.2
Experience-based therapist	10	5.0	8	5.8
Work domain*				
Community-care	60	30.3	51	36.7
Residential care <sup>2</sup>	94	47.2	53	38.1
Day care centre	9	4.5	3	2.2
Expert centre	34	17.0	31	22.3
Other	1	0.5	-	-
Working experience*				
<5 years	52	26.3	34	24.5
6 – 10 years	20	10.1	15	10.8
11 – 15 years	35	17.7	25	18.0
16 – 20 years	31	15.7	21	15.1
>20 years	60	30.3	44	31.7

Note. <sup>1</sup> High = higher and scientific education. <sup>2</sup> sum of two types of residential care. \* one case missing, so totalled amounts and percentages are < then total n and %

### 2.3. Procedures

Professionals who met the inclusion criteria received an invitation via e-mail to participate in the study, by, depending on the preference of the care organisation, either the first author or a contact person within the care organisation for people with IDs they were affiliated to. In the event that the researcher sent the e-mail within the



care organisation, the e-mail addresses were provided by a human resources employee with the approval of the board of directors of the care organisation. The e-mail was accompanied by an information sheet about the study. A reminder e-mail to participate was sent after a 3-week period. One care organisation invited participants indirectly via both a link to the survey and an information sheet on the organisation's website. The link led to the online survey in QUALTRICS<sup>XM</sup>, and the participants were asked to provide informed consent prior to the questions being presented. The link remained open from June 2021 until September 2021. Participants were asked to think of one specific client with intellectual disabilities they provided support or therapy while rating the 12 items of the WAI-SF-MID. Participants who specified working with at least one eHealth tool with people with mild IDs were asked to think of the eHealth application they primarily used while rating the TAI-SF-MID. These instructions were provided to ensure a consistent way of rating for all the participants.

## 2.4. Measurements

### 2.4.1. Working Alliance Inventory – Short Form

The original WAI-SF contains 12 items with a 5-point Likert scale, ranging from 1 (totally disagree) to 5 (totally agree) with higher mean scores reflecting a stronger working alliance. The WAI-SF contains three factors: (1) bond, which focuses on the emotional relationship between healthcare professional and clients; (2) goals, which focus on the mutual agreements between healthcare professionals and clients regarding the perspective and objectives; and (3) tasks, which focus on the mutual agreement over the activities healthcare professionals and clients users will engage in when working together to achieve the agreed goals. The WAI-SF is a self-reported measurement which is scored by healthcare professionals themselves. The model fit indexes for the WAI-SF 3-factor model are  $\chi^2 = 128.9$ , root mean square error of approximation (RMSEA) = 0.10, comparative fit index (CFI) = 0.92 and Tucker-Lewis index (TLI) = 0.90. Reported internal consistency for the WAI-SF total scale is  $\alpha = 0.927$ ; for the subscales Tasks, Goals and Bond it is  $\alpha = 0.845$ ,  $\alpha = 0.862$ , and  $\alpha = 0.804$ , respectively (Paap et al., 2018).

#### 2.4.1.1. Adaptation procedure

The Dutch version of the WAI-SF (Paap et al., 2018) formed the basis for the adaptation procedure carried out in the present study. A systematic translation procedure in Dutch was conducted by Paap et al. using the COSMIN guidelines (Mokkink et al., 2010). In the present study, this Dutch version was adapted for administration by healthcare professionals working with people with mild intellectual disabilities. First, the first author adapted the 12-item version for clients by changing the formulation into the perspective of healthcare professionals (i.e., the new items focused on healthcare professionals' perceptions of how the people with mild intellectual disabilities they

were working with would evaluate the working alliance between them). Further, in accordance with the suggestion of both Beaton et al. (2000) and Hoben et al. (2013) to consult an expert group when adapting instruments for use in another context, experts in the field of intellectual disability were also invited to participate in the adaptation. Specifically, two groups of experts comprising experienced healthcare professionals with diverse positions (e.g., support staff members, psychologists and team managers) were contacted by the first author to ensure heterogeneous perspectives from an experienced group of professionals. The first expert group ( $N = 5$ ) individually read the formulation of the 12 adapted items, before subsequently evaluating the readability, recognisability, and suitability for use within the context of care organisations for people with mild intellectual disabilities. Generally speaking, the healthcare professionals deemed that most of the formulations were understandable and recognisable, but they did advise to avoid the usage of abstract concepts (e.g., 'appreciates him/her', which were adapted into '...feels that I recognise his/her potential and strengths') and noted some overlap and similarities between several items (e.g., '... how I might be able to change/achieve my goals' and '...working towards mutually agreed upon goals'). Recommendations for improving the formulations led to some items being adjusted, while, simultaneously, ensuring that the items retained the meanings of the original instrument. Based on the advice of the first expert group, the first author prepared an overview of the 12 adapted items, which was then discussed with the present authors. Next, the 12 items were also discussed with the second group of experts ( $N = 6$ ) by means of video conferencing because of COVID-19 restrictions. The discussion with the second expert group led to adaptations in the formulation of certain items. More specifically, those items that emphasised the individual and personal responsibility of clients were adapted to stress the shared responsibility of clients and healthcare professionals (e.g., the item 'As a result of these sessions [name of client] it is clearer as to how he/she might be able to change' was changed to 'My client and I agree about what we need to do to improve his/her situation'). This formulation was perceived to be more appropriate within the context of care organisations for people with mild intellectual disabilities. Another critical piece of feedback from the expert group pertained to the usage of the term 'problems'. They recommended changing a problem-oriented item description into a more helpful and supportive tone, in addition to making some other minor linguistic adjustments. Finally, an overview of all adaptations was discussed with the present authors, and as recommended by Beaton et al. (2000), the adapted items in Dutch were then translated into English by a professional native editor in order to ensure a proper translation of the adapted items into English in preparation for publication.

#### **2.4.2. Technical Alliance Inventory – Short Form**

The Dutch version of the TAI-SF formed the basis for the adaptation for healthcare professionals working with people with mild intellectual disabilities. This instrument

has previously been used in a large European study (for more details, see Kleiboer et al., 2016). Originally, this 12-item measurement was designed to assess the working alliance within a self-guided online intervention for depression amongst mental health populations (Herrero et al., 2020). This measure, which encompasses the same three factors as the WAI-SF (i.e., bond, goals, and tasks), originally used a 7-point Likert scale. For the purposes of the present study, a 5-point Likert scale was used to rate the statements in a similar manner as to all the other statements within the online questionnaire. The scores ranged from 1 (totally disagree) to 5 (totally agree), with a higher mean score indicating a better working alliance using an eHealth application. The Cronbach's alpha coefficient for the total TAI-SF scale was high ( $\alpha = .97$ ) (Herrero et al., 2020). Kiluk et al. (2014) reported good internal consistency for the subscales of the WAI-SF (Bond  $\alpha = .78$ ; Task  $\alpha = .84$ ; Goal  $\alpha = .75$ ) applied in an online intervention. Gómez Penedo et al. (2020) examined a three-factor model within online interventions and found the following model fit indexes:  $\chi^2(51) = 155.008$ ,  $p < 0.001$ , CFI = 0.996, TLI = 0.995, RMSEA = 0.099 and standardised root mean square residual (SRMR) = 0.062.

#### **2.4.2.1. Adaptation procedure**

Similar to the adaptation procedure of the WAI-SF, the formulation of the TAI-SF items was adapted based on the comments of the first expert group, who stressed the importance of a concrete and understandable formulation of the items. The second expert group also received a written overview with the original formulation and an adapted formulation of the TAI-SF-MID items. As a result of a short discussion with the expert group, the concept of trustworthiness referred to in one of the items was changed to reflect trust in the eHealth tool itself. Similar to the adaptation procedure of the WAI-SF, an overview of the adapted 12 items and the final adaptation of the TAI-SF were discussed with all present authors after consultation with the expert groups. A small number of linguistic adjustments were made to improve the understandability of some of the items.

## **2.5. Data analysis**

The data analysis was performed using IBM SPSS for Windows (version 24), JASP software package (JASP Team 2019) and MPLUS version 8.1 (Muthén & Muthén 1998–2017) and comprised three steps. First, the latent factor structure of both the WAI-SF-MID and TAI-SF-MID was tested by means of confirmatory factor analyses (CFAs). Although the WAI-SF-MID is an adapted scale that was developed for the purposes of this study, testing a three-factor model that distinguished between the factors tasks, goals and bond was preferred over an exploratory factor analysis because of the robust evidence in extant literature for the three-factor structure of the WAI-SF (e.g., Hatcher & Gillaspay 2006; Munder et al., 2010; Lamers et al., 2015). With respect to the TAI-SF-MID, three models were tested: a three-factor model, which distinguished between the factors tasks, goals,

and bond (Munder et al., 2010); a two-factor model, which distinguished between the factor bond and a factor consisting of both tasks and goals (Gómez Penedo et al., 2020); and a one-factor model (Miragall et al., 2015). The robust maximum likelihood MLR estimator for continuous data was used. Although data were collected on a 5-point Likert scale, they were handled as continuous data because continuous MLR is deemed to be a good estimator for ordinal data with  $\geq 5$  categories (Rhemtulla et al., 2012). The model fit was examined via four traditional model fit indices: the normed  $\chi^2$ , the RMSEA, the CFI and the SRMR. Whereas cut-off values of normed  $\chi^2 < 3.00$ , RMSEA  $< 0.08$ , CFI  $> 0.90$  and SRMR  $< 0.10$  indicate an acceptable model fit, cut-off values of normed  $\chi^2 < 2.00$ , RMSEA  $< 0.08$ , CFI  $> 0.95$ , and SRMR  $< 0.10$  indicate a good model fit (Schweizer, 2010; Kline, 2011). In addition, as these traditional fit indices control for neither type I nor type II errors (Marsh et al., 2004), the 'detection of misspecification' procedure of Saris et al. (2009) was also used. The minimum size of the misspecification detected by the modification index test with a power  $> 0.80$  (i.e., a high likelihood) was set at 0.10, in order to interpret the modification index test for each restricted parameter of the model (Saris et al., 2009). Hence, the modification index was used to increase the model fit. That is to say, those parameters that would increase the model fit if they were freed were identified. Further improvement to the model fit was achieved by removing items with factor loadings  $< 0.40$  (Field, 2013).

Second, descriptive statistics for both the WAI-SF-MID and TAI-SF-MID scales were calculated. Third, internal reliability estimates of the WAI-SF-MID and TAI-SF-MID were measured. Specifically, Cronbach's alpha ( $\alpha$ ) and McDonald's omega ( $\omega$ ) were computed to examine the internal reliability of both scales; values between 0.70 and 0.80 were considered as acceptable, while values  $\geq 0.80$  were deemed to be good (Field, 2013).

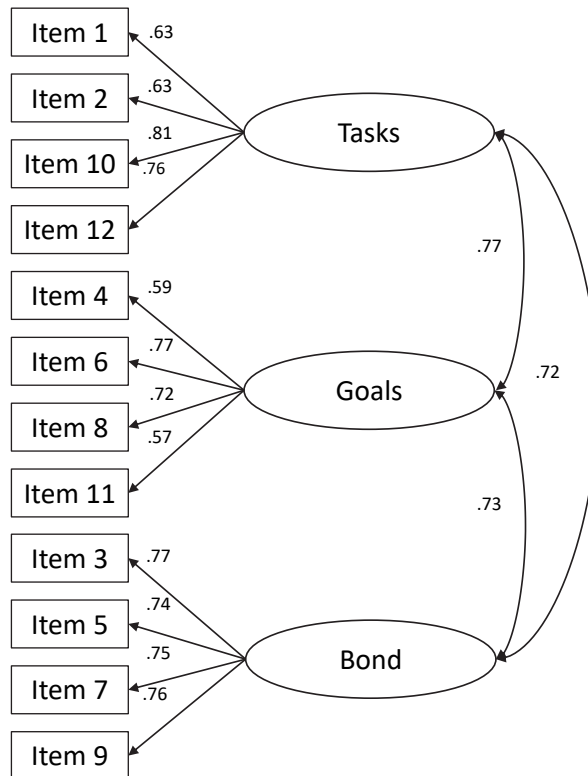
## 3. Results

### 3.1. Psychometric examination of the WAI-SF-MID

To investigate the factor structure of the WAI-SF-MID, a three-factor model, distinguishing between the factors tasks, goals and bond, was tested by means of a CFA. Based on the global fit measures, this three-factor model had an acceptable to good model fit: normed  $\chi^2 = 1.87$ , RMSEA = 0.066 [90% confidence interval (CI) 0.045–0.087], CFI = 0.93, SRMR = 0.048. Based on the 'detection of misspecification' procedure, modification index inspection showed no relevant misspecifications.

The standardised factor loadings ranged from 0.57 and 0.81 and were all found to be significant at the  $P < .001$  level (Fig. 1). The means, standard deviations and range of scores on the WAI-SF-MID scales are shown in Table 2. The overall internal consistency

of the WAI-SF-MID was found to be 0.92 for both Cronbach's alpha and MacDonald's omega. The internal consistency scores for each scale of the WAI-SF-MID are presented in Table 4; the Cronbach's alphas and the MacDonald's omegas ranged from 0.76 to 0.85.



**Figure 1.** Visual representation of the three-factor model of the WAI-SF-MID ( $N = 199$ ; 12 items).

*Note:* The circles represent the latent variables, while the rectangles represent the items. The numbers between the single-arrow lines that connect the items and latent variables are standardised factor loadings. The numbers between the bidirectional arrows that connect the latent variables indicate the relationship between factors (expressed as correlations).

**Table 2.** Means, standard deviations and ranges of scores on the WAI-SF-MID and TAI-SF-MID scales

Factor	WAI-SF-MID			TAI-SF-MID		
	Mean	SD	Min-Max	Mean	SD	Min-Max
Tasks	3.83	0.47	1.50-5.00	3.38	0.63	1.00-5.00
Goals	3.89	0.48	2.25-5.00	3.36	0.72	1.25-5.00
Bond	4.02	0.51	1.75-5.00	3.35	0.74	1.00-5.00

### 3.2. Psychometric examination of the TAI-SF-MID

A series of CFAs were conducted to explore which of the three models (i.e. a one-factor model, a two-factor model or a three-factor model) had the best model fit. Based on the global fit measures (Table 3), the fit of the three-factor model performed better than the other two models. While the  $\chi^2$  test for this model was significant, three global fit measures demonstrated an acceptable fit: normed  $\chi^2 = 2.12$ , CFI = 0.94, and SRMR = 0.049. Despite the unacceptable value of RMSEA (0.091), the model nevertheless showed potential and thus served as the basis for further examination.

**Table 3.** Global fit measures of the three tested models regarding TAI-SF-MID

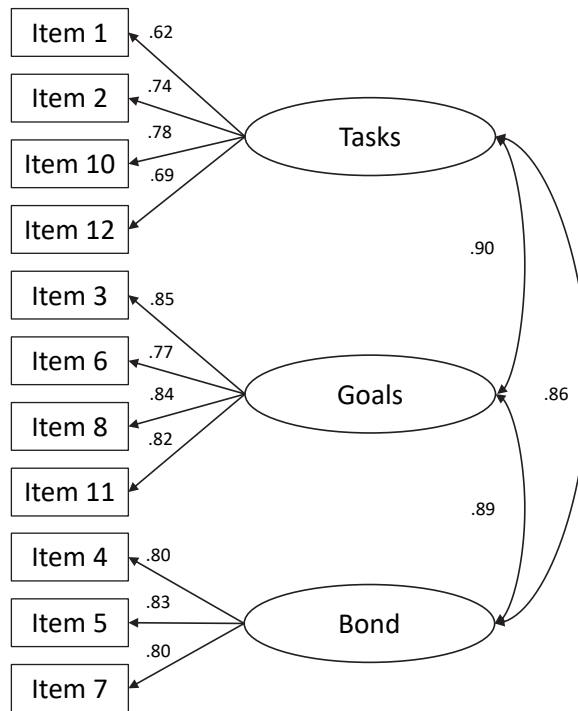
Model	$\chi^2$	df	$\chi^2 / df$	RMSEA (90% CI)	CFI	SRMR	BIC
1. Three-factor model	108.36*	51	2.12	0.091 (0.067–0.114)	0.94	0.049	3014.98
2. Two-factor model	121.96*	53	2.30	0.097 (0.075–0.120)	0.92	0.050	3021.98
3. One-factor model	122.25*	54	2.26	0.096 (.073–0.119)	0.93	0.050	3017.13

Note. \*  $P < 0.05$

BIC, Bayes Information Criterion; CFI, Comparative Fit Index; CI, confidence interval, df, degrees of freedom; RMSEA, Root Mean Square Error of Approximation; SRMR, Standardised Root Mean Square Residual.

As no items had factor loadings  $< 0.40$  (Field, 2013), no items were removed in advance. Based on the 'detection of misspecification' procedure, modification index inspection showed three relevant misspecifications. The modification index between items 1 and 9 most affected the model fit; however, adding a parameter between these two items was not appropriate as these items pertained to different latent variables. Therefore, a parameter was added between the two items that affected the model second most and belonged to the same latent variable: items 7 and 9. This resulted in a comparable model fit: normed  $\chi^2 = 2.05$ , RMSEA = 0.087, CFI = 0.94, SRMR = 0.048; the RMSEA criterium was still not met. Moreover, modification index examination showed two relevant misspecifications. These misspecifications were related to items pertaining to different latent variables, which meant that adding a parameter was not appropriate. However, in order to examine the impact of these misspecifications upon the model, additional parameters were added to these two misspecifications. First, a parameter was added between items 1 and 9, which, in turn, resulted in a comparable model fit, while a parameter was subsequently added between items 9 and 10, which resulted in an improved model fit with acceptable-to-good model fit measures (normed  $\chi^2 = 1.69$ , RMSEA = 0.071, CFI = 0.96, SRMR = 0.041), without misspecifications. Hence, adding two inappropriate parameters to the model increased the model fit. Interestingly, it should be noted that all additional parameters were related to item 9. In light of this, a model without item 9 was tested, and the model fit substantially increased as a result: normed  $\chi^2 = 1.53$ , RMSEA = 0.062 [90% CI 0.027–0.092], CFI = 0.97, SRMR = 0.039. This model contained one misspecification between two items (i.e., 10 and 11) pertaining

to different latent variables, which, in turn, resulted in a slightly increased model fit. However, as the addition of this parameter was inappropriate and the model fit without this parameter was also acceptable to good, this parameter was ignored. Hence, to summarise, the three-factor model without item 9 was adopted (Fig. 2).



**Figure 2.** Visual representation of the three-factor model of the TAI-SF-MID ( $N = 139$ ; 11 items).

*Note:* The circles represent the latent variables while the rectangles represent the items. The numbers between the single-arrow lines that connect the items and latent variables are standardised factor loadings. The numbers between the bidirectional arrows that connect the latent variables indicate the relationship between factors (expressed as correlations).

The standardised factor loadings ranged from 0.62 and 0.85 and were all found to be significant at the  $P < 0.001$  level (Fig. 2). The means, standard deviations and range of scores on the TAI-SF-MID scales are shown in Table 2. The overall internal consistency of the TAI-SF-MID was found to be 0.95 for both Cronbach's alpha and MacDonald's omega. The internal consistency scores for each scale of the TAI-SF-MID are presented in Table 4; the Cronbach's alphas and MacDonald's omegas ranged from 0.81 to 0.89.

**Table 4.** Internal consistencies of the WAI-SF-MID and TAI-SF-MID

Scale	Internal consistencies WAI-SF-MID		Internal consistencies TAI-SF-MID	
	Cronbach's alpha	McDonald's omega	Cronbach's alpha	McDonald's omega
Total scale	0.92	0.92	0.95	0.95
Sub-scale 1: Tasks	0.80	0.81	0.81	0.81
Sub-scale 2: Goals	0.76	0.76	0.89	0.89
Sub-scale 3: Bond	0.85	0.84	0.85	0.85

## 4. Discussion

The present study evaluated the factor structure and reliability of both the WAI-SF-MID and TAI-SF-MID for administration by healthcare professionals working with people with mild intellectual disabilities. Both measurements were adapted in collaboration with experienced healthcare professionals working with people with an intellectual disability. In accordance with previous studies, CFA confirmed that the three-factor model was a good model of fit for the WAI-SF-MID. For the TAI-SF-MID, the same three-factor model displayed greater potential in comparison to both the one-factor and two-factor models; further examination showed that one item had to be removed for an acceptable-to-good model fit for this three-factor model. The internal consistency for the sub-scales and the total scores of both the WAI-SF-MID and TAI-SF-MID were good to excellent. These findings are in line with research investigating the use of WAI-SF and TAI-SF by healthcare professionals working with patient groups without IDs (e.g., Hatcher & Gillaspay, 2006; Flückiger et al., 2018; Kiluk et al., 2014; Herrero et al., 2020). One potential explanation for removing the TAI-SF-MID item is that the adapted translation for healthcare professionals working with people with an intellectual disability (i.e., 'My client feels comfortable using the eHealth tool') was less accurate compared to the original one (i.e., 'My client trusts the online program'). Furthermore, the participants may have perceived that 'feeling comfortable' referred to them, rather than to the eHealth tool, which may have led to a different response. The WAI-SF-MID measures healthcare professionals' perceptions of how clients experience the working alliance. In this respect, it stimulates professionals' awareness and sense of alignment in the provision of support and therapy. Moreover, the WAI-SF-MID could be helpful for identifying and monitoring changes over time via repeated measurements. Several studies amongst (mental) health populations without an intellectual disability have underlined the importance of the working alliance in the early stages of therapy, namely, in terms of adherence, symptom change, outcomes and tailoring the intervention to the needs of clients (e.g., Barber et al., 2013; Flückiger et al., 2018; Baier et al., 2020; O'Keeffe



et al., 2020). Further, Krause et al. (2011) underlined the development of alliance over time and the evaluation 'in the context of an asymmetric relationship in which one is the help-seeker and the other one the help-giver' (p. 274). People with mild intellectual disabilities experience more barriers in communicative, cognitive and executive functioning. These barriers require that healthcare professionals be sensitive and responsive to the specific needs of persons with mild intellectual disabilities. The quality of the working alliance may therefore conceivably take on even greater importance for clients with mild intellectual disabilities (e.g., Ramsden et al., 2016). When using digital tools for support and therapy, attention should be paid to matching a suitable eHealth tool to the support needs, appropriate adjustments and digital/other abilities of people with mild intellectual disabilities (Oudshoorn et al., 2020). Hence, further research into the role of the working alliance in the field of intellectual disability warrants attention, insofar as it could help to facilitate process–outcome studies (e.g., Cameron et al., 2020).

In recent years, both support and therapy are increasingly being provided via either digital tools like computers and smartphones or a combination of face-to-face contact with digital applications (i.e., blended care) (Riper et al., 2010; Wentzel et al., 2016). The COVID-19 pandemic has accelerated the use of eHealth (World Health Organization, 2020), which, in turn, has impacted upon the working alliance (e.g., Aafjes-Van Doorn et al., 2020; Poletti et al., 2021). In light of this trend, Van Daele et al. (2020) recommend to include valid measurements in future research in order to discern what precisely works for whom in eHealth interventions. Further research on healthcare professionals working with people with mild intellectual disabilities is urgently needed, as the majority of studies on eHealth interventions merely focus on clients' perspectives. This is problematic given that healthcare professionals' attitudes towards eHealth and the working alliance, as well as their perceptions of what the added value of these are for clients, are crucial for successful implementation (e.g., Parsons et al., 2008; Clifford Simpican et al., 2017).

For clinical practice, both the WAI-SF-MID and TAI-SF-MID measurements seem valuable for evaluating the working alliance within professional face to face and digital contact with people with mild intellectual disabilities, as well as for goal attainment, supportive autonomy or monitoring therapeutic progress. In the research literature on relationships between clients with mild intellectual disabilities and support staff as well as therapists, the main focus is on the perceived relationship. Less attention is paid to the bidirectional collaboration between client with mild intellectual disabilities and healthcare professional (Goals and Tasks component of Working Alliance) over time, as is rather the case in client populations without intellectual disabilities (e.g., Krause et al., 2011; Gelso, 2014). Based on the feedback of the expert group, some WAI/TAI items were reformulated for the context of care for people with mild intellectual disabilities.

For example, the Goal items underline the shared instead of a personal responsibility to formulate goals. The Bond items emphasised being seen and understood, a main topic in research on collaboration between people with mild intellectual disabilities and professionals, instead of kindness as formulated in the original instrument. In the Task items, 'insight' is too abstract because of cognitive limitations of people with mild intellectual disabilities. In the adaptation of the WAI items, a better understanding and focus on needs instead of problems were formulated. In the adaptation of the TAI items, technology as complement to support or therapy was mentioned to increase our knowledge on the possible impact of eHealth in developing a working alliance. The application of both instruments could contribute to developing knowledge on this collaboration process, the role of support staff and therapists and the possible impact of eHealth in developing a working alliance. Notwithstanding the application of both instruments within the context of support and therapy, both instruments could also function as reflective tools for healthcare professionals, by virtue of the fact that filling out the questionnaire requires healthcare professionals to reflect on the alliance between themselves and their clients. These instruments enable professionals to objectify the alliance over time and get a better understanding of their own role in the development. When applied in support or therapy for various clients with mild intellectual disabilities, it could also be a helpful instrument for supervision, training and insight in personal strengths and vulnerabilities. It should be noted, however, that it is essential to adapt and test the psychometric properties of both instruments to investigate the perspective of clients with mild intellectual disabilities in intervention studies as well. Getting both partners involved in the alliance to evaluate the alliance would make it possible to customise the support or the therapy to the needs of clients. By measuring both perspectives, any ruptures could be detected earlier in the process, and healthcare professionals would have more time to try to repair them (Eubanks et al., 2018).

Some critical reflections on this study should be delineated. First, the participants were instructed to complete both instruments with a specific client in mind. We are therefore unsure about possible risk of recall bias on scoring the WAI-SF-MID or TAI-SF-MID for former instead of actual clients. Although retrospective assessment is possible in more theoretical studies, it is less common and generally less accurate than actual scoring (Owen et al., 2010). For future studies, we recommend applying these instruments in predefined moments such as post-therapy, as is common in intervention studies (see Flückiger et al., 2018) or when evaluating a support plan. The aim of the current study was to investigate both the factor structure and reliability of the adapted measurements in a cross-sectional design; as such no further information about clients and their reasons for help was collected. Future research should thus include behavioural, mental health or support needs assessments amongst clients as well as providing relevant characteristics

of the healthcare professionals. This could lead to a more nuanced picture of whether specific characteristics of clients, healthcare professionals or a specific eHealth tool impact upon the working alliance (e.g., for clients with complex trauma it might be harder to establish a working alliance). Although this study is a first step to validate these instruments for application in professional relationships between professionals and people with mild intellectual disabilities, it would be important for future research to investigate the predictive and convergent validity of both adapted instruments. Further, we recommend replicating the measurement of model fit indices and the internal consistency of the WAI-SF-MID and TAI-SF-MID in future intervention studies. Second, the authors used a convenience sampling method, which potentially resulted in only participants with a positive attitude towards eHealth participating in the study and in line with this, high technical alliance scores. This could have led to a different response pattern compared to the entire population of healthcare professionals working in care organisations for people with IDs. Therefore, it is recommended that future studies employ random sampling methods. Third, the collaboration with a broad group of experienced healthcare professionals working in various domains of a care organisation (e.g., community care and residential care) in the adaptation of both measurements is a key strength of the study. The final expert group also represented various domains within the field of care for people with IDs. This increased the face validity of both the WAI-SF-MID and the TAI-SF-MID. Finally, with respect to the TAI-SF-MID, the participants evaluated different kinds of eHealth tools, which resulted in responses related to eHealth tools in a broad context (e.g., videoconferencing, use of apps, and remote forms of support or therapy). It is thus recommended that future studies focus on specific eHealth tools to extract the potential influence of a specific tool.

People with mild intellectual disabilities deserve high standards of support and therapy, including within eHealth delivered forms (Aref-Adin & Hassiotis, 2021). The working alliance is essential for establishing meaningful relationships and contributes to enhancing clients' quality of life. Both the WAI-SF-MID and the TAI-SF-MID are expedient and successfully adapted instruments through which to capture the quality of the working alliance within the innovative sphere of eHealth delivery.

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**CHAPTER 7**



# Acceptance and use of eHealth in support and psychological therapy for people with intellectual disabilities: Two cross-sectional surveys of healthcare professionals

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## Abstract

### Background

Acceptance of healthcare professionals is of paramount importance for the uptake and implementation of eHealth. The Unified Theory of Acceptance and Use of Technology (UTAUT) model is a widely used framework for studying healthcare professionals' acceptance and actual use of eHealth among general client populations. However, there is limited understanding of the eHealth acceptance of healthcare professionals working with people with intellectual disabilities (ID).

### Methods

Two cross-sectional survey studies were conducted among healthcare professionals from five healthcare organizations for people with ID in the Netherlands, in 2018 ( $N=311$ ) and in 2021 during the Covid-19 pandemic ( $N=326$ ). In addition to confirmatory and exploratory factor analyses (CFA/EFA) to evaluate both the original UTAUT model and an extended version, descriptive analysis was utilized to explore participants' characteristics, acceptance levels, and eHealth usage. Moderator analysis and multi-regression analysis were employed.

### Results

CFA indicated a poor fit for both the original four-factor UTAUT model and the extended version. An EFA was then conducted, resulting in a more satisfactory five-factor model after removing one item with a factor loading  $< .40$ . Internal consistency of the five factors ranged from acceptable to good (Cronbach's  $\alpha=.76-.85$ ). Collectively, all factors predicted the intention to use eHealth in 2018 ( $R^2 = 0.47$ ,  $F(5, 305) = 54,885$ ,  $p < .001$ ) and in 2021 ( $R^2 = 0.43$ ;  $F(5, 320) = 49,32$ ,  $p < .001$ ). Participants scored moderately on all five acceptance factors in both 2018 and 2021. Moderator analysis indicated that age and voluntariness influence the relationship between factors that determined acceptance and intention to use eHealth.

### Conclusion

The findings from two cross-sectional studies conducted in 2018 and 2021, utilizing an extended UTAUT model, gave a deeper understanding of eHealth acceptance among healthcare professionals who work with people with ID.

## 1. Introduction

Healthcare organizations are increasingly incorporating eHealth, a term denoting the use of technology for promoting health, well-being, and healthcare (Van Gemert-Pijnen et al., 2018). This approach has also been adopted to provide support and psychological therapy to people with intellectual disabilities. People with an intellectual disability are characterized by significant limitations in intellectual functioning and adaptive behavior, encompassing conceptual, social, and practical adaptive skills (Schalock et al., 2021). The primary objective of professional support and psychological therapy offered by healthcare organizations for people with an intellectual disability is to bridge the gap between individual capabilities and environmental demands (Schalock et al., 2021; Wehmeyer et al., 2012). These services are delivered in various settings, including residential and community-care environments. Given the lifelong and life-broad support required by people with an intellectual disability, professional support plays a crucial role. In recent years, support and therapy are increasingly delivered by using digital technology (e.g., Cooney et al., 2018; De Wit et al., 2015). The use of eHealth in healthcare organizations serving people with an intellectual disability, as in other healthcare sectors, accelerated during the Covid-19 pandemic in 2020 (Lunsky et al., 2022).

While some studies report positive experiences of healthcare professionals utilizing eHealth for ongoing support or psychological therapy during the pandemic (Oudshoorn et al., 2022; Zaagsma et al., 2022), others identify challenges in effectively delivering digital mental health support among people with an intellectual disability (Chadwick et al., 2021; Gregson et al., 2022; Lunsky et al., 2022). A particular concern for healthcare professionals is building a working alliance virtually (Rawlings et al., 2021), which is crucial for the perceived value of eHealth usage. Factors such as digital literacy, availability of suitable equipment, and on-site support from direct support staff or relatives for people with an intellectual disability to use equipment properly also affect the willingness of healthcare professionals to use eHealth (Frielink et al., 2020; Lake et al., 2021).

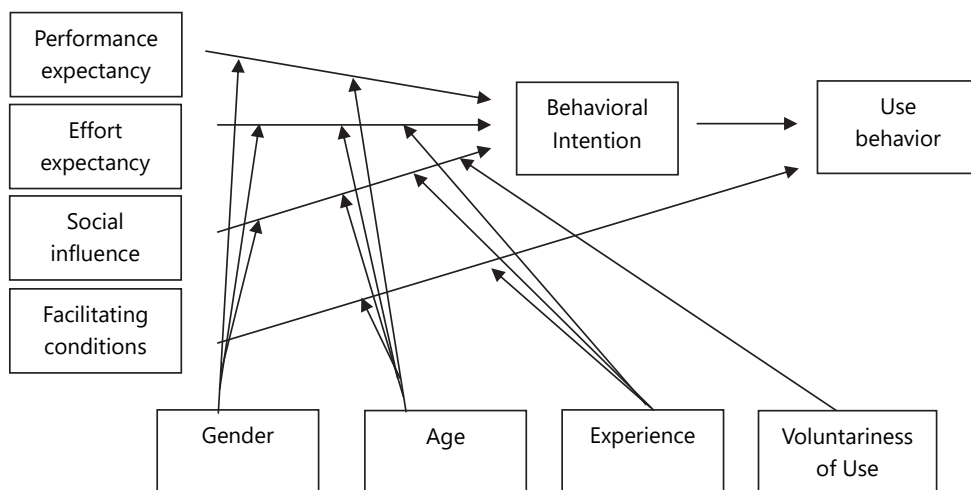
Acceptance is likewise key in influencing healthcare professionals' willingness towards eHealth (Wennberg & Kjellberg, 2010), in terms of their perception of eHealth as appropriate, feasible, and suitable for delivering support or therapy (Klaic et al., 2022; Proctor et al., 2011). Acceptance at an individual level is associated with the intention to use eHealth and contributes to the success or failure of eHealth implementation (e.g., Henneman et al., 2017; Vis et al., 2018). One commonly employed theoretical model to explain the acceptance and usage (or non-usage) of eHealth in clinical practice is the Unified Theory of Acceptance and Use of Technology (UTAUT; Venkatesh et al., 2003).

### 1.1. The UTAUT model: The role of acceptance

The UTAUT model aggregates various theories to explain individuals' acceptance and usage of technology (Venkatesh et al., 2003). While initially designed for industry and business services (Khechine et al., 2016), the model has also been applied in various healthcare contexts, such as rehabilitation (Liu et al., 2015), mental health counselling in family practices (van der Vaart et al., 2016), psychotherapy (Békés et al., 2022), and pediatric care (Janssen et al., 2021).

According to the UTAUT model, three factors – performance expectancy, effort expectancy, and social influence – are related to the behavioral intention to use eHealth, subsequently impacting the actual usage of eHealth. Performance expectancy refers to healthcare professionals' perceived added value of eHealth, while effort expectancy represents the ease in becoming familiar with using eHealth applications. Social influence encompasses the perceived social pressure or support of important others, such as colleagues or managers, in relation to the intention to use eHealth. The fourth factor in the UTAUT model includes facilitating conditions, which directly affect the actual usage of eHealth. Facilitating conditions relate to the extent to which healthcare professionals perceive the organizational context and available technological infrastructure as supportive of eHealth usage (Venkatesh et al., 2003).

The correlations between performance expectancy, effort expectancy, and social influence with the behavioral intention to use eHealth can be influenced by four moderators: gender, age, experience, and voluntariness of eHealth use (see Figure 1). Experience refers to the extent to which individuals feel comfortable and proficient using technology in daily life, voluntariness pertains to the degree of choice individuals have in using eHealth instead of being required to do so by the healthcare organization.



**Figure 1.** Original Unified Theory Acceptance and Use Technology (UTAUT) (Venkatesh et al. 2003). Figure used with permission Copyright Clearance Center.

## 1.2. Acceptance of eHealth among healthcare professionals working in healthcare organizations for people with intellectual disabilities

Also among healthcare professionals working with people with an intellectual disability, both organizational and individual factors have been identified as influencing the acceptance and use of eHealth. Organizational factors include the culture surrounding ICT implementation, technical challenges, and the quality of training received, which can impact the acceptance and use of eHealth either positively or negatively (Konttila et al., 2018; Parsons et al., 2008). At the individual level, the digital experience and communication skills of both people with an intellectual disability and support staff or therapists have been identified as facilitators or barriers to the acceptance and use of eHealth (De Wit et al., 2015; Zaagsma et al., 2022). The willingness of support staff to introduce eHealth to people with an intellectual disability and their belief in its potential benefits are also crucial toward fostering eHealth acceptance. Finally, several studies show that healthcare professionals' digital experience can influence their acceptance and behavioral intention to use eHealth in practice (Clifford Simplican et al., 2017; Söderström et al., 2021; Wade et al., 2014).

While the aforementioned studies have identified relevant factors related to the organization, healthcare professionals, and clients for implementing eHealth in the care and support for individuals with an intellectual disability, there is a lack of research that specifically addresses the acceptance and usage of eHealth among healthcare professionals working with this population using a theoretical model as starting point.

Therefore, the present study aimed to explore the applicability of the UTAUT model toward understanding the acceptance, intention to use, and actual use of eHealth among support staff and therapists working with people with an intellectual disability. The study also explored the level of acceptance and utilization of eHealth for support and psychological therapy among support staff and therapists in the care and support for people with ID, and examined whether the acceptance and usage of eHealth changed during the COVID-19 pandemic. The research questions derived from these aims are:

- 1) Is the UTAUT model applicable for understanding healthcare professionals' acceptance and intention to use eHealth for support and psychological therapy among people with an intellectual disability?
- 2) What is the level of acceptance and utilization of eHealth among support staff and therapists providing support and psychological therapy for people with an intellectual disability, and did the acceptance and usage change during the COVID-19 pandemic?

## 2. Methods

### 2.1. Design

To investigate the acceptance and usage of eHealth among healthcare professionals in support and psychological therapy for people with an intellectual disability, two cross-sectional online surveys were conducted. The first survey took place in 2018, and the second survey – which included the same items as the 2018 survey along with additional questions concerning COVID-19 and perceptions of working alliance when utilizing eHealth – was administered in 2021. During this period, official measures included the conclusion of a lockdown period (November 2020 to June 2021), the discontinuation of the 1.5m social distancing measure in August 2021, availability of vaccines, and a gradual reopening of society (e.g., higher education resumed live classes) as indicated in the Central Government's coronavirus timeline (2021).

### 2.2. Participants

The Ethics Review Board of Tilburg University approved the study [EC-2016.71]. The participants in the study were support staff and therapists, including psychologists and experience-based therapists (e.g., art or drama therapists), who utilized at least one eHealth tool (e.g., secure videoconferencing tool or a mindfulness app) to support or provide psychological therapy to people with an intellectual disability. The analysis in the 2018 survey included data from 311 eHealth users of 673 participating support staff and therapists. In the 2021 survey, data from 326 eHealth users were available.



The demographic characteristics of support staff and therapists who participated in the online survey in 2018 and 2021 are presented in Table 1. Participants were asked about their voluntary or mandatory use of eHealth within their healthcare organization in both years, with the majority reporting voluntary use (2018: 75%; 2021: 77%). Only a small percentage of participants reported being obligated to use eHealth (2018: 17%; 2021: 19%). A minority of participants (8% in 2018 and 4% in 2021) indicated that their organization had no specific policy regarding use of eHealth. Both surveys also examined participants' eHealth education and training. In 2018, 60% reported not having received any education or training. Similarly, in 2021 over 60% of the participants reported a lack of education or training, and 71% reported not having received any education or training within the past year.

### **2.3. Procedure**

Participants were recruited from five healthcare organizations for people with an intellectual disability, located in both urban and rural areas in the western and southern regions of the Netherlands. In both 2018 and 2021, professionals were invited to participate via personalized emails sent either by the researchers or a designated contact person from the participating organization. The email addresses were obtained from human resources employees with the approval of the board of directors of the care organization. The email invitation included a link to the online survey, which was constructed using the Qualtrics™ software program, as well as an information sheet about the study. In 2021, one organization preferred an indirect invitation approach by placing the survey link and information sheet on their internal organizational website. In both years, a reminder was sent to participants within a month of the initial invitation. The 2018 survey was open for responses from December 2017 to April 2018. In 2021, the survey remained open from June to September. Participants provided electronic informed consent after reviewing the information about their rights, data protection, and processing of data provided in the online survey. The survey was designed to maintain anonymity, ensuring the confidentiality of participants' responses.

**Table 1.** Participant characteristics online survey 2018 (N = 311) and 2021 (N = 326)

Demographic attribute	N = 311 <sup>1</sup>		N = 326 <sup>2</sup>	
	N	%	N	%
<b>Gender</b>				
Male	45	14.5	44	13.5
Female	266	85.5	281	86.2
Other	-	-	1	0.3
<b>Age*</b>				
<30 years	54	17.4	67	20.5
30-39 years	113	36.6	103	31.6
40-49 years	73	23.5	78	23.9
50 and over	71	22.8	76	23.3
<b>Education</b>				
Lower	1	0.3	1	0.3
Secondary	92	29.6	114	35.2
Higher	218	70.1	204	62.9
Other	-	-	5	1.5
<b>Profession*</b>				
Support staff	243	78.1	232	71.2
Psychologist	56	18	83	25.5
Experience-based therapist	12	3.9	11	3.4
<b>Work domain*</b>				
Community care	53	17	67	20.6
Residential care <sup>3</sup>	158	50.8	175	47.0
Day care centre	35	11.3	31	9.5
Expert centre	46	14.8	41	12.6
More than one	16	5.1	8	2.5
Other	3	1	2	0.6
<b>Working experience</b>				
<5 years	48	15.4	83	25.5
6-10 years	76	24.4	48	14.7
11-15 years	53	17	67	20.6
16-20 years	55	17.7	40	12.3
>20 years	79	25.4	87	26.6
<b>Education/training</b>				
<1 year	79	25.4	84	25.8
>1 year	120	38.6	113	34.7
<b>Organizational policy towards eHealth use**</b>				
Voluntary	232	74.7	223	76.9%
Required	52	16.8	54	18.6%

Note: <sup>1</sup> 2018 wave <sup>2</sup> 2021 wave <sup>3</sup> sum of two types of residential care

\* one case missing, so total amounts and percentages are < than total n and %

\*\* 2018: one case missing, 26 respondents' organization did not use eHealth; 2021: 36 cases missing, 13 respondents' organization did not use eHealth

## 2.4. Measures

### 2.4.1. Acceptance and use of eHealth

For this study, the authors adapted and extended the UTAUT questionnaire (Venkatesh et al. 2003) for healthcare professionals working in care organizations for people with an intellectual disability. This process involved five steps. In the first step, two focus groups with healthcare professionals working with people with an intellectual disability and familiar with eHealth discussed the suitability of the UTAUT model factors and the corresponding 19 items in the context of an intellectual disability. Based on their feedback, one original facilitating conditions item did not fit the present context (“If I use the system, I will increase my chances of getting a raise”) and six additional items were added to enhance alignment with the work context – that is, three items were added to the performance expectancy factor, focusing on collaboration, working together with clients, and effectiveness of support/therapy provision. Three items were also added to the facilitating conditions factor, addressing the client’s facilities, digital literacy, and healthcare professionals’ time availability. In the second step, the original English items were translated into Dutch using a stepwise forward-backward translation procedure (Cull et al., 2002) – that is, the original English items were translated into Dutch by two researchers independently, then back-translated into English by two native speakers. Third, a consensus Dutch translation was achieved by the two researchers with the help of an experienced manager familiar with healthcare organizations for people with an intellectual disability, resulting in minor revisions for item clarification. The fourth step involved three healthcare professionals reviewing the adapted items to assess their suitability for various eHealth tools, such as videoconferencing and virtual reality. Minimal adjustments were made to the item formulation based on their feedback. Finally, in the fifth step the wording and sequence of the survey items were reviewed, and a pilot survey flow was tested by six fellow researchers. Minor suggestions from this pilot testing were incorporated into the final survey. These five steps resulted in an extended UTAUT survey consisting of 25 items, all measured on a 5-point Likert scale response format ranging from 1 (*totally disagree*) to 5 (*totally agree*). Higher scores indicated a greater acceptance of using eHealth to support or provide therapy for people with ID.

In addition to the UTAUT-based questionnaire, information on eHealth usage by healthcare professionals was collected. Questions assessed familiarity, frequency, and intensity of usage for six eHealth applications: apps, online platforms, serious gaming, videoconferencing, video modelling, and virtual reality. These eHealth tools were selected based on existing literature and their relevance to clinical practice for people with ID (Den Brok et al., 2015; Oudshoorn et al., 2020; Standen & Brown, 2006).

### **2.4.2. eHealth experience and voluntariness**

To measure eHealth experience, which was a moderator in the present study, the computer self-efficacy subscale of the Dutch e-Health attitude questionnaire (Aerts & van Dam, 2015) was utilized. This subscale consisted of seven items that evaluated personal experience with information and communication technology (ICT) (e.g. "I feel capable of using various computer programs"). Three items were reverse-coded, and participants responded on a 5-point Likert scale ranging from 1 (*totally disagree*) to 5 (*totally agree*). Higher scores indicated greater experience with using IT and computer programs.

To assess voluntariness of eHealth use, which was also a moderator in the present study, a single item inquiring about the organization's policy on eHealth usage ("How is eHealth usage arranged within your organization?") was included in the survey.

### **2.4.3. Digital working alliance**

In order to explore participants' perception of the contribution of eHealth to the working alliance and its impact on their intention to use eHealth, digital working alliance was included as a moderator in 2021. Participants working with people with mild intellectual disabilities completed the TAI-SF-MID (Oudshoorn et al., 2022) (11 items), while those working with people with severe intellectual disabilities completed the TAI-SF-SID (12 items). The items were rated on a 5-point Likert scale, ranging from 1 (*totally disagree*) to 5 (*totally agree*). Higher scores indicated a more positive perception of the role of eHealth in collaboration with people with an intellectual disability. Further details on the psychometric properties for the TAI-SF-MID for professionals working with mild intellectual disabilities can be found in the study of Oudshoorn et al. (2022).

### **2.4.4. eHealth training**

To enhance the understanding of the organizational context as perceived by participants, two additional items were included in the questionnaire to assess the training they received in working with eHealth.

### **2.4.5. Impact of COVID-19 pandemic**

The impact of the COVID-19 pandemic on acceptance and usage of eHealth by healthcare professionals was captured by three items based on relevant literature (Feijt et al., 2020; McBeath et al., 2020; Rettinger et al., 2021): "Due to the Covid-19 pandemic I have used eHealth increasingly", "Due to the Covid-19 pandemic I have used eHealth differently", and "Due to the Covid-19 pandemic I have a different perception of eHealth use". Participants rated these items on a 5-point Likert scale ranging from 1 (*totally disagree*) to 5 (*totally agree*). Higher scores indicated a greater impact of the pandemic

on eHealth acceptance and use. In 2021, the sequence of items was adjusted to ensure a logical flow of the survey in light of the inclusion of additional topics.

#### **2.4.6. Demographic information**

Gender and age, two moderators in the present study, were measured as part of the demographic information collected, which also included profession, working experience, and educational level. Age was categorized into four groups: under 30, 30-39, 40-49, and 50 and over. Gender was measured by male, female, or other.

### **2.5. Analysis**

The data analysis<sup>3</sup> was conducted using Mplus version 8.1 (Muthén & Muthén, 1998-2017) and IBM SPSS for Windows (version 25). The analysis involved five steps to examine the factors and relationships within the dataset. First, a combination of confirmatory factor analysis (CFA) and exploratory factor analysis (EFA) was used to evaluate the factor structure for the UTAUT model among healthcare professionals in support and psychological therapy for people with an intellectual disability, following the approach of Békés et al. (2022). The original four-factor UTAUT model, as well as the extended four-factor model with six additional items, were tested using CFA. The EFA aimed to identify latent constructs and to arrive at a parsimonious representation of the associations among measured variables. Data from the 2018 dataset were used for these analyses. With respect to the CFA, the robust maximum likelihood MLR estimator for continuous data was used, treating the 5-point Likert scale responses as continuous given the adequacy of the continuous MLR estimator for ordinal data with  $\geq 5$  categories. (Rhemtulla et al., 2012). Several fit statistics were used to examine goodness-of-fit, with acceptable model fit indicated by normed  $\chi^2 < 3.00$ , RMSEA  $< 0.08$ , CFI  $> 0.90$ , and SRMR  $< 0.10$  (Schweizer, 2010; Kline, 2011).

Second, because the CFA did not yield satisfactory model fit (see Results section for additional information), an EFA was deployed to explore the factor structure based on the procedure described in the development of the UTAUT-T model by Békés et al. (2022). Bartlett's test of sphericity was significant ( $\chi^2 (210) = 3133,886$ ,  $p < 0.001$ ), indicating that it was appropriate to use the factor analytic model on this dataset. Next, the Kaiser-Meyer-Olkin measure of sampling adequacy indicated that the strength of the variables' relationship was high (KMO = 0.86), justifying the execution of EFA. The 25 items were subjected to maximum likelihood factor extraction with Oblimin rotation. Based on the commonly accepted extraction rules (scree plots, eigenvalues  $> 1$ , items with factor loadings  $> .40$ ), five factors were found.

3 Only participants who filled out  $\geq 80\%$  of the UTAUT statements (20/25) were included in further data analysis.

Third, descriptive statistics were calculated for both datasets to provide an overview of the data. Fourth, a multiple regression analysis was performed to examine the impact of the five individual factors on the Behavioral intention factor. Last, a stepwise regression analysis was conducted to explore the potential role of four moderators (gender, age, experience, and voluntariness of eHealth use) on the relationship between the five UTAUT factors and Behavioral intention. In the regression analysis for 2021, the Technical Alliance mean score was included as a fifth moderator. No Bonferroni corrections were applied to the separate regression analyses due to the study's exploratory nature and focus on individual scores of the five factors (Armstrong, 2014).

### 3. Results

#### 3.1. Confirmatory factor analysis and extended UTAUT model

The original four-factor model and the extended four-factor model, including six additional items, exhibited inadequate model fit in the CFA analysis. Specifically, the original four-factor model had a normed  $\chi^2$  of 3.25, RMSEA = 0.085, CFI = 0.868, and SRMSR = 0.109, while the extended four-factor model had a normed  $\chi^2$  of 3.09, RMSEA = 0.082, CFI = 0.832, and SRMSR = 0.103. These findings suggest that neither of the UTAUT models was suitable for the present dataset.

#### 3.2. Exploratory factor analysis

EFA was employed to explore a new model. Table 2 presents the pattern matrix obtained, including only items with factor loadings > 0.40 (one item excluded from the dataset). The pattern matrix revealed the presence of five factors: Factor 1, Perceived added value (7 items;  $\alpha = 0.85$ ); Factor 2, Convenience and self-confidence (6 items;  $\alpha = 0.78$ ); Factor 3, Social pressure from colleagues and support from manager (3 items,  $\alpha = 0.79$ ); Factor 4, Organizational support (3 items,  $\alpha = 0.76$ ); and Factor 5, Facilitating conditions for people with ID (such as devices and digital skills) (2 items,  $\alpha = 0.78$ ). Additionally, three items composed the Behavioral intention factor (3 items,  $\alpha = 0.95$ ).

**Table 2.** Factor loadings of UTAUT items and added items from the focus group consultation

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Using eHealth facilitates working together with my client to reach their goals*	<b>0,703</b>	-0,008	0,068	0,108	0,171
The use of eHealth supports the provision of support/therapy more effectively*	<b>0,697</b>	0,207	0,000	-0,076	0,004
eHealth enables collaboration with other persons involved in the client's formal and informal network*	<b>0,693</b>	0,051	-0,037	0,130	-0,084
I find eHealth useful for my work	<b>0,687</b>	0,150	-0,016	0,160	-0,011
It would be easy for me to become skilful in using eHealth	<b>0,638</b>	-0,192	0,034	0,045	0,089
Using eHealth increases my productivity	<b>0,554</b>	0,407	0,057	-0,378	-0,037
Using eHealth enables me to accomplish tasks more quickly	<b>0,541</b>	0,373	0,157	-0,305	-0,083
I clearly understand how to use eHealth as part of the support and/or therapy I provide	-0,007	<b>0,723</b>	-0,050	0,168	0,075
I have the knowledge necessary to use eHealth	-0,189	<b>0,709</b>	0,036	0,308	0,147
I find eHealth easy to use	0,199	<b>0,698</b>	-0,053	0,013	0,038
By using eHealth, I will increase the extent to which I am valued (e.g., I am able to get a targeted training, I could become an eHealth ambassador in my organization)†	0,227	<b>0,610</b>	0,064	-0,369	-0,160
Learning to operate an eHealth tool is easy for me	0,087	<b>0,533</b>	0,011	0,068	0,105
I have sufficient time to make eHealth my own*	-0,040	<b>0,533</b>	0,161	0,195	0,198
Colleagues who influence my behavior think that I should use eHealth	-0,068	-0,051	<b>0,980</b>	-0,034	-0,038
Colleagues who are important to me think that I should use eHealth	0,000	-0,095	<b>0,972</b>	-0,021	0,006
The senior management of my care organization has been helpful in the use of eHealth	0,125	0,222	<b>0,430</b>	0,395	0,046
There is a specific person (or group) available for assistance with eHealth difficulties	0,140	0,037	-0,007	<b>0,798</b>	-0,045
In general, the organization has supported the use of eHealth	0,293	0,095	0,063	<b>0,727</b>	0,010
I have the resources necessary to use eHealth	-0,062	0,298	0,056	<b>0,613</b>	0,083
My client has the facilities (e.g., computer, laptop, smartphone, internet access) necessary to use eHealth*	0,025	0,073	-0,030	-0,092	<b>0,902</b>
My client has the necessary digital literacy to use eHealth*	0,069	0,006	0,009	-0,075	<b>0,901</b>

Note: \* added items by focus group consultation. Factor loadings in bold represent the final items related to their own factor.

† original UTAUT item adapted for cross-cultural reasons; one item with factor loading <.40 deleted

### 3.3. Descriptive analysis

Tables 3a and 3b present the descriptive statistics and correlations of the five factors in the extended UTAUT model, derived from both datasets. Mean scores were calculated for each factor to assess the acceptance of eHealth among support staff and therapists. Acceptance scores were categorized as low (1–2.34), moderate (2.35–3.67), or high (3.68–5), following the acceptance study by Henneman et al. (2017). In both the 2018 and 2021 datasets, the mean scores for all five factors were found to be moderate. For more detailed information, reference is made to Tables 3a and 3b. Item means and standard deviations scores can be found in Appendix 1. Additionally, participants in 2021 expressed agreement that the Covid-19 pandemic had resulted in increased eHealth usage ( $M = 3.85$ ;  $SD = 1.008$ ). They also indicated that their utilization of eHealth changed due to the pandemic ( $M = 3.58$ ;  $SD = 1.054$ ) and that it had influenced their opinion about eHealth ( $M = 3.58$ ;  $SD = 1.008$ ).

**Table 3a.** Means and standardized deviations of factors and inter-correlations, 2018 dataset

Factor	<i>M (SD)</i>	1	2	3	4	5
1. Perceived added value	3.46 (.606)					
2. Convenience and self-confidence	3.18 (.627)	,654**				
3. Social pressure from colleagues and support from manager	2.64 (.811)	,320**	,355**			
4. Organizational support	3.41 (.824)	,264**	,503**	,352**		
5. Facilitating conditions of client with intellectual disabilities	2.84 (.898)	,187**	,354**	,181**	,310**	
Behavioral intention	3.66 (.883)	,436**	,548**	,298**	,581**	,400**

Note: \*\* Correlation is significant at the 0.01 level (2-tailed)

\* Correlation is significant at the 0.05 level (2-tailed)

**Table 3b.** Means and standardized deviations of factors and inter-correlations, 2021 dataset

Factor	<i>M (SD)</i>	1	2	3	4	5
1. Perceived added value	3.44 (.580)					
2. Convenience and self-confidence	3.18 (.591)	,653**				
3. Social pressure from colleagues and support from manager	2.57 (.797)	,260**	,369**			
4. Organizational support	3.27 (.845)	,341**	,585**	,403**		
5. Facilitating conditions of client with intellectual disabilities	2.63 (.885)	,329**	,398**	,283**	,281**	
Behavioral intention	3.71 (.872)	,558**	,508**	,314**	,511**	,312**

Note: \*\* Correlation is significant at the 0.01 level (2-tailed)

\* Correlation is significant at the 0.05 level (2-tailed)



Regarding the moderator experience, participants in both 2018 and 2021 reported high levels with mean scores of 3.79 ( $SD = 0.67$ ) and 3.73 ( $SD = 0.70$ ), respectively. Table 4 presents the descriptive statistics for familiarity and actual usage of different eHealth tools. In 2018, support staff and therapists were most familiar with apps and virtual reality; 73% of participants reported using apps, 37% reported using video modelling. Both apps and video modelling were primarily used in support and therapy for over a year.

In 2021, the majority of participants was familiar with videoconferencing, apps, and virtual reality. Specifically, 73% of participants reported using apps, 69% reported using videoconferencing, and 64% reported using video modelling. It is worth noting that the adoption of videoconferencing may have been more recent, potentially influenced by the ongoing Covid-19 pandemic during the data collection period.

### 3.4. Multiple regression analysis

A multiple regression analysis was conducted to examine the effect of the five factors on behavioral intention. In 2018, the combined influence of the five factors significantly predicted behavioral intention ( $R^2 = .47$ ;  $F(5, 305) = 54,89$ ,  $p < .001$ ). Four factors had individual significant effects on behavioral intention: Factor 1 ( $\beta = 0.19$ ;  $t = 3.46$ ;  $p = .001$ ), Factor 2 ( $\beta = 0.16$ ;  $t = 2.46$ ;  $p = .015$ ), Factor 4 ( $\beta = 0.39$ ;  $t = 7.78$ ;  $p < .001$ ), and Factor 5 ( $\beta = 0.19$ ;  $t = 4.13$ ;  $p < .001$ ). However, Factor 3 did not show a significant effect on behavioral intention ( $\beta = 0.01$ ;  $t = 0.215$ ;  $p = .830$ ).

In 2021, the combined influence of the five factors also predicted behavioral intention significantly ( $R^2 = 0.43$ ;  $F(5, 320) = 49,32$ ,  $p < .001$ ). Two factors had individual significant effects on behavioral intention: Factor 1 ( $\beta = 0.41$ ;  $t = 7.28$ ;  $p < .001$ ) and Factor 4 ( $\beta = 0.33$ ;  $t = 6.15$ ;  $p < .001$ ). Factor 2 ( $\beta = 0.001$ ;  $t = 0.019$ ;  $p = .985$ ), Factor 3 ( $\beta = 0.06$ ;  $t = 1.160$ ;  $p = .247$ ), and Factor 5 ( $\beta = 0.07$ ;  $t = 1,49$ ;  $p = .135$ ) had no significant effect on behavioral intention.

**Table 4.** Familiarity and actual use of 6 eHealth applications of participants in 2018 and 2021

Application	2018 (N=311)	2021 (N=326)
	n (%)	n (%)
<b>Apps</b>		
Familiarity	292 (93.9%)	291 (91.1%)
Actual use	213 (72.9%)	216 (72.7%)
Use since (< 1 yr <sup>1</sup> )	76	54
Use since (> 1 yr)	137	161
Use frequency (< 1/p wk <sup>2,3</sup> )	61	60
Use frequency (≥ 1/p wk <sup>4</sup> )	152	156
<b>Videoconferencing</b>		
Familiarity	145 (46.6%)	315 (96%)
Actual use	57 (39.3%)	218 (69.2%)
Use since (< 1 yr)	30	76
Use since (> 1 yr)	27	142*
Use frequency (< 1/p wk)	27	106
Use frequency (≥ 1/p wk)	30	112
<b>Online platform</b>		
Familiarity	201 (64.6%)	126 (38.7%)
Actual use	116 (57.7%)	49 (38.9%)
Use since (< 1 yr)	69	14
Use since (> 1 yr)	47	35
Use frequency (< 1/p wk)	51	28
Use frequency (≥ 1/p wk)	65	21
<b>Virtual reality</b>		
Familiarity	222 (71.6%)	221 (67.8%)
Actual use	19 (8.6%)	15 (6.8%)
Use since (< 1 yr)	11	6
Use since (> 1 yr)	8	9
Use frequency (< 1/p wk)	16	12
Use frequency (≥ 1/p wk)	3	3
<b>Serious Gaming</b>		
Familiarity	53 (17%)	49 (15%)
Actual use	4 (7.5%)	7 (14.3%)
Use since (< 1 yr)	2	2
Use since (> 1 yr)	2	5
Use frequency (< 1/p wk)	3	6
Use frequency (≥ 1/p wk)	1	1
<b>Video modeling</b>		
Familiarity	174 (55.9%)	197 (60.4%)
Actual use	65 (37.4%)	126 (64%)
Use since (< 1 yr)	26	42
Use since (> 1 yr)	39	82
Use frequency (< 1/p wk)	57	90
Use frequency (≥ 1/p wk)	8	36

Note: <sup>1</sup>yr = year, <sup>2</sup>wk = week, <sup>3</sup>< 1/p wk = once a month and incidental use added, <sup>4</sup> ≥ 1/p wk = daily, 2-3 times and once a week added

\* 2 missing values

### 3.5. Moderator analyses

Finally, we conducted moderation analyses to examine the potential moderating effects of age, gender, experience, voluntariness, and technical alliance on the relationship between the individual UTAUT factors and behavioral intention. Only the significant moderating effects are reported here; detailed results for all moderation analyses in the datasets of 2018 and 2021 datasets can be found in Appendix 2.

In the 2018 dataset, several significant moderating effects were observed. First, age was found to moderate the relationship between Factor 1 and behavioral intention negatively for the 40-49 age group ( $B = -.357, p < 0.05$ ). This suggests that this age group was not as motivated to engage in the intended behavior when perceiving less added value. Second, for the same age group the relationship between Factor 4 and behavioral intention was again negatively moderated ( $B = -.273, p = 0.031$ ), indicating that they perceived less organizational support for their intended behavior. Third, age also significantly moderated the relationship between Factor 3 and behavioral intention – that is, a negative relationship was found for the 30-39 age group ( $B = -.281, p = 0.024$ ), while a positive relationship was observed for the 50 and over age group ( $B = .332, p = 0.036$ ). This suggests that the intended behavior of younger professionals (30-39) was less influenced by colleagues and their manager, whereas for professionals of 50 and over the opposite held true.

Experience as a moderator had a negative effect on the relationship between Factor 4 and behavioral intention ( $B = -.167, p = 0.028$ ), indicating that those with more experience may be less motivated to engage in the intended behavior when perceiving less organizational support. Last, voluntariness as a moderator had a negative effect on the relationship between Factor 5 and behavioral intention ( $B = -.327, p = 0.004$ ). This suggests that when the intended behavior is perceived as voluntary, the presence of facilitating conditions for people with an intellectual disability may not be sufficient to motivate individuals to engage in the behavior.

In the 2021 dataset, gender was found to have a positive moderating effect on the relationship between Factor 2 and behavioral intention ( $B = .376, p = .038$ ), indicating that men felt more convenience, self-confidence, and organizational support to engage in the intended behavior. Gender also has a positive moderating effect on the relationship between Factor 4 and behavioral intention ( $B = .341, p = .022$ ), suggesting that men perceived more organizational support for their intended behavior. Moderator voluntariness had a negative effect on the relationship between Factor 3 and behavioral intention ( $B = -.277, p = 0.018$ ). Voluntariness also negatively moderated the relationship between Factor 4 and behavioral intention ( $B = -.382; p < .001$ ) as well between Factor 5 and behavioral intention ( $B = -.404; p < .001$ ). These findings indicate that those who

perceived the intended behavior as voluntary were less influenced by pressure from colleagues, support from their manager or the organization, or digital facilitating conditions for people with an intellectual disability. Technical alliance moderated the relationship between Factor 5 and behavioral intention positively ( $B = .157, p = 0.048$ ). This suggests that when there is a higher level of technical alliance among support staff and therapists, the facilitating conditions for people with mild intellectual disabilities are perceived to be more effective in promoting behavioral intention.

## 4. Discussion

This study aimed to assess the applicability of the UTAUT model in understanding healthcare professionals' acceptance and intention to use eHealth for support and psychological therapy among people with an intellectual disability. Additionally, it explored the level of acceptance and utilization of eHealth among support staff and therapists providing support and psychological therapy for people with an intellectual disability, and whether the acceptance and usage changed during the Covid-19 pandemic.

With respect to the first research question (applicability of UTAUT model), a questionnaire based on the UTAUT model was adapted and extended for healthcare professionals working with people with an intellectual disability. However, based on this questionnaire neither the original UTAUT model nor the extended UTAUT model yielded satisfactory model fit results according to the CFA. Therefore, an EFA was conducted to explore the underlying latent factors for the extended model, resulting in a five-factor model demonstrating acceptable-to-good internal consistency. This extended model served as the reference for further analysis on the acceptance of eHealth among support staff and therapists in two cross-sectional online survey studies in 2018 and 2021. The five-factor model, which determined acceptance, accounted for 43–47% of the variance in the intention to use eHealth. This is in line with the findings of the UTAUT-T (Békés et al., 2022), showing that the five UTAUT-T subscales (Therapy quality expectancy, Pressure from others, Professional support, Ease of use, and Convenience) collectively predicted 42% of the average behavioral intention.

Other studies applying the UTAUT model to investigate acceptance among healthcare professionals working with general patient/client populations found varied explained variance in intended behavior percentages, ranging from 31% to 78% (Harst et al., 2019). This led to the conclusion that the extended UTAUT model partially applies to understanding the acceptance and intention to use eHealth of support staff and therapists working with people with an intellectual disability. The factor "Facilitating

conditions of clients”, which was included in the present study based on advice of the expert group, was confirmed in factor analysis as a relevant factor for acceptance. Notably, this unique factor was not present in previous healthcare context studies examining the UTAUT model or recommended for inclusion in future studies (e.g., Békés et al., 2022; Henneman et al., 2017; Philippi et al., 2021). Further, confirmatory factor analysis is needed to examine the extended UTAUT model among a larger group of healthcare professionals working with people with an intellectual disability, in order to establish the generalizability and robustness of the extended UTAUT model’s findings.

While the extended UTAUT model partially applies to eHealth acceptance and intention among support staff and therapists working with individuals with an intellectual disability, there are still unknown factors influencing their intentions to use eHealth. A possible reason for this knowledge gap is that the UTAUT model primarily focuses on individual user perspectives at specific moments, overlooking contextual factors that affect eHealth implementation and the roles of healthcare professionals (Li et al., 2013; Vis et al., 2018). This one-sided perspective of the UTAUT model might not align well with multilateral contexts within healthcare organizations, which significantly influence healthcare professionals’ behavior (Heinsch et al., 2021; Sovacool & Hess, 2017).

With regard to the second research question (level of acceptance and utilization of eHealth), the present study found that support staff and therapists demonstrated moderate acceptance, determined by five influencing factors. Notably, the perceived added value of eHealth and organizational support emerged as the primary drivers for acceptance, consistent with prior research (Connolly et al., 2018; Harst et al., 2019). Interestingly, participants in our study did not experience significant social pressure from colleagues to adopt eHealth, aligning with findings in rehabilitation care (Liu et al., 2015), primary mental healthcare (Van der Vaart et al., 2016) and psychotherapy (Baumeister et al., 2020). Instead, their willingness to use eHealth appeared to be more dependent on perceived benefits for their clients (Ramsten & Blomberg, 2019; Vereenoghe et al., 2017). However, in the current study participants did express concerns regarding the facilitating conditions for clients, such as access to proper equipment and digital skills required to benefit from eHealth interventions, a sentiment echoed in several studies (e.g., Barlott et al., 2020; Selick et al. 2022). Moreover, the study’s moderator analysis revealed that participants aged 40-49, as well as those who viewed the use eHealth as voluntary, displayed a negative influence on their intention to adopt eHealth. Chiu et al. (2015) states that factors influencing eHealth use might differ in healthcare organizations with mandatory or voluntary use policies. The role of age in eHealth adoption has been studied, but findings have not been consistent (e.g., Connolly et al., 2020; Dwivedi et al., 2019).

With regard to eHealth utilization, participants in 2018 showed a preference for using apps and video modelling most frequently. In 2021 this trend continued, with apps and video modelling remaining the most commonly used eHealth tools. Notably, video modelling saw a more substantial increase in usage compared to 2018; telecare, particularly video conferencing technology, experienced a significant surge in adoption in 2021, likely attributable to the impact of the Covid-19 pandemic. However, the adoption of more innovative eHealth tools like virtual reality and serious gaming remains limited in clinical practice. The findings align with observations in other care domains, such as mental healthcare, where video conferencing also increased during the pandemic but innovative tools continued to be underutilized (e.g., Feijt et al., 2023).

Despite the differences in participant groups and contexts between the two surveys (2018 and 2021) due to their cross-sectional designs and the impact of the pandemic, the results pertaining to acceptance factors were found to be comparable. Participants in 2021 acknowledged that the pandemic significantly influenced their views on eHealth, as indicated by the additional Covid-19 questions. Contrary to our expectations, this influence did not lead to a distinct acceptance profile based on the extended UTAUT model. The similarity in acceptance profiles observed in both survey years might be explained by several factors. First, the significant increase in videoconferencing in 2021 may have played a role. Studies show that videoconferencing can serve as a viable alternative to in-person services without negatively affecting acceptance (Parisi et al., 2021). Due to restrictive measures, out-reach support staff and therapists had to adapt to virtual work, with videoconferencing proving to be a time-efficient alternative (Vromans et al., 2023). However, the main group of participants in the present study consisted of residential support staff, who were less obligated to shift from face-to-face support to virtual support, potentially influencing acceptance scores. Lastly, over time the surveyed support staff and therapists may have become more accustomed to videoconferencing since a year after the start of the pandemic, which could explain the consistent acceptance profile. In previous studies, findings on the impact of the Covid-19 pandemic on eHealth acceptance among healthcare professionals described some healthcare professionals reporting negative experiences, as well as others who felt surprised about the opportunities (Békés & Aafjes-van Doorn, 2020; Békés et al., 2021; Staeck et al., 2022). In this study, despite the pandemic's influence, the acceptance profile remained comparable between the two survey years.

Knowledge about eHealth is necessary for acceptance, but insufficient for actual usage (e.g., Ross et al., 2016). Factors like training, integrating eHealth into education, workflow, and organizational culture improve acceptance (Connolly et al., 2020; Staeck et al., 2022). In our study, support staff and therapists lacked eHealth training, even during the pandemic. Accessible training methods, such as short videos demonstrating benefits,

have proven effective (Baumeister et al., 2020). However, research on eHealth acceptance and training needs of professionals working with people with an intellectual disability is lacking. Conducting such research is crucial to adequately prepare professionals for effective eHealth utilization, enhancing the quality of care for this population.

## 4.2. Strengths and limitations

The UTAUT model primarily focuses on the individual perspective of eHealth acceptance and usage, but these processes are complex and involve various factors (Heinsch et al., 2021). In our study, we expanded the analysis to include organizational aspects like eHealth policy and training provided by care organizations. To gain a comprehensive understanding, future research should consider perspectives from people with an intellectual disability and their relatives. Collaboration with professionals working with mild intellectual disabilities during survey development was a notable strength of the present study.

Although we carefully translated UTAUT statements into Dutch, some items might not have accurately reflected participants' clinical practice or their perception of "eHealth", possibly impacting the model's explained variance. Nevertheless, our study's strengths include covering familiar eHealth tools and various working domains (community care, long-term care), representing a broad spectrum of professional care.

A potential limitation is self-selection bias, as those interested in eHealth and adept at online surveys might have been more likely to participate. Caution is needed when interpreting findings, avoiding automatic generalization to all support staff and therapists working with individuals with an intellectual disability.

## 4.3. Conclusion

In conclusion, the extended UTAUT model is partially applicable to understanding the acceptance and intention to use eHealth among healthcare professionals working with people with an intellectual disability. Future research is needed to fully understand what additional factors determine healthcare professionals' acceptance and eHealth use among clients with an intellectual disability. The level of acceptance was moderate, with perceived added value of using eHealth among clients with an intellectual disability and organizational support as the most relevant determinants of acceptance. This study provides valuable insights into the acceptance of eHealth among support staff and therapists in healthcare organizations for people with an intellectual disability, as they play a crucial role in supporting and motivating clients to embrace eHealth, making their acceptance relevant for the success of healthcare innovations (Connolly et al., 2020).

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**Appendix 1.** Mean and standard deviations for factors and items participants 2018 and 2021

	2018 (N=311)	2021 (N=326)
<b>Experienced added value (n=7 items)</b>	M=3.46 (SD=.606) α=.78	M=3.44 (SD=.580) α=.75
Using eHealth facilitates working together with my client to reach their goals	M=3.53 (SD=.806)	M=3.22 (SD=.846) <sup>†</sup>
The use of eHealth supports the provision of support/therapy more effectively	M=3.35 (SD=.820)	M=3.28 (SD=.788) <sup>†</sup>
eHealth enables collaboration with other persons involved in the client's formal and informal network	M=3.61 (SD=.811)	M=3.74 (SD=.830) <sup>†</sup>
I find eHealth useful for my work	M=3.77 (SD=.848)	M=3.82 (SD=.804) <sup>††</sup>
It would be easy for me to become skillful at using eHealth	M=3.74 (SD=.865)	M=3.66 (SD=.921) <sup>†</sup>
Using eHealth increases my productivity	M=3.11 (SD=.834)	M=3.19 (SD=.829) <sup>††</sup>
Using eHealth enables me to accomplish tasks more quickly	M=3.13 (SD=.844)	M=3.23 (SD=.839) <sup>†</sup>
<b>Convenience and self-confidence (n=6 items)</b>	M=3.18 (SD=.627) α=.79	M=3.18 (SD=.591) α=.77
I clearly understand how to use eHealth as a part of the support and/or therapy I provide	M=3.20 (SD=.950)	M=3.22 (SD=.918) <sup>†</sup>
I have the knowledge necessary to use eHealth	M=3.01 (SD=1.035)	M=3.09 (SD=.999) <sup>†††</sup>
I find eHealth easy to use	M=3.20 (SD=.947)	M=3.27 (SD=.851) <sup>†</sup>
By using eHealth, I will increase the extent to which I am valued (e.g., I am able to get a targeted training, I could become an eHealth ambassador in my organization) <sup>†</sup>	M=2.95 (SD=.923)	M=2.83 (SD=.975) <sup>†</sup>
Learning to operate an eHealth tool is easy for me	M=3.53 (SD=.879)	M=3.58 (SD=.918) <sup>†</sup>
I have sufficient time to make eHealth my own	M=2.63 (SD=.955) <sup>††</sup>	M=2.67 (SD=.965)
<b>Social pressure and support from colleagues and support from manager (n=3 items)</b>	M=2.64 (SD=.811) α=.76	M=2.57 (SD=.797) α=.79
Colleagues who influence my behavior think that I should use eHealth	M=2.40 (SD=.929) <sup>†</sup>	M=2.38 (SD=.918) <sup>†</sup>
Colleagues who are important to me think that I should use eHealth	M=2.47 (SD=.951) <sup>†</sup>	M=2.45 (SD=.979) <sup>††</sup>
The senior management of my care organization has been helpful in the use of Health	M=3.04 (SD=.991)	M=2.90 (SD=.990) <sup>†</sup>
<b>Organizational support (n=3 items)</b>	M=3.41 (SD=.824) α=.78	M=3.27 (SD=.845) α=.79
There is a specific person (or group) available for assistance with eHealth difficulties	M=3.41 (SD=1.075) <sup>†</sup>	M=3.10 (SD=1.093) <sup>†††</sup>
In general, the organization has supported the use of eHealth	M=3.65 (SD=.907)	M=3.55 (SD=.887) <sup>††</sup>
I have the resources necessary to use eHealth	M=3.17 (SD=1.011)	M=3.17 (SD=1.029) <sup>††</sup>
<b>Facilitating conditions of client with ID (devices and digital skills) (n=2 items)</b>	M=2.84 (SD=.898) α=.78	M=2.63 (SD=.885) α=.70
My client has the facilities (e.g., computer, laptop, smartphone, internet access) necessary to use eHealth	M=3.07 (SD=1.034)	M=2.82 (SD=1.030) <sup>†</sup>
My client has the necessary digital literacy to use eHealth	M=2.63 (SD=.955)	M=2.45 (SD=.983) <sup>††</sup>

Note. <sup>†</sup> 1 missing value; <sup>††</sup> 2 missing values; <sup>†††</sup> 3 missing values

**Appendix 2. Results of moderator analysis of data 2018 and 2021**

<b>2018</b>						
<b>Moderator Gender on relationship Factors-&gt;BI</b>						
	B	SE	Beta	t	Sig	
IntF1_Geslacht	-0,151	0,211	-0,040	-0,717	0,474	
IntF2_Geslacht	-0,328	0,211	-0,079	-1,556	0,121	
IntF3_Geslacht	-0,185	0,173	-0,063	-1,073	0,284	
IntF4_Geslacht	-0,333	0,175	-0,092	-1,908	0,057	
IntF5_Geslacht	-0,274	0,164	-0,093	-1,665	0,097	
<b>Dummy = Male</b>						
<b>Moderator Experience on relationship Factors-&gt; BI</b>						
	B	SE	Beta	t	Sig	
IntF1_CompGeb	-0,072	0,100	-0,036	-0,721	0,471	
IntF2_CompGeb	-0,078	0,086	-0,043	-0,906	0,365	
IntF3_CompGeb	-0,118	0,090	-0,068	-1,318	0,188	
IntF4_CompGeb	-0,167	0,076	-0,099	-2,211	0,028	p <.05
IntF5_CompGeb	-0,046	0,071	-0,032	-0,646	0,519	
<b>Moderator Voluntariness on relationship Factors-&gt; BI</b>						
	B	SE	Beta	t	Sig	
IntF1_Vrijblijv	-0,052	0,160	-0,030	-0,327	0,744	
IntF2_Vrijblijv	0,014	0,143	0,008	0,098	0,922	
IntF3_Vrijblijv	-0,236	0,133	-0,185	-1,773	0,077	
IntF4_Vrijblijv	-0,106	0,106	-0,081	-1,001	0,318	
IntF5_Vrijblijv	-0,327	0,113	-0,282	-2,895	0,004	p<.01
<b>Dummy = Voluntariness</b>						
<b>Moderator Age ranges on relationship Factors-&gt; BI 2018</b>						
<b>Age group &lt; 30</b>						
	B	SE	Beta	t	Sig	
IntF1_LeeftijdCatJongerdan30	0,332	0,175	0,111	1,891	0,060	
IntF2_LeeftijdCatJongerdan30	0,218	0,156	0,076	1,400	0,163	
IntF3_LeeftijdCatJongerdan30	0,231	0,148	0,096	1,563	0,119	
IntF4_LeeftijdCatJongerdan30	0,176	0,120	0,077	1,465	0,144	
IntF5_LeeftijdCatJongerdan30	0,327	0,129	0,146	2,540	0,012	p <.05
<b>Age group 30-39</b>						
	B	SE	Beta	t	Sig	
IntF1_LeeftijdCat30_39	0,020	0,162	0,008	0,122	0,903	
IntF2_LeeftijdCat30_39	-0,179	0,141	-0,076	-1,272	0,204	
IntF3_LeeftijdCat30_39	-0,281	0,124	-0,153	-2,271	0,024	p <.05
IntF4_LeeftijdCat30_39	-0,127	0,103	-0,073	-1,241	0,215	
IntF5_LeeftijdCat30_39	-0,047	0,109	-0,028	-0,436	0,663	
<b>Age group 40-49</b>						
	B	SE	Beta	t	Sig	
IntF1_LeeftijdCat40_49	-0,357	0,168	-0,126	-2,122	0,035	p <.05
IntF2_LeeftijdCat40_49	-0,226	0,172	-0,069	-1,312	0,190	
IntF3_LeeftijdCat40_49	-0,102	0,135	-0,048	-0,752	0,453	
IntF4_LeeftijdCat40_49	-0,273	0,126	-0,111	-2,167	0,031	p <.05
IntF5_LeeftijdCat40_49	-0,282	0,129	-0,127	-2,185	0,030	p <.05

**Appendix 2. Continued****Age group > 50**

	B	SE	Beta	t	Sig	
IntF1_ LeeftijdCat50enouder	0,033	0,193	0,010	0,169	0,866	
IntF2_ LeeftijdCat50enouder	0,216	0,164	0,071	1,319	0,188	
IntF3_ LeeftijdCat50enouder	0,332	0,157	0,129	2,109	0,036	p <.05
IntF4_ LeeftijdCat50enouder	0,225	0,120	0,098	1,873	0,062	
IntF5_ LeeftijdCat50enouder	-0,007	0,116	-0,004	-0,061	0,951	

**2021****Moderator Gender on relationship Factors->BI**

	B	SE	Beta	t	Sig	
IntF1_ Geslacht	0,239	0,164	0,077	1,460	0,145	
IntF2_ Geslacht	0,376	0,181	0,112	2,080	0,038	p <.05
IntF3_ Geslacht	0,066	0,172	0,022	0,384	0,701	
IntF4_ Geslacht	0,341	0,149	0,120	2,293	0,022	p <.05
IntF5_ Geslacht	0,173	0,152	0,067	1,135	0,257	

**Dummy = Male****Moderator Experience on relationship Factors-> BI**

	B	SE	Beta	t	Sig	
IntF1_ CompGeb	0,099	0,081	0,059	1,219	0,224	
IntF2_ CompGeb	0,097	0,088	0,056	1,095	0,274	
IntF3_ CompGeb	-0,022	0,075	-0,016	-0,299	0,765	
IntF4_ CompGeb	0,079	0,061	0,062	1,291	0,198	
IntF5_ CompGeb	0,050	0,068	0,040	0,737	0,461	

**Moderator Voluntariness on relationship Factors-> BI**

	B	SE	Beta	t	Sig	
IntF1_ Vrijblijv	-0,034	0,139	-0,017	-0,243	0,808	
IntF2_ Vrijblijv	-0,212	0,137	-0,104	-1,550	0,122	
IntF3_ Vrijblijv	-0,277	0,116	-0,200	-2,387	0,018	p <.05
IntF4_ Vrijblijv	-0,382	0,097	-0,289	-3,930	0,000	p <.001
IntF5_ Vrijblijv	-0,404	0,103	-0,321	-3,908	0,000	p <.001

**Dummy = Voluntariness****Moderator Age ranges on relationship Factors-> BI 2021****Age group < 30**

	B	SE	Beta	t	Sig	
IntF1_ LeeftijdCatJongerdan30	0,171	0,174	0,051	0,984	0,326	
IntF2_ LeeftijdCatJongerdan30	0,020	0,163	0,007	0,122	0,903	
IntF3_ LeeftijdCatJongerdan30	-0,022	0,143	-0,009	-0,151	0,880	
IntF4_ LeeftijdCatJongerdan30	0,043	0,121	0,019	0,357	0,721	
IntF5_ LeeftijdCatJongerdan30	-0,146	0,132	-0,065	-1,106	0,270	

**Age group 30-39**

	B	SE	Beta	t	Sig	
IntF1_ LeeftijdCat30_39	-0,034	0,144	-0,014	-0,239	0,811	
IntF2_ LeeftijdCat30_39	0,119	0,151	0,046	0,788	0,431	
IntF3_ LeeftijdCat30_39	0,110	0,120	0,061	0,920	0,358	
IntF4_ LeeftijdCat30_39	0,086	0,106	0,047	0,806	0,421	
IntF5_ LeeftijdCat30_39	0,146	0,111	0,085	1,317	0,189	

**Appendix 2. Continued**

<b>Age group 40-49</b>						
	B	SE	Beta	t	Sig	
IntF1_LeeftijdCat40_49	0,006	0,158	0,002	0,041	0,967	
IntF2_LeeftijdCat40_49	0,041	0,174	0,013	0,237	0,813	
IntF3_LeeftijdCat40_49	0,112	0,138	0,048	0,806	0,421	
IntF4_LeeftijdCat40_49	-0,072	0,116	-0,035	-0,623	0,534	
IntF5_LeeftijdCat40_49	-0,033	0,123	-0,016	-0,271	0,786	
<b>Age group &gt; 50</b>						
	B	SE	Beta	t	Sig	
IntF1_LeeftijdCat50enouder	-0,141	0,181	-0,040	-0,777	0,438	
IntF2_LeeftijdCat50enouder	-0,185	0,173	-0,057	-1,068	0,286	
IntF3_LeeftijdCat50enouder	-0,259	0,144	-0,106	-1,803	0,072	
IntF4_LeeftijdCat50enouder	-0,077	0,122	-0,034	-0,629	0,530	
IntF5_LeeftijdCat50enouder	0,017	0,123	0,008	0,138	0,890	
<b>2021</b>						
<b>Moderator TAI MID on relationship Factors-&gt;BI</b>						
	B	SE	Beta	t	Sig	
IntF1_TAIhoog	0,160	0,121	0,103	1,326	0,187	
IntF2_TAIhoog	0,084	0,116	0,056	0,727	0,469	
IntF3_TAIhoog	0,084	0,116	0,056	0,727	0,469	
IntF4_TAIhoog	0,118	0,086	0,103	1,368	0,174	
IntF5_TAIhoog	0,157	0,079	0,150	1,993	0,048	p <.05

Note. Results of moderator analysis with interaction between acceptance factors and behavioural intentions. All moderators belonging to the UTAUT model were tested. Moderator age was separated in four age groups: < 30, 30-39, 40-49, and > 50.





# CHAPTER 8



# General Discussion



Care organizations that support people with intellectual disabilities are increasingly utilizing eHealth technologies, such as domotics, electronic health records, apps and telecare (VGN, 2021; De Wit et al., 2015; Perry et al., 2012; Vereenooghe et al., 2017; Zaagsma et al., 2020). However, despite eHealth's growing prevalence, there is limited evidence and understanding of how it is practically applied within this field and of its effectiveness. This gap is particularly evident in areas such as support across various life domains and psychological treatment for people with intellectual disabilities (Sheehan & Hassiotis, 2017). While several studies highlight the potential of technology to enhance empowerment and autonomy of people with intellectual disabilities, care organizations remain uncertain about its value and appropriateness for addressing this population's unique needs (VGN, 2021). This uncertainty is due to a lack of research on the impact of eHealth on support and psychological interventions. Understanding the factors that influence stakeholders' intentions to use eHealth is crucial (Greenhalgh et al., 2017). Therefore, insights from service users, relatives, and healthcare professionals on the appropriateness, feasibility, and suitability of eHealth are vital (Ramsten et al., 2019; Wennberg & Kjellberg, 2010).

This thesis explores the perspectives on eHealth of people with intellectual disabilities, their relatives, and healthcare professionals, with a particular emphasis on the acceptance and integration of eHealth by support staff and therapists, who play a crucial role in motivating and supporting these people. Despite the recognized importance of healthcare professionals in providing ongoing support to people with intellectual disabilities (Giesbers et al., 2020; Van Asselt-Goverts, 2013), concerns about safety, inadequate training, and conflicting interests often impede the adoption of eHealth in care practices (Parsons et al., 2008; Clifford Simpican et al., 2017). Research that specifically addresses the acceptance of eHealth by healthcare professionals in this field is scarce. This PhD project, which is comprised of six studies, contributes to the existing body of knowledge by examining the use of eHealth in daily support and psychological interventions. All studies focussed on people with mild intellectual disabilities or healthcare professionals working with them, with one study (*Chapter 3*) also targeting people with more severe intellectual disabilities. It delves into how healthcare professionals perceive their role in facilitating the meaningful use of eHealth and assesses the long-term alliances formed between service users and healthcare professionals. To evaluate the impact of eHealth on these alliances, two existing measures of working alliances were adapted to investigate both the digital and technical aspects from the perspectives of support staff and therapists. This final chapter presents a reflection on the main findings, discusses the limitations and strengths of the research, and offers recommendations for future research, policy, and practice, concluding with a summary of the key contributions to the field.

## Summary of the main findings

### **eHealth for support and psychological interventions: literature review studies**

Chapters 2 and 3 of this thesis present an overview of existing research on the use of eHealth to support people with intellectual disabilities and its involvement in psychological interventions for those facing mental health challenging (e.g. anxiety, depression) or exhibiting challenging behaviour (e.g. aggression, self-injurious, stereotyped behaviour). More specifically, Chapter 2 comprises a systematic review that explores the use of eHealth to support people with mild intellectual disabilities in their daily lives. Employing the Matching Person to Technology (MPT) model (Scherer et al., 2005), this review focussed on three key areas that contribute to successful eHealth use: the characteristics of people with mild intellectual disabilities, environmental factors and the features of eHealth applications. The review found limited attention has been paid to systematically assessing the needs, preferences expectations and digital skills of people with mild intellectual disabilities regarding the use of eHealth. Three key applications of eHealth were identified: using eHealth to learn practical skills; enabling self-support by providing real-time information for specific activities; and enabling healthcare professionals to provide remote practical or emotional support. These applications supported skill development, potentially enhancing independence and societal participation. Various technologies facilitated progress monitoring, prompting tasks, providing real-time context-specific information, ensuring safe skill learning, and enabling remote contact with healthcare professionals.

Chapter 3 presents an overview of psychological eHealth interventions for people with intellectual disabilities who deal with mental health problems or challenging behaviours. The review outlines the features, target demographics, intervention deliverers and content of these interventions. It shows that the majority of eHealth interventions were delivered individually to people from a wide age group with various levels of intellectual disabilities and a few targeted parent-child dyads or practiced skills learned in group interventions. A mix of healthcare professionals and non-professionals delivered the interventions in the daily living environments that reflected their primary context. Challenging behaviours and anxiety disorders were the primary reasons for eHealth interventions, and some addressed a combination of mood disorders and self-injurious behaviours. Behavioural analysis and therapeutic approaches were commonly used theoretical frameworks within eHealth interventions, supplemented by cognitive behavioural therapy, circle of security (which is attachment theory-based), mindfulness and two practice-based interventions tailored for people with intellectual disabilities.

## Stakeholders' views on eHealth in care practice

To gain a better understanding of the perspectives on eHealth of service users, relatives, and healthcare professionals (i.e. support staff and therapists), we explored their views on using eHealth in support and therapy.

Chapter 4 explored the perspectives of service users, relatives, and healthcare professionals on the advantages and disadvantages of eHealth, and what facilitated and hindered eHealth use in care practice. All participants assumed that eHealth provided people with intellectual disabilities more control over their personal lives and enhanced mutual communication opportunities. Further, service users and healthcare professionals mentioned increased independence as a benefit. At last, improved and effective care was mentioned by relatives and healthcare professionals, especially focussed on personal information in health records and opportunities to exchange information. Participants mentioned eHealth could not replace in-person contact, and they emphasized that careful consideration of what type of contact (i.e. face-to-face vs. digital contact) is necessary for providing adequate support, ensuring emotional connection, and addressing the specific needs of people with intellectual disabilities. Furthermore, participants mentioned the privacy and safety risks of eHealth and difficulties due to digital literacy as negative consequences of eHealth.

During the COVID-19 pandemic lockdowns, healthcare professionals and people with mild intellectual disabilities faced an unprecedented situation. Chapter 5 described the experiences of therapists who performed psychological assessments and therapies during the first lockdown period of the pandemic. Prohibitions on in-person contact, mandated by care organizations in accordance with government policies, led therapists transitioning to virtual meetings using videoconferencing technology. This shift required the acquisition of new skills, such as coaching service users to activate links and navigate a video conferencing application. Amidst this somewhat surreal period, therapists had to find creative virtual means to help service users and loved ones cope with stress and anxiety. Therapists reported challenges, including dealing with assumptions about online therapy, especially since they had no prior training on how to work remotely with people with mild intellectual disabilities in stressful situations. Difficulties associated with intellectual disabilities, such as planning and maintaining overviews, became more pronounced in video conferencing meetings, necessitating a more directive and supportive approach from the therapists. Relatives and residential staff played an essential role in assisting service users with practical matters (e.g., supporting service users in installing and activating videoconferencing applications). Service users with more complex support needs proved harder to reach. This study showed that, while eHealth emerged as an alternative for continuing service delivery during the pandemic, it was not universally suitable for all people with intellectual disabilities.

## **Assessing the Working alliance in face-to-face and eHealth interactions**

The increasing prominence of eHealth in supporting and providing therapy for people with intellectual disabilities signifies a shift from traditional in-person professional services. Integrating eHealth into supportive and therapeutic interactions may significantly affect working alliances between healthcare professionals and people with mild intellectual disabilities, thereby potentially influencing outcomes such as mental wellbeing and quality of life. To comprehensively explore the impact of eHealth on these alliances, it is essential to employ robust measurement methodologies. In Chapter 6, we examined the adaptation of the abbreviated versions of the Working Alliance Inventory (WAI-SF) and the Technical Alliance Inventory (TAI-SF) to measure the working alliance in face-to-face interactions and when incorporating eHealth into support or therapy for people with mild intellectual disabilities. These measures were employed to assess the working alliance from the perspective of professionals engaged with people with mild intellectual disabilities. In a cross-sectional study that involved support staff and therapists who worked with this target group, we examined the three-factor structure of the adapted measures and evaluated their internal consistency. Confirmatory factor analysis verified the three-factor structure of both measurements, displaying acceptable to good model fits. The internal consistency of both total scales was excellent, with the three subscales of WAI-SF-MID and TAI-SF-MID demonstrating good consistency. These measures exhibit promise in capturing professionals' perspectives on the (digital) working alliance. The availability of the WAI-SF-MID and the TAI-SF-MID could contribute a better understanding of the impact of working alliance on relevant aspects like satisfaction, adherence, changes in the course of therapy and determining the contribution of eHealth to this process.

## **eHealth acceptance and actual eHealth use of healthcare professionals**

Chapter 7 considered the role of healthcare professionals in utilizing eHealth in care practice in more detail. Two cross-sectional studies, one conducted before and one during the COVID-19 pandemic, focussed on the acceptance of eHealth amongst support staff and therapists. Additional topics included the digital working alliance (TAI-SF), whether they were obligated or compelled to use eHealth, and the extent of the training they had received. To measure eHealth acceptance and actual eHealth use, the UTAUT model, a model for the explanation of technology use on an individual level, was adapted in collaboration with experienced professionals to apply in care organizations for people with intellectual disabilities. This resulted in an extended UTAUT model in which relevant items for the context of professional care for people with intellectual disabilities were added. As a confirmatory analysis yielded unacceptable model fit results for both the original and the extended UTAUT model, an exploratory factor analysis was conducted. This resulted in a five-factor model with acceptable to good internal consistency. This new model explained 43–47% of the variance of the intention to use eHealth. It was



shown that perceived added value and organizational support have the most impact on the intention to use eHealth, with digital facilitating conditions for service users being a relevant factor. The acceptance scores for all five factors were average both in 2018 and 2021. This indicated a consistent level of openness amongst support staff and therapists towards using eHealth in supporting service users in everyday lives and providing psychological therapy. Notably, apps, video modelling, and telecare were the most commonly used technologies, with a significant increase in the use of telecare in 2021, likely due to the pandemic. Despite this openness, there are notable gaps in organizational eHealth policies and training. While support staff and therapists had the freedom to choose whether to deploy eHealth, three-quarters of them reported they had not received any recent training or training at all in using these technologies. This lack of training highlights the need for better organizational support to enhance the effective integration of eHealth into practice.

## Reflections and insights from the results

In this section, four key themes that derived from the findings of this thesis are explored.

### **Cautious optimism about the potential of eHealth for support and psychological therapy**

The findings of this thesis show the various opportunities eHealth presents to support people with mild intellectual disabilities in their daily lives. First, eHealth can contribute to skill development and to enhance their control over their personal lives by providing tailor-made information on demand. These results are consistent with other studies that discuss the potential of eHealth for tailor-made support in various life domains (Collins & Collet-Klingenberg, 2017; Den Brok & Sterkenburg, 2015; Manzoor & Vimarlund, 2018). Further, eHealth enables the remote provision of practical and emotional support, as well as psychological therapy. It also facilitates the organisation of support delivery within the personal living environment, such as home, work/day care centre, or community (Tassé et al., 2020; Zaagsma et al., 2021). This thesis highlights that video conferencing technology could provide a solution to continue psychological assessments and interventions for some service users with mild intellectual disabilities, particularly if healthcare accessibility is under pressure. The COVID-19 pandemic clearly demonstrated the potential of this technology to maintain essential services during a crisis. However, its relevance extends beyond the pandemic, as current challenges, like financial constraints and staff shortages, continue to place significant pressure on healthcare systems. Thus, video conferencing is still an important tool for ensuring that people with mild intellectual disabilities receive the necessary psychological support even in times of limited resources and personnel. Finally, eHealth has the potential to

facilitate collaboration between healthcare professionals and other key stakeholders, such as relatives and other professionals. This can be achieved through well-structured interventions conducted with remote professional coaching, participating in online meetings, and working complementary roles to support people with intellectual disabilities. Research on the necessary adaptations for psychological therapy for people with intellectual disabilities highlights the importance of support from relatives and staff (e.g., Scott et al., 2021; Tournier et al., 2021). Parents and staff can play a crucial role in helping people with intellectual disabilities apply the insights and skills learned from online therapy and training to their daily lives, leading to more effective interventions (Surley & Dagnan, 2019; Taylor et al., 2013). Notably, this thesis found no evidence of self-guided psychological eHealth interventions specifically designed for people with intellectual disabilities. This contrasts with eMental health interventions for the general population, which include self-guided options alongside guided self-help interventions more often (Riper & Cuijpers, 2016). Instead, eHealth for people with intellectual disabilities is predominantly used to supplement onsite or face-to-face support and psychological interventions.

While some findings on the potential of eHealth for people with intellectual disabilities are promising, caution is warranted. The analyzed reviews mainly focussed on case design studies with a limited number of participants, concentrating on the feasibility and suitability of eHealth. This highlights that research in this area is still in its early stages and primarily exploratory, with few studies that rigorously evaluate the effectiveness of eHealth interventions for this population (e.g., Thornicroft et al., 2011).

### **Importance of experiential knowledge and involving significant others**

The systematic review in Chapter 2 on support demonstrated that no structural attention was given to assessing the needs, preferences, expectations and digital skills of people with mild intellectual disabilities concerning eHealth use. In addition, the experiential knowledge of significant others and healthcare professionals was relatively unused and limited to providing information to facilitate smooth eHealth interventions. This is remarkable because the empirical studies in this thesis show that significant others and healthcare professionals play an important role in helping people with intellectual disabilities use eHealth successfully. This includes creating conducive conditions, solving digital issues, and participating in online meetings with therapists. Additionally, the support context provided by significant others received little attention in the reviewed studies. However, existing research indicates that the familiarity and attitudes of significant others towards eHealth can significantly influence its successful adoption and integration into the daily lives of people with intellectual disabilities (Chadwick et al., 2013; Heitplatz et al., 2021; Ramsten & Blomberg, 2019; Wennberg & Kjellberg, 2010). Further, the research emphasizes the importance of support in accessing ICT, identifying

digital needs, developing digital skills, and adopting a possibility-focussed mindset for the digital inclusion of people with intellectual disabilities (Chadwick et al., 2023; Seale, 2023). The qualitative studies in this thesis on the views and experiences of significant others and healthcare professionals (i.e., support staff and therapists) confirmed that those close to people with mild intellectual disabilities play a significant role in the successful use of eHealth. This role became particularly evident during the pandemic, when the need for digital solutions in support and therapy was heightened. In addition, significant others, support staff, and teachers can be involved as lay therapists in delivering psychological eHealth interventions, aligning with broader research on the involvement of support staff and family members in traditional therapy settings that do not involve eHealth (Jahoda et al., 2013; Scott et al., 2017).

### **Value of theories and models for the context of care organizations for people with intellectual disabilities**

In this thesis, established theories and models from general populations were used to examine the factors that influenced healthcare professionals' acceptance and use of eHealth within care organizations for people with intellectual disabilities. These models were selected for their comprehensive focus on the emotional, psychological, and social characteristics that affect technology users, thereby considering both the personal and interpersonal aspects of eHealth adoption (Federici et al., 2023; Heinsch et al., 2021; Smith et al., 2018). This approach aligns with the perspective that eHealth encompasses not just technological factors but also human and contextual influences (e.g., Eysenbach, 2001).

The Matching Person to Technology (MPT) model (Scherer et al., 2007) prioritizes the service user's perspective on eHealth usage, while the Unified Theory of Acceptance and Use of Technology (UTAUT) model (Venkatesh et al., 2003) examines healthcare professionals' intentions to use eHealth. This is critical because health care professionals play a key role in motivating and supporting people with intellectual disabilities. Unlike other models applied in eHealth research, the MPT and UTAUT models focus on understanding the factors that lead to successful eHealth use in care settings (Heinsch et al., 2021; Wouters, 2022). Consequently, these models provided valuable frameworks for investigating individual perspectives and driving factors behind eHealth adoption and use amongst people with intellectual disabilities and their caregivers.

Although the UTAUT and MPT models have been employed in research within other healthcare fields (Henneman et al., 2017; Liu et al., 2015; Van der Vaart et al., 2016), this thesis is pioneering in applying them to the intellectual disability context. Their use allows for rigorous research and offers insights into the key drivers for various eHealth users. This can inform developers, policymakers, and decision-makers in care

organizations about relevant factors for effective eHealth implementation (Taherdoost, 2018).

Moreover, Bordin's working alliance model was employed to develop tools for assessing the impact of eHealth on the alliance between people with intellectual disabilities and healthcare professionals. Studies in general patient populations have shown that uncertainty about eHealth can impede its implementation due to concerns over its potential negative impact on professional-patient alliances (Békés et al., 2021; Berger, 2015; Connolly et al., 2020). For people with intellectual disabilities who often need lifelong support, the relationship with professionals is particularly significant (Giesbers et al., 2019; Van Asselt-Goverts, 2013). Therefore, understanding and developing measures to assess the impact of eHealth on these crucial relationships is vital for ensuring successful eHealth integration.

In summary, this thesis underscores the importance of considering the unique needs of people with intellectual disabilities in the adoption and use of eHealth. By applying established theories and models to this specific context, the research highlights the critical role of healthcare professionals and the necessity of supportive conditions for effective eHealth implementation. This provides a foundation for informed decision-making in developing and implementing eHealth solutions that enhance care for people with intellectual disabilities.

### **The changing role of healthcare professionals and considering professionals' needs**

This thesis highlights the impact of incorporating eHealth on the work routines of support staff and therapists. For example, utilizing videoconferencing technology introduces additional challenges, demanding a heightened online presence due to service users' attention, planning, and digital literacy skills. Healthcare professionals have to select the appropriate technology attuned to the capabilities and needs of service users. Barrett (2016) describes how working with eHealth affects the presence of healthcare professionals, distinguishing clinical, therapeutic, social, and operational presence. The latter concerns aiding service users in handling or resolving digital problems before or during online meetings, and it can be considered as a new dimension in professional responsibility. In addition to supporting service users in acquiring digital skills, the thesis shows that support staff and therapists also have to evaluate the added value of eHealth, select appropriate and feasible eHealth tools for service users attuned to the context of support or therapy, and manage these new tasks that impact their work routines. This increased demand necessitates that healthcare professionals are not only comfortable and proficient with eHealth, but they are also empathetic towards service users who experience stress due to digital challenges. Studies amongst healthcare professionals

working with other patient populations also reported that the new demands of using eHealth can affect the working alliance and may adversely affect implementation in healthcare practice (e.g., Feijt et al., 2018; Granja et al., 2018; Li et al., 2013; Ross et al., 2016), matching the challenges explored in this thesis.

In this thesis, we found that certain conditions among people with intellectual disabilities can hinder successful eHealth implementation. Healthcare professionals, like support staff and therapists, highlighted challenges such as a lack of specialized training for digital therapies and difficulty in building effective alliances online. Similar concerns are seen in healthcare professionals working with other patient groups (e.g., Békés & Aafjes-van Doorn, 2020; Konttila et al., 2018). During the COVID-19 pandemic, therapists were especially uncertain about adapting therapies to digital formats and maintaining good alliances with clients online. This thesis contributes by emphasizing that service user conditions, like their readiness for eHealth, significantly affect how healthcare professionals accept and use digital therapies.

## **Strengths and limitations of the present thesis**

Besides several strengths, this thesis also knows various limitations, which are both discussed in the following section.

### **Enhancing ecological validity in intellectual disability care: collaborative adaptations of eHealth acceptance and alliance models**

Adapting existing theories and models (applied in eHealth acceptance and working alliance research in general patient populations) to make them more appropriate for research in the field of intellectual disabilities can be considered as a strength of this thesis. The adaptation procedure for the items belonging to the UTAUT model, as well as for the items of the Working (WAI) and Technical (TAI) Alliance Inventory measurements were undertaken together with an expert group, consisting of a broad group of healthcare professionals (i.e., support staff and therapists) working with people with intellectual disabilities in various domains (i.e., residential care), utilizing their professional knowledge. It enabled to check and refine our assumptions as researchers on the topic of eHealth and include relevant issues specific to intellectual disability care in the studies. For example, the original items of the WAI and TAI measurements place a strong emphasis on personal responsibility of service users and were problem-oriented, which proved to be less fitting in intellectual disability care, as within intellectual disability care the focus is on quality of life domains (e.g., Schalock et al., 2021) and support needs (Thompson et al., 2009), instead of problems or deficits of service users. Feedback from the expert group of healthcare professionals led to a reformulation of

the items, focussing on shared responsibility, joint decision-making between service users and support staff or therapists, and replacing the word 'problems' with 'needs'.

However, when including the WAI-SF-MID and TAI-SF-MID in the online survey as part of this thesis, participants were instructed to consider a specific service user and the eHealth tool they most frequently utilized when answering the questions. This hypothetical approach was a necessary step in developing these measurements, but should be considered as a limitation of this thesis. Participants did not evaluate the working alliance during an actual therapy or support session, which may have negatively impacted the ecological validity of the findings. Therefore, future research should assess the psychometric properties of the adapted WAI-SF-MID and TAI-SF-MID among healthcare professionals, ideally within real-world care practices.

The WAI-SF-MID seemed to fit best measuring the perspective on dyadic alliances between a service user and a healthcare professional. However, not all alliances in care organizations for people with intellectual disabilities are dyadic in nature. For example, in residential care, instead of a dyad, there is often a triad, where service users, professionals, and family members collaborate together (e.g., Roest et al., 2023). In these contexts, the concept of alliance is more systemic rather than purely dyadic.

### **Focus on primary care process**

This thesis has shed a light on the views on eHealth in daily life and care practice by investigating the experiences of service users with intellectual disabilities, relatives, and in particular support staff and therapists. Relatives, support staff and therapists are the most important stakeholders that use or facilitate use of eHealth for service users in daily life. This is where eHealth can be most effectively applied, providing an opportunity for people with mild intellectual disabilities to benefit from eHealth as a valuable addition to, or a means of enhancing, service delivery. The primary focus on integrating eHealth into core care practices for people with intellectual disabilities is a notable strength of this thesis.

This thesis focussed on the personal and interpersonal aspects of eHealth implementation in care organizations for people with intellectual disabilities, providing a detailed understanding of the role of healthcare professionals in this context. It is the first thesis to offer an in-depth exploration of how healthcare professionals position themselves and their responsibilities in applying eHealth with service users who have intellectual disabilities. While personal and interpersonal factors are crucial, organizational features are also important for understanding eHealth implementation in practice. However, this thesis collected limited information on organizational aspects such as ICT support and infrastructure, eHealth policies, implementation strategies, eHealth training, and

facilitating conditions. The models used in this thesis, the Matching Person to Technology (MPT) and the Unified Theory of Acceptance and Use of Technology (UTAUT), primarily focus on the individual level of adoption, which may have constrained the exploration of these broader organizational factors. Future research should aim to address these gaps by investigating the impact of organizational factors on eHealth implementation in care organizations for people with intellectual disabilities, employing comprehensive methodologies that capture both individual and organizational perspectives.

### **Representativeness of participating healthcare professionals**

In the study on eHealth acceptance described in Chapter 7, support staff working in different domains (e.g., outreach support, residential care) and therapists from five care organizations participated, thereby including a relatively large and varied group of professionals. Although the participants represent a broad range of domains and intellectual disability care organizations, there is a risk of non-response bias. That is, people not interested in eHealth might have been less likely to participate in the studies. This is even more true of the study that used an online survey format, which necessitates digital skills and access to the internet, both of which also influence the use of eHealth. Most participants in this thesis reported to have more than average experience in using digital tools or became proficient in applying eHealth over time. As this group can be considered to be a precursor in eHealth adoption (Rogers, 2003), the generalizability of the findings to the total group of health professionals working in care organizations for people with intellectual disabilities is limited. Future research is necessary to understand what drives or hinders healthcare professionals representing other adopter categories of Rogers' classification (2003), such as sceptical or traditional adopters. The Levels of Adoption of eMental Health model (LAMH model) (Feijt et al., 2018) combines adopter categories with elements of the UTAUT model and offers leads for further exploration in the ID care.

### **Focus on a broad range of eHealth applications**

In this thesis, a wide range of eHealth applications was explored, each serving distinct purposes and demonstrating variations in usage. For instance, video conferencing technology primarily facilitates remote communication, while apps guiding step-by-step meal preparation aim to promote independence goals. Van Gemert-Pijnen (2015) emphasized gaps in knowledge concerning design choices, feasibility testing, and end-users' utilization in eHealth effectiveness studies. Understanding these aspects is crucial, especially for people with intellectual disabilities who may encounter difficulties processing sensory, verbal, and written information, requiring adaptations in technology for support and therapy (Lussier-Desrochers et al., 2017). This thesis aimed to enhance the understanding of eHealth applications in support and therapy without a predefined focus on specific technologies or interventions, instead encompassing the

most discussed eHealth tools in the literature. As such, no definitive conclusions can be drawn regarding the effects or value of specific eHealth tools for people with intellectual disabilities. Future research should focus on conducting rigorous effectiveness studies of specific eHealth interventions tailored to the unique needs of people with intellectual disabilities, including comprehensive assessments of usability, feasibility, and user satisfaction.

## Directions for future research

Based on the results of the studies in this thesis, this section discusses several directions for future research. Some interesting developments in eHealth research in various healthcare sectors are worth exploring in the context of eHealth research in the field of intellectual disabilities.

Contemporary technologies (e.g., mobile phones) are increasingly utilized for real-time data collection through experience sampling, capturing subjective experiences or behaviours like mood or substance use. However, the application of experience sampling in the field of intellectual disabilities is not adequately studied. Two exploratory studies amongst people with mild intellectual disabilities using mobile phones demonstrated feasibility when tailored to their needs and preferences for research on psychological interventions (Hulsmans et al., 2023; Gosens et al., 2024). While these studies were small-scale, well-designed quantitative studies with N=1 designs could provide deeper insights into how and why innovative interventions like experience sampling are effective in support and therapy for people with intellectual disabilities (Ganz & Ayres, 2018; Kratochwill et al., 2013).

In addition to assessing intervention effectiveness, Nuij et al. (2022) highlighted the potential for tailoring interventions to individual user needs through personalized messaging. This approach could be adapted to meet the specific needs of people with intellectual disabilities. Furthermore, the use of individual personal data (IPD) holds promise for delivering personalized interventions in the future. Karyotaki et al. (2021) used IPD in a meta-analysis to identify effective elements of internet-delivered cognitive behavioural therapy for depression in general patient populations. Exploring the feasibility and effectiveness of the IPD of people with intellectual disabilities in similar studies could provide clearer insights into the effectiveness of eHealth interventions tailored to this population. Future research should focus on conducting robust studies with larger sample sizes and diverse methodologies, including N=1 designs, to explore the full potential of experience sampling and personalized interventions in the context of intellectual disabilities. This approach will help bridge current gaps in knowledge and



enhance the application of eHealth innovations in supporting people with intellectual disabilities effectively.

Second, this thesis highlights knowledge gaps related to the acceptance of eHealth amongst healthcare professionals. Larger-scale research into acceptance, use, and implementation of eHealth is essential to identify the elements and necessary components for successful eHealth implementation in the context of care organizations for people with intellectual disabilities. Age revealed to be a moderating variable that could influence healthcare professionals' intention to use of eHealth, and this needs further exploration in future research.

Third, this thesis focussed on support staff and therapists, who play a key role in the selecting, proposing, and implementing of eHealth in professional support and therapy. However, the research literature identifies managers as another crucial stakeholder group in eHealth implementation (Granja et al., 2018). They facilitate, motivate, and support eHealth implementation in their organizations as so called 'digital leaders' (Kujala et al., 2019). Therefore, future research should also focus on the role of managers in eHealth implementation in care organizations for people with intellectual disabilities.

Fourth, future research on eHealth implementation should encompass models that elucidate the intricate interplay across multiple levels, including service user support needs, technological aspects, adopters of eHealth, characteristics of care organizations, and broader systemic factors, such as advocacy organizations, political environments, and health insurance policies. These models are essential for a thorough understanding of how eHealth can be effectively integrated into care organizations for people with intellectual disabilities. Models such as the non-adaption, abandonment, scale-up, spread, and sustainability (NASSS) framework (Greenhalgh et al., 2017) or the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework (Glasgow et al., 2006) offer broad perspectives that can inform eHealth implementation strategies. Additionally, theories such as the Normalization Process Theory (NPT) (May & Finch, 2009) may be helpful to provide insights into the factors that influence the integration of eHealth into healthcare professionals' daily routines. These frameworks and theories are instrumental in understanding the dynamics between individual factors that influence eHealth adoption and the organizational efforts required for successful integration within care services (Greenhalgh et al., 2017). Recent applications of the Normalization Process Theory by Bisschops et al. (2022) in intellectual disability care demonstrate its utility in evaluating implementation strategies effectively. Future research should build on these frameworks and theories to comprehensively explore and optimize eHealth implementation practices to support people with intellectual disabilities.

Finally, the perspectives of people with intellectual disabilities on eHealth acceptance received limited attention in this thesis. Future studies should prioritize understanding the experiences of service users of various age groups who receive support or therapy through eHealth interventions. It is crucial to involve them collaboratively in both the development and implementation phases of eHealth interventions, as they are experts in their own lives, experiences, and preferences (Van Gemert-Pijnen et al., 2018). Working closely together with experts-by-experience in this adaptation procedure is highly recommended (Embregts & Frielink, 2023). Additionally, the impact of eHealth on the working alliance between service users and healthcare professionals was only explored from the professionals' perspective. Given that this alliance involves both parties, future research should adapt the WAI-SF-MID and TAI-SF-MID measures to include the perspectives of service users with mild intellectual disabilities. This approach will provide a more comprehensive understanding of how eHealth influences the therapeutic alliance.

Further research could also differentiate between specific support settings in intellectual disability care, such as 24-hour residential support in comparison to outreach support settings. People with mild intellectual disabilities who live independently likely have distinct support needs in which eHealth can play a significant role compared to people with severe intellectual disabilities who live in residential facilities (e.g., Zaagsma et al. (2019).

## **Implications for policy and practice**

The findings of this thesis have significant implications for policy and practice in healthcare.

### **Policy**

First, governmental policies and organizational plans, such as those of the Dutch Association of Healthcare Providers for People with Disabilities (VGN), promote eHealth as a potential solution to challenges in healthcare delivery. Despite the substantial number of healthcare professionals – 188,000 – who work in organizations for people with intellectual disabilities (CBS working in healthcare data, Langenberg et al., 2022), these professionals are often overlooked in large-scale eHealth studies (Keij et al., 2023). This neglect highlights the importance of exploring the perspectives of these professionals, who play a crucial role in implementing eHealth for service users (Chapter 4 and Chapter 7). The digital divide between them and people with intellectual disabilities became apparent during the COVID-19 pandemic, exacerbating mental health challenges and complicating virtual service delivery (Lunsky et al., 2022).

Governmental reports also recognize this divide, emphasizing the potential threats posed by the rapid rise of eHealth for this vulnerable population (e.g., RVS, 2022; ZIN, 2022). Addressing the digital literacy and support needs of healthcare professionals and service users is crucial, especially considering the complexities discussed in this thesis and other research (e.g., Geukes et al., 2019; Seale, 2023).

Second, in the realm of healthcare policy and eHealth interventions, a critical oversight exists in the assumption that all individuals possess the necessary digital literacy to benefit from these technologies, leading to policies that predominantly cater to the digitally proficient and neglect the specific needs of people with intellectual disabilities (Selick et al., 2021; Sheenan & Hassiotis, 2017). This oversight results in interventions that fail to address the accessibility and support requirements of this population, thereby creating significant barriers to accessing mental healthcare (Ee et al., 2022; Nieuwenhuis et al., 2017; Ramsden et al., 2016). It also raises concerns that the ongoing shift towards digitalization in healthcare may exacerbate disparities in access and quality of care (Selick et al., 2021; SER, 2020). The rapid adoption of digital healthcare services risks premature dropout from eHealth interventions and compromises the overall quality of life for individuals with intellectual disabilities (Chadwick et al., 2022; Liaanen et al., 2021). Therefore, it is imperative for healthcare policies to actively address these barriers and ensure equitable access to digital healthcare services, thereby preventing the perpetuation of inequities in healthcare access and quality (Woittiez et al., 2018).

Third, this thesis also underscores that not all service users are willing to adopt eHealth solutions. Respect for individual preferences and concerns is crucial. This is particularly highlighted by surveys during the pandemic that emphasized the need to guarantee access to human professional help alongside eHealth options (Centre for Ethics and Healthcare, 2020). Service users expressed concerns about eHealth potentially replacing human care, which underscores the importance of balancing technological integration with maintaining human-centred care (Chapter 4). While eHealth is touted as a solution to healthcare challenges, particularly in light of healthcare staff shortages, it is essential to approach its implementation inclusively. Recommendations for effective eHealth integration should encompass perspectives from care organizations, health insurers, IT developers, and government stakeholders, ensuring that solutions meet the diverse needs of all healthcare users (Coetzer et al., 2024).

## Practice

The implications for care organizations and practice derived from this thesis are manifold. First, the review study (Chapter 2) reveals that selecting eHealth applications often lacks transparency and is driven more by trends than thorough assessment of how well an application fits an individual's support needs. Thus, a comprehensive understanding

of the individual's functional profile, support requirements, technological possibilities, and user capabilities is crucial for effective eHealth implementation. The Matching-to-Technology framework provides a structured approach to assess these factors, facilitating the optimal utilization of eHealth by people with intellectual disabilities.

Second, another significant implication for care practice is the potential of eHealth to facilitate collaborative treatment that involves family members or other professionals pivotal in the lives of people with intellectual disabilities (delegated treatment). By equipping these stakeholders early on, eHealth can enhance their confidence, reduce isolation, and provide timely access to specialized knowledge. These capabilities align with the principles of Appropriate Care, emphasizing value-driven, shared decision-making tailored to individual health needs (National Health Care Institute, 2022). It is crucial to explore the experiences and support needs of informal and formal caregivers to effectively integrate eHealth into care practices.

Third, while intellectual disability (ID) care traditionally lacks routine outcome measurement practices common in mental healthcare, instruments like the Working Alliance Inventory (WAI-SF-MID) and Technical Alliance Inventory (TAI-SF-MID) offer valuable tools. These instruments, adapted for healthcare professionals working with people with mild intellectual disabilities, can facilitate discussions on therapeutic relationships and goal achievement. Incorporating service user perspectives through these measures enhances evaluation interviews, providing insights beyond subjective impressions or sporadic outcome assessments, thereby improving treatment quality over time.

Fourth, the integration of eHealth in direct service provision has become indispensable for healthcare professionals. The transition highlighted during the COVID-19 pandemic (Chapter 5) underscores the need for healthcare professionals to possess both technical proficiency and enhanced skills in remote engagement. Studies consistently indicate challenges in virtual care for people with intellectual disabilities (Chadwick et al., 2022; Lunskey et al., 2022), reflecting the ongoing struggle for adequate preparation and integration of eHealth within care services.

Fifth, the eHealth acceptance study (Chapter 7) identifies varying levels of eHealth acceptance across different age groups and professional perceptions of service user capabilities, such as digital literacy and access to devices. These differences underscore the importance of tailored support strategies for healthcare professionals. Clear organizational vision and effective communication regarding the benefits of eHealth for service users are crucial motivators for healthcare professionals. Addressing current challenges, such as workload and treatment efficiency, requires structured

implementation plans that promote trialability and ensure successful integration into care practices (Rogers, 2003). ID care organizations need to acknowledge and cater to the needs of their staff. Providing direction on eHealth expectations, enhancing technological infrastructure, and fostering a supportive environment are essential for maximizing the added value of eHealth in service delivery.

## **Concluding remarks**

Aligning eHealth with the unique needs, capabilities, and preferences of people with intellectual disabilities in collaboration with their support network may leverage eHealth to enhance rather than replace traditional human-centred care. Care organizations should empower primary healthcare professionals with clear vision, training opportunities, and robust technical infrastructure. This approach ensures judicious use of eHealth, emphasizing its potential to positively affect health, participation, and psychological wellbeing. These efforts harness the benefits of eHealth while preserving the indispensable role of in-person care.

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# Academic summary

This thesis aims to provide insights into the use of eHealth among people with intellectual disabilities who receive care services from organizations that provide care to people with such disabilities. Although eHealth is becoming more common in the care of people with intellectual disabilities, relatively little research has been done so far into the use of eHealth in this sector.

The thesis focuses on the use of eHealth to support day-to-day life and psychological treatments among people with intellectual disabilities. Alongside family members, healthcare professionals play a crucial role in providing support and care. This thesis examines how people with intellectual disabilities, their family members and healthcare professionals view the use of eHealth. Particular attention is paid to the factors that influence acceptance of eHealth by healthcare professionals, as they play an important role in deciding whether or not to use eHealth.

## **Chapter 1 General introduction**

This chapter describes the growing role of eHealth in caring for people with intellectual disabilities, defining eHealth as the use of digital technologies to promote health and well-being. eHealth can support personalized care and enable remote care, with the aim of providing high-quality care that is more sustainable. Both the Dutch Ministry of Health, Welfare and Sport and the Vereniging Gehandicaptenzorg Nederland ('Netherlands Association of Disability Care', VGN) see eHealth as an important pillar of future care, while care providers are already implementing a range of initiatives to integrate eHealth into their care and services.

Care for people with intellectual disabilities is characterized by lifelong support in various areas of life, such as self-care, day-to-day life, work and participation in society. The support provided depends on the severity of the individual's disability and their support needs. This thesis focuses specifically on two forms of care: support and psychological treatment (also referred to as 'therapy'). Support is about strategies aimed at promoting personal development, well-being and independence; the intensity of the support depends on context, life stage, skills and other (mental) health conditions. Psychological therapy includes interventions based on psychological theories that focus on behavioural change, interpersonal relationships and systems. Although there are some indications that cognitive behavioural therapy (CBT) can provide effective treatment for conditions such as anxiety disorders, there is limited evidence regarding the effectiveness of other forms of therapy in treating behavioural problems. In general, group interventions seem to be more effective than individual therapies when it comes to mental health problems, and the use of digital technology is limited.



This thesis defines eHealth as the use of the internet or related technologies to promote health and well-being and to support conventional healthcare strategies. eHealth offers opportunities for self-management, strengthens collaboration between healthcare professionals and increases the involvement of the individual's social network. It can be deployed in a variety of ways, for example through video conferencing, and it can be offered both in isolation and in hybrid form (alternating between independent eHealth use and professional support).

Research has shown that eHealth helps people with intellectual disabilities to develop greater autonomy but, despite this evidence, many healthcare professionals are not convinced that eHealth is suitable for this target group. Although the use of eHealth increased sharply during the COVID-19 pandemic, there is still little available data on the role of health professionals in applying eHealth to the care of people with intellectual disabilities. Acceptance of eHealth by healthcare professionals is essential to successful implementation. Some healthcare professionals see eHealth as an opportunity to improve communication, while others have concerns about the quality of remote care. This thesis investigates the factors that influence healthcare professionals' intentions and use of eHealth. The UTAUT (Unified Theory of Acceptance and Use of Technology) model was used to understand how healthcare professionals accept eHealth when working with their service users. In addition, two existing tools were modified so as to measure cooperation between the healthcare professional and the client, with and without eHealth.

## **Outline of the thesis**

The available scientific knowledge on the use of eHealth to support the day-to-day lives of people with mild intellectual disabilities and to provide psychological therapy was discussed by means of a systematic review and a scoping review (Chapters 2 and 3). Implementation research has shown that a good understanding of different user perspectives contributes to successful implementation in healthcare, with healthcare professionals playing a key role. This insight led to an in-depth study of the experiences of service users with intellectual disabilities, service user' relatives and healthcare professionals (Chapter 4). We also looked specifically at the experiences of therapists, for whom video conferencing during the first COVID-19 lockdown was not optional – it was essential for them to continue their work (Chapter 5). To better understand the impact of eHealth on collaboration in clinical practice and future research, we modified two existing working alliance questionnaires for healthcare professionals working with people with mild intellectual disabilities and studied the psychometric quality of these tools (Chapter 6). Finally, we evaluated the applicability of the UTAUT model, with certain modifications and additions, to research into the care provided to people with intellectual disabilities. We also examined the acceptance and use of eHealth in two

cross-sectional studies (one from 2018 and one conducted in 2021, during the COVID-19 pandemic) among support staff and therapists in this sector (Chapter 7).

## **Chapter 2 Systematic literature review**

This chapter describes a systematic literature review of eHealth applications used to support people with mild intellectual disabilities in their day-to-day lives. Seven databases (Embase, Medline, Cochrane, Web of Science, PsycINFO, CINAHL and Google Scholar) were searched for relevant studies from 1996-2019. The inclusion criteria were: a) people with mild intellectual disabilities (IQ 50-69), b) use of eHealth/technology for support, and c) individual psychological or behavioural outcomes. Most of the 46 studies included in the research used a single-case or group design. Quality was assessed using Reichow's EMDEBP tool. Of the 36 single-case studies, 26 had acceptable to good descriptions; for the group studies, nine out of 10 were not adequately described. The studies were analysed using Scherer's MPT model, which emphasizes three factors in the effective use of technology: 1) characteristics of people with mild intellectual disabilities (abilities, preferences, needs), 2) environmental factors (context and support), and 3) characteristics of the technology concerned.

The review generated three main conclusions. First, most of the studies did not take personal preferences into account in the selection of eHealth applications, resulting in a lack of customization. Second, key stakeholders such as family and support staff were rarely engaged with selecting or implementing the technology, despite these people being crucial to its success. Third, it was found that structured training, in which it is often possible to adapt the technology to an individual's personal preferences, can enable people with mild intellectual disabilities to use eHealth effectively. Three functions of eHealth were identified: support with the learning process, self-support in specific contexts (e.g. work) and remote communication with healthcare professionals. eHealth shows potential for offering support in day-to-day life; however, the research is not of the highest quality, and this field is still in its infancy.

## **Chapter 3 Scoping literature review**

Chapter 3 summarizes psychological interventions from 33 studies in which eHealth was used to treat psychological and/or behavioural problems in people with intellectual disabilities. Most studies focused on individual psychological treatments that were conducted in the individual's own living environment and based on principles from behavioural therapy. Two studies examined parent-child treatments, while two further

studies looked into the use of eHealth in group treatments. In addition to behavioural therapy, the studies also used other approaches practice-based evidence.

The psychological eHealth treatments focused on both children and adults, with an emphasis on people with severe or very severe intellectual disabilities and multiple disabilities. The treatments were designed to reduce self-injurious, stereotypical or problem behaviour and teach adaptive behaviour. For people with mild to moderate intellectual disabilities, treatments were mainly aimed at alleviating disorders related to anxiety and mood. The treatments were carried out by a range of people: in addition to therapists and psychologists, treatment was also administered by parents, teachers, support staff and research assistants under the supervision of a psychologist.

eHealth was incorporated into the treatments in four ways:

1. Before, during and after the sessions, images or video footage of desired behaviours or skills were shown in an eHealth application on a device such as a tablet, to encourage people to apply these strategies more often in day-to-day life.
2. Healthcare professionals used video conferencing and chat functions to coach service users in how to deal with emotions and learn adaptive behaviour. Parents received remote coaching in how to implement the intervention in their child's life.
3. CBT principles were applied, with service users using avatar characters and social scripts on a computer to reduce feelings of anxiety and depression.
4. When sensors detected desired behaviour, service users received positive reinforcement in the form of a reward, such as their favourite music clip or video being played.

The scoping review shows that, although eHealth still plays only a limited role in psychological treatments for people with intellectual disabilities and problem behaviour or mental health problems, it offers opportunities for real-time remote supervision by healthcare providers and parents. eHealth can also be a useful treatment tool, helping individuals to learn desired social behaviour and apply it in daily life.

## **Chapter 4 Focus group study among service users, relatives, and healthcare professionals**

Chapter 4 describes the expectations and ideas of service users, relatives and healthcare professionals as regards the use of eHealth for support in day-to-day life. The data was gained through a qualitative focus group study in which 16 people participated in three focus groups

healthcare professionals. Familiar eHealth applications included social media in general, smart home devices for observation, e-mail, WhatsApp, video conferencing and specific tools such as a website for people with intellectual disabilities and computers with a voice-user interface for augmentative and alternative communication (AAC). Healthcare professionals were also familiar with sensor technology for measuring physiological responses to stress, and they indicated that the concept of eHealth covers a broad range of applications.

Both people with an intellectual disability and healthcare professionals saw greater self-management as a major benefit of eHealth. Other key benefits cited by participants included increased independence and improved, more effective care. Relatives experienced the fact that digital reports allowed them to stay better informed as a positive result, although they also raised concerns about privacy and security risks and about a lack of digital skills in their family member with an intellectual disability. For service users with an intellectual disability, it was important for the people who were crucial to them to be involved in the process.

One disadvantage raised by participants was that eHealth is no substitute for in-person contact. The use of eHealth was also hampered by a lack of devices such as mobile phones or tablets, unstable internet connection, pressure of time for healthcare professionals and too little IT support from the organization. A positive factor was that technology makes it easier to involve people who are important to the client in the care strategy. For eHealth to be of real value, it must meet the needs of people with intellectual disabilities, for example through the use of visual aids and simple language. It was also considered relevant that certain people, for example older people or people who are not familiar with eHealth, may be less likely to use this resource.

## **Chapter 5 Qualitative study among therapists during COVID-19**

Chapter 5 describes a small-scale qualitative study among five psychologists and two experience-based therapists (one psychomotor therapist and one art-based therapist) during the first COVID-19 lockdown. They conducted diagnostic tests and offered video conferencing-based therapy to people with mild intellectual disabilities. The therapists shared their experiences in self-submitted audio messages and e-mails.

A thematic analysis generated the following five key themes: 1) an immediate transition to virtual working, 2) the development of virtual ways to support service users with mild intellectual disabilities in cope with COVID-19-related stress and continue therapy, 3) the

lack of appropriate equipment for all participants in the video conferencing sessions, 4) the limitations of virtual attuning to people with mild intellectual disabilities, and 5) unforeseen opportunities to continue psychological assessment and therapy remotely, even once the situation changed.

Participants had a steep learning curve to work out how to use video conferencing software, which demanded a lot of flexibility and time. Initially, therapists were uncomfortable and felt insufficiently prepared to offer diagnostics and therapy in video conferencing sessions, but this became easier over time. However, it proved difficult to successfully use video conferencing with highly emotional service users or complex families, with interaction being harder to follow through a screen. Therapists helped service users develop skills and supported them to cope with the stress and uncertainty caused by the pandemic. The choice of service users for whom video conferencing is suitable, treatments (such as EMDR for complex trauma) and suitable topics for video conferencing sessions required careful consideration.

Access to appropriate equipment, user-friendly video conferencing applications and a stable internet connection were essential for both service users and therapists. Therapists were not familiar with all the features of the video conferencing software, leading to tools such as the digital whiteboard going unused. Service users with mild intellectual disabilities also struggled with planning and structure, which made it difficult for them to log in on time and in appropriate surroundings. On the other hand, this period also brought unexpected benefits, such as a better understanding of the service user's home situation and the opportunity to apply certain skills straight away in the right context, which helped to generalize what the service users were learning.

## **Chapter 6 Validation of working alliance measurement tools**

Chapter 6 describes how two existing working alliance questionnaires were modified to achieve a better understanding of eHealth's effect on the collaboration between a support staff member or therapist and a person with a mild intellectual disability. The aim was to develop a quantitative measurement tool that would allow healthcare professionals to assess their experience of working with service users with mild intellectual disabilities, both with and without the use of eHealth in support or psychological therapy. Healthcare professionals can also use these questionnaires to identify changes in the collaborative relationship during support meetings and therapy sessions.

An expert group of healthcare professionals who work with people with an intellectual disability helped to modify the questionnaires' methodology for use in their sector through a stepwise approach. In addition to suggesting ways to make the items easier to understand, the professionals recommended strengthening the emphasis on shared responsibility and a support-oriented rather than problem-oriented approach. This strategy is more appropriate when providing care to people with an intellectual disability.

Confirmatory factor analysis (CFA) and reliability testing showed that the three-factor structure of the modified working alliance questionnaire (with subscales for emotional bond, agreement on goals and agreement on what tasks/activities are needed to reach these goals) demonstrated acceptable to good model fit, with an excellent Cronbach's alpha and McDonald's omega for the overall scale. After one item was removed, the technical alliance questionnaire (which measures working alliance when using eHealth) also showed an acceptable model fit and an excellent Cronbach's alpha and McDonald's omega for the overall scale. The results of the three subscales (bond, goals and tasks/activities) showed acceptable to good internal consistency.

## **Chapter 7 Questionnaire studies on acceptance and use of eHealth (2018 and 2021)**

Chapter 7 describes a quantitative study in which we used an web-based survey to explore how familiar support staff and practitioners (psychologists, orthopedagogues and experience-based therapists) are with eHealth applications, the extent to which they actually use these applications and how they feel about eHealth acceptance. This study used the UTAUT model, which identifies four factors (performance expectancy, effort expectancy, social influence and facilitating conditions) as predictors of intention to use eHealth. We tested the suitability of this model in its original form, and we also conducted a test involving extra items suggested by healthcare professionals specializing in care for people with disabilities.

A total of 19 items from the UTAUT model were presented to two groups of healthcare professionals who already used eHealth in their work. The study assessed the items' recognizability and applicability to care for people with disabilities. One item was modified for use in a Dutch context, and six further items were added that related to eHealth in care for people with intellectual disabilities. As well as UTAUT items, the study also included questions about demographics, eHealth applications and any training received. In 2021, the measurement was supplemented with questions about working alliances and the influence of COVID-19 on the use of eHealth.

A CFA of the UTAUT model did not generate adequate results for the 2018 data; a later exploratory factor analysis (EFA) identified five factors that influence eHealth acceptance: 1) perceived added value of eHealth, 2) convenience and self-confidence, 3) social pressure from colleagues and support from the manager, 4) organizational support, and 5) whether facilitating conditions (such as devices and digital skills) were in place for service users. The behavioural intention factor was made up of three items.

In addition to validating the UTAUT model, the study also described the use of eHealth applications and their level of acceptance. In 2018, 311 healthcare professionals participated in the survey, while 326 took part in 2021. Acceptance scores remained stable despite the increased experience with eHealth as a result of COVID-19, with video conferencing in particular being used more frequently. Although many healthcare professionals were aware of virtual reality, this technology was not extensively used.

A multiple regression analysis was conducted to measure the influence of the aforementioned five factors on behavioural intention. Taken together, in 2018 the factors explained 47% of the behavioural intention to use eHealth, with all factors except social pressure having a significant effect. In 2021, the factors explained 43% of behavioural intention, with perceived performance expectancy and organizational support as the main predictors. The influence of UTAUT moderators such as age and experience was also investigated. The results lay the foundation for the use of differentiated approaches to improve eHealth implementation in healthcare practice.

## Chapter 8 General discussion

Chapter 8 discusses the main conclusions, strengths and limitations of the study and shares recommendations for policy, care and future research. The four main conclusions of this thesis are

### 1. Cautious optimism about eHealth

The available scientific literature offers opportunities for promoting practical skills, self-management and independence in people with mild intellectual disabilities, as long as these characteristics are tailored to individuals' needs and abilities. eHealth facilitates remote supervision and therapy, allowing healthcare professionals to be present even at a distance and making it possible for skills to be practised in an individual's own living environment (such as at home or at work). With the assistance of parents, teachers and support staff, video conferencing-based treatment offers an opportunity to make sure care remains accessible, as was the case during the pandemic. However, most of the available research uses case studies involving small groups and focuses on the feasibility of eHealth, without the independent use of

eHealth by people with intellectual disabilities. From this, it is clear that research on the effectiveness of eHealth is still in its infancy, and we should not overestimate its potential at this stage.

## 2. The importance of experiential knowledge

The literature places significant importance on personal experience, but the experiences, needs, preferences and digital skills of people with an intellectual disability, and the knowledge their loved ones have gained from experience, are not always recognized. Relatives and support staff play a crucial role in day-to-day support, and any strategy to make eHealth more accessible should include collaboration with these people. During the pandemic, family members often helped resolve IT problems and realized which digital skills were needed to use eHealth. Family members' personal experience and positive attitudes are important factors in the success of eHealth. This thesis shows that family members, support staff and teachers can play a key role in the use of eHealth, and recognizing the importance of their role opens the door to opportunities for collaboration.

## 3. The value of models and theories

Three studies in this thesis were based on models and theories that are often applied in broader healthcare studies. These theoretical frameworks provided an opportunity to explore both the technology and the human side of eHealth in care organizations. The MPT and UTAUT models helped identify organizations' specific needs in terms of care for people with an intellectual disability, while also adding insights into the adoption of eHealth by care professionals. In addition, Bordin's working alliance theory provided a framework for devising questionnaires for collaboration between service users and healthcare professionals, both with and without eHealth.

## 4. The changing role of healthcare professionals

eHealth is changing the way healthcare professionals organize their work. Choosing the right eHealth application, assessing its value to the care strategy and becoming familiar with the technology all demand new skills, while at the same time healthcare professionals must also empathize with service user's stress about digital methods. The challenge of translating traditional ways of providing support or therapy to the digital realm can be an obstacle to implementing eHealth. In view of this changing role, healthcare organizations need to offer their staff the right support and training in the use of eHealth, and they need to consider the facilitating conditions for successful use of eHealth with service users.

## **Strengths and limitations of this thesis**

One of the strengths of this thesis is that healthcare professionals were involved as experts in the development of the modified questionnaires and UTAUT items. The emphasis on the perspectives of different eHealth users in healthcare situations, with a special focus on the role of healthcare professionals, is another strong point. Although



contextual factors receive only limited attention in this thesis, we recognize the need for additional research into other layers within care organizations that influence eHealth implementation. One limitation is that the results of this study cannot immediately be generalized to all healthcare professionals in the sector. It is likely that most of the studies' participants were already digitally proficient and had an existing affinity with eHealth. Although one strength of this study is its broad focus on multiple eHealth applications and the participation of healthcare professionals from different sectors, such as outreach support and residential care, no definitive conclusions can be drawn about which eHealth application is most suited to specific support needs or healthcare sectors. Future research should focus on identifying which eHealth applications are feasible, appropriate and effective in meeting the different support needs of the members of this target group.

### **Implications for future research**

Thanks to modern technology, as with experience sampling, it is now possible to measure people's experiences by collecting data directly from sources such as mobile phones. These techniques are already in use for other target groups, to personalize eHealth interventions by analysing personal data, and they deserve further investigation in the field of care for people with intellectual disabilities. They may be suitable for evaluating the effectiveness of eHealth in interventions. This thesis further showed that the UTAUT model can partly explain the usage intention and use of eHealth by care professionals, but that its acceptance is also based on factors that are still unknown. Age emerged as a possible factor that may influence the relationship between acceptance and use. In addition, despite the literature highlighting the crucial importance of managers' digital leadership to the success of eHealth implementation, the role of managers in this care sector has not attracted enough attention to date. In terms of examining eHealth implementation in healthcare practice, theoretical models such as Normalization Process Theory, the RE-AIM framework and the NASSS model serve as valuable tools to study the complex layers of implementation, from individual users to government policy. Finally, this thesis has devoted relatively little space to the perspective of people with an intellectual disability themselves. Further research is needed in this area, including the development of a client version of the questionnaires on the (digital) working alliance, in order to achieve a more comprehensive understanding of how this target group feels about eHealth and its impact on the collaborative relationship.

### **Implications for policy and practice**

With regard to policy, despite the large number of healthcare professionals and the long-term nature of the sector, there is a striking lack of discussion of care for people with an intellectual disability in policy documents and large-scale studies, such as the annual eHealth monitor. The COVID-19 pandemic showed that the use of eHealth

to ensure that care remains accessible for this target group can be complex and lack robustness, especially as care becomes ever more digitized. If specific needs are not taken into account, digitization could put further strain on access to care and lead to greater health disparities, which would be especially detrimental to people with intellectual disabilities. This thesis makes clear that, rather than replacing human care, eHealth should be viewed as complementing that care. The right of service users who do not wish to receive care through eHealth should also be respected.

For healthcare organizations, this thesis offers several implications. First, the MPT model provides a structured approach for the better implementation of eHealth applications, based on the relevant performance profile and personal support needs. This approach increases the likelihood that the use of eHealth will be successful in practice. eHealth also facilitates remote care and supporting for the people concerned, which can help ensure the provision of appropriate care. Another important implication is the availability of two valid, reliable questionnaires to measure (digital) working alliance, allowing healthcare professionals to evaluate the quality of their collaborative relationship with service users. These questionnaires can also be integrated into routine outcome monitoring (ROM), which is beneficial to the quality of care. Care organizations should also formulate a clear vision for eHealth, bearing in mind the differing support needs and training requirements between younger and older colleagues. Sound technical infrastructure is essential to this vision.

Where eHealth is tailored to the specific needs, abilities and wishes of the person with an intellectual disability, and where the client's network is engaged with professional care, eHealth can make a valuable contribution to health, psychological well-being and participation, while maintaining the human aspect of care.

# Wetenschappelijke samenvatting

Dit proefschrift heeft als doel om meer inzicht te krijgen in het gebruik van eHealth bij mensen met een verstandelijke beperking die zorg ontvangen van zorgorganisaties voor mensen met een verstandelijke beperking. In de zorg voor mensen met een verstandelijke beperking wordt steeds vaker gebruik gemaakt van eHealth, echter onderzoek naar de toepassing van eHealth in deze sector is nog schaars.

Het proefschrift richt zich op het gebruik van eHealth ter ondersteuning van het dagelijks leven en psychologische behandelingen van mensen met een verstandelijke beperking. Naast familieleden spelen zorgprofessionals een cruciale rol in de ondersteuning en zorgverlening. In dit proefschrift zijn de perspectieven op het gebruik van eHealth van mensen met een verstandelijke beperking, hun familieleden en zorgprofessionals onderzocht. Daarbij is specifiek gekeken naar de factoren die de acceptatie van eHealth door zorgprofessionals beïnvloeden, omdat zij een belangrijke rol spelen bij het al dan niet inzetten van eHealth.

## Hoofdstuk 1 Algemene inleiding

Dit hoofdstuk beschrijft de toenemende rol van eHealth in de zorg voor mensen met een verstandelijke beperking, waarbij eHealth wordt gedefinieerd als het gebruik van digitale technologieën om gezondheid en welzijn te bevorderen. eHealth kan gepersonaliseerde zorg ondersteunen en zorg op afstand mogelijk maken, met als doel duurzamere en kwalitatief goede zorg te bieden. Zowel het ministerie van VWS als de Vereniging Gehandicaptenzorg Nederland (VGN) zien eHealth als een belangrijke pijler voor toekomstige zorg. Zorgorganisaties nemen verschillende initiatieven om eHealth te integreren in hun zorg- en dienstverlening.

De zorg voor mensen met een verstandelijke beperking kenmerkt zich door levenslange ondersteuning op verschillende levensgebieden zoals zelfzorg, wonen, werk en participatie in de maatschappij. Deze ondersteuning varieert afhankelijk van de ernst van de beperking en de ondersteuningsbehoeften. Dit proefschrift richt zich specifiek op twee zorgvormen: ondersteuning en psychologische behandeling (c.q. therapie). Onder ondersteuning worden strategieën verstaan om ontwikkeling, welzijn en zelfredzaamheid te bevorderen, waarbij de intensiteit afhangt van context, levensfase, vaardigheden en bijkomende problematiek. Psychologische therapie omvat interventies gebaseerd op psychologische theorieën die gericht zijn op het veranderen van gedrag, interpersoonlijke relaties en systemen. Hoewel er enige aanwijzingen zijn dat cognitieve gedragstherapie effectief kan zijn bij bijvoorbeeld angststoornissen, is er beperkt bewijs voor de effectiviteit van andere therapievormen bij gedragsproblemen. Groepsinterventies lijken over het algemeen effectiever te zijn dan individuele

therapieën voor psychische problemen, en digitale technologie wordt slechts in beperkte mate toegepast.

eHealth wordt in dit proefschrift gedefinieerd als het gebruik van internet of gerelateerde technologieën om gezondheid en welzijn te bevorderen en gezondheidszorg te ondersteunen. eHealth biedt mogelijkheden voor zelfregie, versterkt de samenwerking tussen zorgprofessionals en vergroot de betrokkenheid van het sociale netwerk. eHealth kan op verschillende manieren worden ingezet, bijvoorbeeld via beeldbellen, en kan zowel zelfstandig als in hybride vorm (afwisselend zelfstandig en ondersteund door een professional) worden aangeboden.

Uit eerder onderzoek blijkt dat eHealth bijdraagt aan meer autonomie van mensen met een verstandelijke beperking. Toch twijfelen veel zorgprofessionals of eHealth geschikt is voor deze doelgroep. Tijdens de COVID-19-pandemie nam het gebruik van eHealth sterk toe, maar er is nog steeds weinig bekend over de rol van zorgprofessionals bij de invoering ervan in de zorg voor mensen met een verstandelijke beperking. De acceptatie van eHealth door zorgprofessionals is essentieel voor een succesvolle implementatie. Sommige zorgprofessionals zien eHealth als een kans om de communicatie te verbeteren, terwijl anderen twijfels hebben over de kwaliteit van zorg op afstand. Dit proefschrift onderzocht de factoren die de intentie en het gebruik van eHealth door zorgprofessionals beïnvloeden. Het UTAUT-model (Unified Theory of Acceptance and Use of Technology) werd gebruikt om te begrijpen hoe zorgprofessionals eHealth accepteren in hun werk met cliënten. Daarnaast werden twee aangepaste meetinstrumenten ontwikkeld om de samenwerking tussen zorgprofessional en cliënt, met en zonder eHealth, te meten.

## **Opbouw van het proefschrift**

De beschikbare wetenschappelijke kennis over eHealth ter ondersteuning van het dagelijks leven van mensen met een licht verstandelijke beperking en in psychologische therapie is besproken in een systematische en een scoping review (hoofdstuk 2 en 3). Uit implementatieonderzoek blijkt dat het begrijpen van verschillende gebruikersperspectieven bijdraagt aan een succesvolle invoering in de zorg, waarbij zorgprofessionals een sleutelrol spelen. Dit leidde tot een verdiepend onderzoek naar de ervaringen van cliënten met een verstandelijke beperking, hun naasten en zorgprofessionals (hoofdstuk 4). Daarnaast hebben we specifiek gekeken naar de ervaringen van therapeuten, voor wie beeldbellen tijdens de eerste lockdown van de COVID-19-pandemie geen optie, maar een noodzaak was om hun werk voort te zetten (hoofdstuk 5). Om beter inzicht te krijgen in de invloed van eHealth op de samenwerking in de klinische praktijk en toekomstig onderzoek, hebben we twee bestaande werkalliantie-vragenlijsten aangepast voor zorgprofessionals die werken met mensen met een licht verstandelijke beperking, en deze instrumenten onderzocht

op hun psychometrische kwaliteit (hoofdstuk 6). Tot slot hebben we de toepasbaarheid van het UTAUT-model geëvalueerd, met enkele aanpassingen en toevoegingen, voor onderzoek in de zorg voor mensen met een verstandelijke beperking. Daarbij hebben we de acceptatie en het gebruik van eHealth in twee cross-sectionele studies (uit 2018 en tijdens de COVID-19-pandemie in 2021) onder begeleiders en behandelaren in deze sector onderzocht (hoofdstuk 7).

## Hoofdstuk 2 Systematische literatuur review

Dit hoofdstuk beschrijft een systematische literatuurstudie naar eHealth-toepassingen ter ondersteuning van mensen met een licht verstandelijke beperking in het dagelijks leven. Zeven databases (Embase, Medline, Cochrane, Web of Science, PsycINFO, CINAHL en Google Scholar) werden doorzocht voor relevante studies uit 1996-2019. Inclusiecriteria waren: a) mensen met een licht verstandelijke beperking (IQ 50-69), b) gebruik van eHealth/technologie voor ondersteuning, en c) individuele psychologische of gedragsuitkomsten. Van de 46 geïnccludeerde studies gebruikten de meesten een single-case of groepsdesign. De kwaliteit werd beoordeeld met het EMDEBP-instrument van Reichow. Van de 36 single-case studies hadden 26 een acceptabele tot goede beschrijving; voor de groepsstudies waren 9 van de 10 onvoldoende beschreven. De studies werden geanalyseerd met Scherer's MPT-model, dat drie aspecten benadrukt voor effectief gebruik van technologie: 1) kenmerken van mensen met licht verstandelijke beperking (mogelijkheden, voorkeuren, behoeften), 2) omgevingsfactoren (context en ondersteuning), en 3) kenmerken van de technologie.

De review leverde drie hoofdconclusies op. Ten eerste werd in de meeste studies geen rekening gehouden met persoonlijke voorkeuren bij het kiezen van eHealth-toepassingen, waardoor gepersonaliseerd maatwerk ontbreekt. Ten tweede speelden belangrijke betrokkenen, zoals familie en begeleiders, zelden een rol bij de selectie of implementatie van technologie, hoewel zij cruciaal zijn voor succes. Ten derde bleek dat mensen met een licht verstandelijke beperking eHealth effectief kunnen gebruiken via gestructureerde trainingen, waarbij technologie vaak kan worden aangepast aan persoonlijke voorkeuren. Drie functies van eHealth werden geïdentificeerd: ondersteuning van het leerproces, zelfondersteuning in specifieke contexten (bijv. werk), en communicatie met zorgprofessionals op afstand. Hoewel eHealth potentie toont voor ondersteuning in het dagelijks leven, is het onderzoek van bescheiden kwaliteit en staat het nog in de kinderschoenen.

## Hoofdstuk 3 Scoping literatuur review

Hoofdstuk 3 geeft een overzicht van psychologische interventies uit 33 studies waarin eHealth werd ingezet voor de behandeling van psychische en/of gedragsproblemen bij mensen met een verstandelijke beperking. De meeste studies gingen over individuele psychologische behandelingen die in de persoonlijke leefomgeving werden uitgevoerd en gebaseerd waren op gedragstherapeutische principes. Twee studies onderzochten ouder-kind behandelingen, en twee studies keken naar het gebruik van eHealth in groepsbehandelingen. Naast gedragstherapie werden ook cognitieve gedragstherapie (CGT), de gehechtheidsinterventie Cirkel van Veiligheid, systemische ouder-kind behandelingen, mindfulness, en in één studie een op praktijkervaring gebaseerde interventie ter voorkoming van kindermishandeling toegepast.

De psychologische eHealth-behandelingen richtten zich zowel op kinderen als volwassenen, met de nadruk op mensen met een ernstige of zeer ernstige verstandelijke en meervoudige beperking. De behandelingen waren bedoeld om zelfbeschadigend, stereotype of probleemgedrag te verminderen en adaptief gedrag aan te leren. Voor mensen met een matige tot lichte verstandelijke beperking waren de behandelingen vooral gericht op het verminderen van angst- en stemmingsstoornissen. De behandelingen werden uitgevoerd door verschillende personen, waaronder therapeuten en psychologen, maar vaak ook door ouders, leerkrachten, begeleiders of onderzoeksassistenten onder toezicht van een psycholoog.

Er waren vier manieren waarop eHealth werd gebruikt in de behandelingen:

1. Voor, tijdens en na de sessies werden afbeeldingen of videomateriaal van gewenst gedrag of vaardigheden via een eHealth-toepassing (zoals een tablet) bekeken om deze vaker in het dagelijks leven toe te passen.
2. Via beeldbellen of chat werden cliënten door zorgprofessionals gecoacht in het omgaan met emoties en het leren van adaptief gedrag. Ouders werden op afstand gecoacht om de interventie bij hun kind uit te voeren.
3. In cognitieve gedragstherapie werkten cliënten op de computer met avatar-personages en sociale scripts om angstige en depressieve gevoelens te verminderen.
4. Sensoren detecteerden gewenst gedrag, waarna een beloning zoals een favoriete muziekclip of video werd afgespeeld als positieve bekrachtiging.

De scoping review laat zien dat eHealth nog een beperkte rol speelt in psychologische behandelingen voor mensen met een verstandelijke beperking en probleemgedrag of psychische problemen. Toch biedt eHealth mogelijkheden voor real-time begeleiding op afstand door zorgverleners en ouders. Ook kan eHealth een nuttig hulpmiddel in de behandeling zijn om gewenst sociaal gedrag aan te leren en toe te passen in het dagelijkse leven.

## Hoofdstuk 4 Focusgroep studie onder cliënten, naasten en zorgprofessionals

Hoofdstuk 4 beschrijft de verwachtingen en ideeën van cliënten, naasten en zorgprofessionals over het gebruik van eHealth voor ondersteuning in het dagelijks leven, gebaseerd op een kwalitatieve focusgroep studie. Er namen 16 personen deel aan de drie focusgroepen: 8 mensen met een verstandelijke beperking, 4 mannelijke familieleden en 4 zorgprofessionals. Bekende eHealth-toepassingen waren onder andere algemene sociale media, domotica voor toezicht, e-mail, WhatsApp, beeldbellen en specifieke toepassingen zoals een website voor mensen met een verstandelijke beperking en spraakcomputers voor ondersteunende communicatie (AAC). Zorgprofessionals waren ook bekend met sensortechnologie voor het meten van fysiologische reacties op stress en gaven aan dat eHealth een breed begrip is.

Zowel mensen met een verstandelijke beperking als zorgprofessionals zagen meer eigen regie als een groot voordeel van eHealth. Daarnaast werden meer onafhankelijkheid en verbeterde, effectievere zorg genoemd als belangrijke voordelen. Naasten vonden het positief dat ze door digitale rapportages beter geïnformeerd konden blijven. Tegelijkertijd brachten ze zorgen naar voren over privacy- en veiligheidsrisico's en het gebrek aan digitale vaardigheden bij hun familielid met een verstandelijke beperking. Voor mensen met een verstandelijke beperking was het belangrijk dat voor hen cruciale personen betrokken werden bij het proces.

Als nadeel van eHealth werd genoemd dat het geen vervanging kan zijn voor persoonlijk contact. Ook werd de inzet van eHealth bemoeilijkt door een gebrek aan apparaten zoals mobiele telefoons of tablets, een stabiele internetverbinding, tijdsgebrek bij zorgprofessionals en onvoldoende ICT-ondersteuning vanuit de organisatie. Positieve factoren waren dat technologie het eenvoudiger maakt om belangrijke mensen van de cliënt te betrekken bij de zorg. Om eHealth echt van waarde te laten zijn, is het belangrijk om aan te sluiten bij de behoeften van mensen met een verstandelijke beperking, zoals het gebruik van visuele hulpmiddelen en eenvoudige taal. Het werd ook als relevant beschouwd dat sommige mensen, bijvoorbeeld ouderen of mensen met weinig kennis van eHealth, minder geneigd zijn om eHealth te gebruiken.

## Hoofdstuk 5 Kwalitatieve studie onder therapeuten tijdens COVID-19

Hoofdstuk 5 beschrijft een kleinschalige, kwalitatieve studie onder 5 psychologen/orthopedagogen en 2 vaktherapeuten (psychomotorische en beeldende therapie)



tijdens de eerste lockdown als gevolg van de COVID-19-pandemie. Zij deden diagnostisch onderzoek en boden therapie via beeldbellen aan mensen met een licht verstandelijke beperking. De therapeuten deelden hun ervaringen via zelf ingezonden berichten (audio en e-mail).

Uit een thematische analyse kwamen vijf hoofdthema's naar voren: 1) de noodzaak om direct over te schakelen naar een virtuele werkwijze, 2) het ontwikkelen van nieuwe manieren om cliënten met een licht verstandelijke beperking te helpen omgaan met de COVID-19-gerelateerde stress en de therapie voort te zetten, 3) het gebrek aan geschikte apparatuur voor alle deelnemers aan de beeldbelsessies, 4) de beperkingen van virtueel contact met mensen met een licht verstandelijke beperking, en 5) onverwachte kansen om psychologisch onderzoek en therapie toch op afstand te kunnen voortzetten.

Het gebruik van beeldbellen moest snel worden aangeleerd, wat veel flexibiliteit en tijd vergde. Aanvankelijk voelden de therapeuten zich onwennig en onvoldoende voorbereid om diagnostiek en therapie via beeldbellen aan te bieden, maar dit werd na verloop van tijd makkelijker. Beeldbelsessies met zeer emotionele cliënten of complexe gezinnen, waarbij de interactie moeilijk zichtbaar was op het scherm, bleken echter lastig. Therapeuten hielpen cliënten vaardigheden te ontwikkelen en te ondersteunen bij het omgaan met de stress en onzekerheid door de pandemie. Het kiezen van de juiste cliënten, behandelingen (zoals EMDR bij complex trauma) en geschikte onderwerpen voor beeldbelsessies vereiste zorgvuldige afwegingen.

Toegang tot de juiste apparatuur, gebruiksvriendelijke beeldbeltoepassingen en een stabiele internetverbinding waren voor zowel de cliënt als de therapeut essentiële voorwaarden. Niet alle functionaliteiten van de beeldbelsoftware waren bekend bij therapeuten, waardoor bijvoorbeeld het digitale whiteboard niet werd gebruikt. Ook hadden cliënten met een licht verstandelijke beperking moeite met planning en structuur, wat het lastig maakte om op tijd en in de juiste omgeving aanwezig te zijn voor de sessies. Toch bracht deze periode ook onverwachte voordelen, zoals een beter zicht op de thuissituatie van de cliënt en de mogelijkheid om vaardigheden direct in de juiste context toe te passen, wat bijdroeg aan het generaliseren van het geleerde.

## **Hoofdstuk 6 Validatie werkalliantie meetinstrumenten**

Hoofdstuk 6 beschrijft hoe twee bestaande werkalliantie-vragenlijsten zijn aangepast om beter inzicht te krijgen in hoe eHealth de samenwerking tussen begeleider of therapeut en een persoon met een licht verstandelijke beperking beïnvloedt. Het doel was om een kwantitatief meetinstrument te ontwikkelen waarmee zorgprofessionals

kunnen beoordelen hoe zij de samenwerking met cliënten met een licht verstandelijke beperking ervaren, zowel met als zonder het gebruik van eHealth in de ondersteuning of psychologische therapie. Daarnaast kunnen zorgprofessionals met deze vragenlijsten veranderingen in de samenwerkingsrelatie gedurende de begeleiding en behandeling in kaart brengen.

De bestaande vragenlijsten zijn methodisch aangepast voor gebruik in de zorg voor mensen met een verstandelijke beperking, in samenwerking met een expertgroep van zorgprofessionals uit deze sector. Naast suggesties om de begrijpelijkheid van de items te verbeteren, werd aanbevolen om in de items meer nadruk te leggen op het gedeelde verantwoordelijkheidsgevoel en de ondersteuningsgerichte benadering in plaats van een probleemgerichte aanpak. Dit sluit beter aan bij de context van de zorg voor mensen met een verstandelijke beperking.

Uit een confirmatieve factoranalyse en betrouwbaarheidstoetsing bleek dat de 3-factorstructuur van de aangepaste Working Alliance-vragenlijst (met subschalen voor emotionele binding, overeenstemming over doelen en overeenstemming over taken/activiteiten) een acceptabele tot goede modelfit had, met een uitstekende Cronbach's alpha en McDonald's omega voor de totale schaal. De Technical Alliance-vragenlijst (die de werkalliantie meet bij het gebruik van eHealth) vertoonde, na het verwijderen van één item, ook een acceptabele modelfit en een uitstekende Cronbach's alpha en McDonald's omega voor de totale schaal. De resultaten van de drie subschalen (band, doelen en taken/activiteiten) lieten een acceptabele tot goede interne consistentie zien.

## **Hoofdstuk 7 Vragenlijst studies acceptatie en gebruik van eHealth (2018 en 2021)**

Hoofdstuk 7 beschrijft een kwantitatieve studie waarin we, via een online survey, onderzochten hoe bekend begeleiders en behandelaren (psychologen, orthopedagogen en vaktherapeuten) zijn met eHealth-toepassingen, in hoeverre ze deze daadwerkelijk gebruiken en hoe ze de acceptatie van eHealth ervaren. Voor dit onderzoek werd het UTAUT-model gebruikt, dat vier factoren (meerwaarde, inspanning, sociale invloed en randvoorwaarden) identificeert als voorspellers van de intentie om eHealth te gebruiken. We toetsten de geschiktheid van dit model, zowel in zijn oorspronkelijke vorm als met extra items voorgesteld door zorgprofessionals uit de gehandicaptenzorg.

In totaal werden 19 items van het UTAUT-model voorgelegd aan twee groepen zorgprofessionals die eHealth al in hun werk gebruiken. De herkenbaarheid en toepasbaarheid van de items voor de gehandicaptenzorg werden beoordeeld. Eén item

werd aangepast voor de Nederlandse context en zes aanvullende items over eHealth in de zorg voor mensen met een verstandelijke beperking werden toegevoegd. Naast UTAUT-items werden vragen over demografische gegevens, eHealth-toepassingen, en ontvangen training opgenomen. In 2021 is de meting aangevuld met vragen over werkalliantie en de invloed van COVID-19 op eHealth-gebruik.

De confirmatieve factoranalyse (CFA) van het UTAUT-model leverde voor de data uit 2018 geen adequate resultaten op, waarna een exploratieve factoranalyse (EFA) vijf factoren identificeerde die de acceptatie van eHealth beïnvloedden: 1) ervaren meerwaarde, 2) gemak en zelfvertrouwen, 3) sociale druk van collega's en steun van de manager, 4) organisatorische steun, en 5) randvoorwaarden bij cliënten (zoals apparaten en digitale vaardigheden). Drie items vormden de factor gedragsintentie.

Naast de validatie van het UTAUT-model, beschreef de studie ook het gebruik van eHealth-toepassingen en de mate van acceptatie. In 2018 deden 311 zorgprofessionals mee aan het onderzoek, en in 2021 waren dit er 326. De acceptatiescores bleven stabiel, ondanks de toegenomen ervaring met eHealth door COVID-19, waarbij vooral beeldbellen vaker werd gebruikt. Hoewel Virtual Reality bekend was bij veel zorgprofessionals, werd deze technologie slechts beperkt toegepast.

Om de invloed van de vijf factoren op gedragsintentie te meten, werd een multi-regressieanalyse uitgevoerd. De factoren verklaarden in 2018 samen 47% van de gedragsintentie om eHealth te gebruiken, waarbij alle factoren, behalve sociale druk, een significant effect hadden. In 2021 verklaarden de factoren 43% van de gedragsintentie, met ervaren meerwaarde en organisatorische steun als belangrijkste voorspellers. Ook de invloed van UTAUT-moderatoren zoals leeftijd en ervaring werd onderzocht. De resultaten bieden aanknopingspunten voor een gedifferentieerde aanpak om de implementatie van eHealth in de zorgpraktijk te verbeteren.

## Hoofdstuk 8 Algemene discussie

Hoofdstuk 8 bespreekt de belangrijkste conclusies, sterke punten en beperkingen van het onderzoek en geeft aanbevelingen voor beleid, de zorgpraktijk en toekomstig onderzoek. De vier belangrijkste conclusies van dit proefschrift zijn

### 1. Voorzichtig optimisme over eHealth

De beschikbare wetenschappelijke literatuur toont kansen voor het bevorderen van praktische vaardigheden, eigen regie en zelfstandigheid van mensen met een licht verstandelijke beperking, mits afgestemd op hun behoeften en mogelijkheden. eHealth maakt begeleiding en therapie op afstand mogelijk,

waardoor zorgprofessionals op afstand aanwezig kunnen zijn en vaardigheden in de eigen leefomgeving (zoals thuis of op het werk) kunnen worden geoefend. Beeldbelbehandelingen via ouders, leerkrachten of begeleiders bieden de kans om de zorg toegankelijk te houden, zoals tijdens de pandemie. De meeste studies zijn echter casestudies met kleine groepen en richten zich op de haalbaarheid van eHealth, zonder dat mensen met een verstandelijke beperking zelfstandig eHealth doorlopen. Daarom staat onderzoek naar de effectiviteit van eHealth nog in de kinderschoenen, en moeten we bescheiden blijven over de mogelijkheden.

## 2. Het belang van ervaringskennis

Het gebruik van de ervaringen, behoeften, voorkeuren en digitale vaardigheden van mensen met een verstandelijke beperking, evenals de ervaringskennis van hun naasten, is niet vanzelfsprekend, ondanks de nadruk op het belang hiervan in de literatuur. Naasten en begeleiders spelen een cruciale rol in de dagelijkse ondersteuning, en samenwerking met hen is essentieel om eHealth toegankelijker te maken. Tijdens de pandemie hielpen familieleden vaak bij ICT-problemen en zagen ze welke digitale vaardigheden nodig waren om eHealth te gebruiken. Ervaringskennis en een positieve houding van familieleden zijn belangrijke factoren in het succes van eHealth. Dit proefschrift laat zien dat familieleden, begeleiders en leerkrachten een belangrijke rol kunnen spelen in het gebruik van eHealth en dat dit kansen biedt voor samenwerking.

## 3. De waarde van modellen en theorieën

Modellen en theorieën die vaak worden toegepast in bredere gezondheidszorgonderzoeken vormden de basis voor drie studies in dit proefschrift. Deze theoretische kaders boden de mogelijkheid om zowel de technologische als menselijke kant van eHealth binnen zorgorganisaties te onderzoeken. Het MPT- en UTAUT-model hielpen om de specifieke behoeften van zorgorganisaties voor mensen met een verstandelijke beperking te identificeren en inzicht te krijgen in de adoptie van eHealth door zorgprofessionals. Daarnaast bood Bordin's theorie over de werkalliantie richting bij het ontwikkelen van vragenlijsten voor de samenwerking tussen cliënten en zorgprofessionals, zowel met als zonder eHealth.

## 4. De veranderende rol van zorgprofessionals

De manier waarop zorgprofessionals hun werk organiseren, verandert door het gebruik van eHealth. Het kiezen van de juiste eHealth-toepassing, het beoordelen van de meerwaarde voor de zorg en het vertrouwd raken met de technologie vraagt nieuwe vaardigheden. Daarnaast moeten zorgprofessionals empathisch zijn voor de digitale stress van cliënten. Het kan een uitdaging zijn om traditionele begeleiding of therapie te vertalen naar een digitale variant, en dit kan de implementatie van eHealth belemmeren. Deze veranderende rol vraagt van zorgorganisaties dat ze hun medewerkers goed ondersteunen en trainen in het gebruik van eHealth, en oog

hebben voor de randvoorwaarden die nodig zijn om eHealth succesvol in te zetten bij cliënten.

### **Sterktes en beperkingen van dit proefschrift**

Het betrekken van zorgprofessionals als experts bij de ontwikkeling van de aangepaste vragenlijsten en UTAUT-items is een sterk punt van dit proefschrift. Dit geldt ook voor de nadruk op het perspectief van verschillende eHealth-gebruikers in de zorgpraktijk, met speciale aandacht voor de rol van zorgprofessionals. Hoewel dit proefschrift zich beperkt aandacht heeft voor contextuele factoren, is aanvullend onderzoek naar andere lagen binnen zorgorganisaties, die de implementatie van eHealth beïnvloeden, noodzakelijk. Een beperking is dat de resultaten van dit onderzoek niet direct generaliseerbaar zijn naar alle zorgprofessionals in de sector. Het is waarschijnlijk dat vooral digitaal vaardige mensen met affiniteit voor eHealth hebben deelgenomen aan de studies. Een ander sterk punt van dit onderzoek is de brede focus op meerdere eHealth-toepassingen en de deelname van zorgprofessionals uit verschillende sectoren, zoals ambulante zorg en 24-uurszorg. Toch kunnen er geen definitieve conclusies worden getrokken over welke eHealth-toepassing het meest geschikt is voor specifieke ondersteuningsvragen of zorgsectoren. Toekomstig onderzoek moet zich richten op het identificeren van welke eHealth-toepassingen haalbaar, geschikt en effectief zijn voor de verschillende hulpvragen binnen deze doelgroep.

### **Implicaties voor toekomstig onderzoek**

Moderne technologieën maken het mogelijk om direct data te verzamelen, bijvoorbeeld via mobiele telefoons, om individuele ervaringen van mensen te meten (zoals met experience sampling). In andere doelgroepen worden deze technieken gebruikt om eHealth-interventies te personaliseren door middel van persoonlijke gegevens. Voor de zorg aan mensen met een verstandelijke beperking verdienen deze technieken echter nader onderzoek. Ze kunnen mogelijk helpen bij het evalueren van de effectiviteit van eHealth in interventies. Dit proefschrift toonde verder aan dat het UTAUT-model gedeeltelijk de intentie en het gebruik van eHealth door zorgprofessionals kan verklaren, maar dat er ook nog onbekende factoren een rol spelen in de acceptatie. Leeftijd kwam naar voren als een mogelijke factor die de relatie tussen acceptatie en gebruik beïnvloedt. Daarnaast benadrukt de literatuur dat digitaal leiderschap van managers cruciaal is voor succesvolle implementatie van eHealth, maar hun rol in deze zorgsector is nog onderbelicht. Om de implementatie in de zorgpraktijk te onderzoeken, bieden theoretische modellen zoals de Normalization Process Theory, het RE-AIM raamwerk en het NASSS-model waardevolle handvatten om de complexe lagen van implementatie te bestuderen, van individuele gebruikers tot overheidsbeleid. Tot slot is het perspectief van mensen met een verstandelijke beperking zelf relatief weinig belicht in dit proefschrift. Er is behoefte aan verder onderzoek, inclusief de ontwikkeling van een cliëntversie van

de vragenlijsten voor (digitale) werkalliantie, om een vollediger beeld te krijgen van hoe eHealth door deze doelgroep wordt ervaren en hoe zij de invloed van eHealth op de samenwerkingsrelatie ervaren.

### **Implicaties voor beleid en de zorgpraktijk**

Met betrekking tot beleid valt op dat de zorg voor mensen met een verstandelijke beperking, ondanks het grote aantal zorgprofessionals en het langdurige karakter van de sector, nauwelijks vertegenwoordigd is in beleidsdocumenten en grootschalige studies, zoals de jaarlijkse eHealth-monitor. De COVID-19-pandemie toonde aan dat het gebruik van eHealth om zorg toegankelijk te houden voor deze doelgroep kwetsbaar en complex kan zijn, vooral nu de digitalisering van de gezondheidszorg toeneemt. Zonder rekening te houden met specifieke behoeften kan digitalisering de toegankelijkheid van zorg verder onder druk zetten en leiden tot grotere gezondheidsverschillen, wat vooral nadelig is voor mensen met een verstandelijke beperking. Dit proefschrift benadrukt dat eHealth menselijke zorg niet mag vervangen, maar als aanvulling moet worden gezien. Ook moet het recht van cliënten die geen zorg via eHealth willen ontvangen, worden gerespecteerd.

Voor zorgorganisaties biedt dit proefschrift verschillende implicaties. Ten eerste biedt het MPT-model een gestructureerde aanpak om, op basis van het functioneringsprofiel en de persoonlijke ondersteuningsbehoeften, eHealth-toepassingen beter te implementeren. Deze aanpak vergroot de kans op succesvol gebruik van eHealth in de praktijk. Verder maakt eHealth zorg op afstand en coaching van betrokkenen gemakkelijker, wat kan bijdragen aan passende zorg. Een andere belangrijke implicatie is de beschikbaarheid van twee valide en betrouwbare vragenlijsten om de (digitale) werkalliantie te meten. Hiermee kunnen zorgprofessionals de kwaliteit van de samenwerking met cliënten evalueren, en deze vragenlijsten kunnen worden geïntegreerd in routinematige uitkomstmonitoring (ROM), wat de kwaliteit van de zorg bevordert. Zorgorganisaties moeten daarnaast een duidelijke visie op eHealth formuleren en oog hebben voor de verschillende ondersteuningsbehoeften en scholingsvragen van zowel jongere als oudere medewerkers. Een goede technische infrastructuur is hierbij essentieel.

Wanneer eHealth wordt afgestemd op de specifieke behoeften, mogelijkheden en wensen van de persoon met een verstandelijke beperking, en wanneer het netwerk van de cliënt erbij wordt betrokken, kan eHealth een waardevolle bijdrage leveren aan gezondheid, psychologisch welzijn en participatie, terwijl het menselijke aspect van de zorg behouden blijft.

Publiekssamenvatting/public  
summary

## Publiekssamenvatting

### Achtergrond

In de zorg voor mensen met een verstandelijke beperking wordt toenemend gebruik gemaakt van eHealth, de toepassing van digitale technologie, om zorg en ondersteuning te bieden. Ondanks de mogelijkheden om de eigen regie, participatie en zelfredzaamheid te versterken en zorg op afstand te bieden met eHealth, zoeken zorgorganisaties hoe ze eHealth een plek kunnen geven in hun zorg- en dienstverlening. Zorgprofessionals voelen zich onzeker of en hoe zij eHealth het beste kunnen integreren in hun werk als begeleider of behandelaar voor mensen met een verstandelijke beperking en welke betekenis eHealth gebruik voor de samenwerkingsrelatie heeft. Of en op welke wijze eHealth van meerwaarde kan zijn in de ondersteuning van het dagelijks leven en in psychologische behandeling van mensen met een verstandelijke beperking, is een uitdagend vraagstuk. Ook hoe door mensen met een verstandelijke beperking zelf, hun naasten en betrokken zorgprofessionals tegen het gebruik van eHealth aangekeken wordt, is nog een onderbelicht terrein.

### Onderzoeken in dit proefschrift

In zes deelonderzoeken is gekeken naar het gebruik van eHealth bij de ondersteuning en psychologische behandeling van mensen met een (licht) verstandelijke beperking. Eerst werd onderzocht wat er al bekend is over eHealth in de wetenschappelijke literatuur. Het eerste deelonderzoek beschrijft hoe eHealth het dagelijks leven kan ondersteunen, terwijl het tweede deelonderzoek kijkt naar eHealth in psychologische therapie en behandeling. Hoe mensen met een verstandelijke beperking, hun naasten en zorgprofessionals aankijken tegen de inzet van eHealth en het gebruik ervaren is onderzocht in het derde deelonderzoek. Tijdens de eerste lockdown van COVID-19-pandemie konden psychologen en vaktherapeuten alleen op afstand diagnostisch onderzoek doen en therapie geven via beeldbellen. Hierdoor werd het gebruik van eHealth geen keuze, maar een noodzaak. Hun ervaringen werden in het vierde deelonderzoek verzameld. Omdat mensen met een verstandelijke beperking vaak langdurige ondersteuning op verschillende levensgebieden nodig hebben, is de vraag of en hoe eHealth de samenwerking, de werkaliantie, tussen cliënten en zorgprofessionals beïnvloedt. Om hier meer zicht op te krijgen, is het gewenst om deze invloed systematisch in kaart te kunnen brengen. Deelonderzoek vijf beschrijft de ontwikkeling van twee vragenlijsten voor werkaliantie, zowel met als zonder eHealth, die speciaal voor deze groep zijn aangepast. Tot slot richt het zesde en laatste deelonderzoek zich op de factoren die de acceptatie en het gebruik van eHealth door zorgprofessionals – in dit proefschrift begeleiders en behandelaren - beïnvloeden.



## Conclusie

eHealth biedt mogelijkheden om praktische vaardigheden te ontwikkelen, in het dagelijks leven toepassen en professionele ondersteuning en psychologische behandeling op afstand te realiseren. Over de linie zien zowel mensen met een verstandelijke beperking, naasten als zorgprofessionals kansen voor meer eigen regie, onafhankelijker zijn van cliënten zelf en de onderlinge communicatie en samenwerking met cliënten en de mensen die bij hen betrokken zijn te verbeteren. Zorgprofessionals staan neutraal tegenover de inzet van eHealth, waarbij de meerwaarde voor hun werk en goede organisatorische ondersteuning de belangrijkste factoren in de acceptatie van eHealth in de zorgpraktijk zijn. Zorgprofessionals ervaren veel ruimte om zelf te mogen beslissen of ze eHealth inzetten en de aandacht voor scholing aangaande eHealth is nog beperkt. Als eHealth goed wordt afgestemd op de behoeften, mogelijkheden en wensen van mensen met een verstandelijke beperking, en het netwerk rondom de cliënt hierbij wordt betrokken, kan eHealth bijdragen aan welbevinden en het bieden van zorg en ondersteuning op maat. Daarbij blijft het van belang om eHealth niet als vervanger van menselijk contact te zien, maar ernaast, zodat het menselijke contact in de zorg behouden blijft.

## Public summary

### Background

The utilisation of eHealth, defined as the application of digital technology in the provision of care and support, is becoming increasingly prevalent in the context of the care of individuals with intellectual disabilities. Notwithstanding the potential for eHealth to facilitate enhanced independency, participation and self-reliance, and the provision of care at a distance, care organisations are seeking to ascertain the optimal manner in which to incorporate eHealth into their care and services. Healthcare professionals are uncertain as to whether and how they can best integrate eHealth into their work as support staff or therapists for people with intellectual disabilities, and what significance eHealth use has for the working alliance. It is also unclear whether and in what way eHealth can add value in daily life support and psychological treatment of people with intellectual disabilities. Furthermore, there is a lack of research exploring how eHealth use is viewed by people with intellectual disabilities themselves, their relatives and involved healthcare professionals.

### Studies in the present thesis

The present thesis comprises six sub-studies, the objective of which was to examine the utilization of eHealth in the context of supporting and providing psychological therapy amongst individuals with (mild) intellectual disabilities. The initial stage of the thesis entailed an examination of the existing scientific literature on this topic. The first substudy delineated the manner in which eHealth can facilitate the activities of daily living, whereas the subsequent substudy examined the role of eHealth in psychological therapy. The third substudy investigated the views of people with intellectual disabilities, their relatives and healthcare professionals on eHealth and their experiences of its use in support. During the initial period of the global health crisis precipitated by the COVID-19 virus, psychologists and experience-based therapists were constrained to conducting diagnostic assessments and providing therapy remotely via videoconferencing. This rendered the utilization of eHealth not a mere option, but an indispensable necessity. Their experiences were collated in the fourth sub-study. Given that individuals with intellectual disabilities frequently require longterm care and support in various life domains, it is imperative to ascertain whether and to what extent eHealth impacts the collaboration and the working alliance between service users and healthcare professionals. To gain a more comprehensive understanding of this, it is essential to be able to systematically map this influence. Sub-study five describes the development of two work alliance questionnaires, both with and without eHealth, specifically adapted for this group. Finally, the sixth and final sub-study focuses on the factors influencing the acceptance and use of eHealth by healthcare professionals – in this thesis, support staff and therapists.

## Conclusion

In conclusion, eHealth presents a unique opportunity for the development of practical skills, their application in daily life, and the provision of remote professional support and psychological therapy. From the perspective of both people with intellectual disabilities, their relatives and care professionals, there is a consensus that improved self-direction, independence and improved communication and cooperation with service users and other relevant people involved are potential benefits of eHealth. The acceptance of eHealth in care practice by healthcare professionals is contingent upon the presence of two key factors: the added value that eHealth offers in terms of enhancing the work of healthcare professionals and the availability of robust organizational support. There is considerable scope for healthcare professionals to determine whether or not to utilise eHealth, and the focus of eHealth training remains relatively limited. If eHealth is properly tailored to the needs, possibilities and wishes of people with intellectual disabilities, and the network around the person is involved, eHealth can contribute to well-being and provide tailored care and support. It is important to ensure that eHealth is not viewed as a substitute for human contact, but rather as a complementary tool that can enhance the quality of human interaction in care.



Dankwoord

Curriculum vitae

Publicaties

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## CURRICULUM VITAE

Cathelijn Oudshoorn-Smit was born on the 30<sup>th</sup> of March, 1972 in Nieuw-Beijerland, the Netherlands. In 1989, she graduated from Senior general secondary education at Willem van Oranje in Oud-Beijerland. Afterwards, she studied Social Work at the University of Applied Studies in Rotterdam. After completing the study in 1993, she started a three-year master program Clinical Child and Adolescent Studies (Orthopedagogiek) at Leiden University. During her study, she worked as a student-assistant in a study of dr. Paul Verkerk at TNO-NIPG in Leiden and as an outreach support worker with the Macquarie early intervention program for young children with Down syndrome at MEE Zuid-Holland-Zuid.

In 1995, she started working as a junior orthopedagogue at a care organization for people with intellectual disabilities in Rotterdam (precursor of ASVZ) and wrote a policy paper about the pedagogical approach for young children with (profound and multiple) intellectual disabilities. After completing her study in 1997, she started to work as an orthopedagogue at ASVZ. In 2015, the research project eHealth in support and psychological therapy among people with intellectual disabilities started. Cathelijn works as a science practitioner, funded by ASVZ, in collaboration with the Academic Collaborative Centre Living with an intellectual disability (Tranzo, Tilburg University). This project was converted into a PhD project in 2019 and she was supervised by prof. dr. Petri Embregts (Tilburg University) and prof. dr. Heleen Riper (VU/Amsterdam UMC). The results of the studies within this PhD project are described in this thesis. She currently works as an orthopedagogue/healthcare psychologist, performs staff tasks in educating healthcare psychologists in care practice, and healthcare quality policy at ASVZ.

Cathelijn Oudshoorn-Smit werd geboren op 30 maart 1972 te Nieuw-Beijerland. In 1989 behaalde zij haar HAVO diploma aan de Willem van Oranje scholengemeenschap te Oud-Beijerland. Daarna studeerde zij Sociaal Pedagogische Hulpverlening aan de Hogeschool Rotterdam. Na het voltooien van deze studie in 1993, begon zij met een driejarige opleiding Pedagogische Wetenschappen, studierichting Orthopedagogiek, aan de Rijksuniversiteit Leiden. Tijdens haar studie werkte zij als student-assistent in een studie van dr. Paul Verkerk bij TNO-NIPG in Leiden en als ambulante begeleider met het Macquarie vroeghulp programma voor jonge kinderen met het syndroom van Down bij MEE Zuid-Holland-Zuid.

In 1995 begon zij als junior orthopedagoog bij SVVGR, een zorgorganisatie voor mensen met een verstandelijke beperking in Rotterdam, (voorganger van ASVZ) en schreef een beleidsnotitie over het pedagogisch behandelklimaat voor jonge kinderen met een meervoudige (en zeer ernstige verstandelijke) beperking. Sinds de afronding van haar

universitaire studie in 1997, werkt zij als orthopedagoog bij ASVZ. In 2015 startte het onderzoeksproject naar eHealth in de ondersteuning en psychologische behandeling van mensen met een verstandelijke beperking. Cathelijn werkte als science practitioner, gefinancierd door ASVZ, samen met de Academische Werkplaats Leven met een verstandelijke beperking (AWVB, Tranzo, Tilburg University). Dit project werd in 2019 omgezet naar een aanstelling als promovenda begeleid door prof. dr. Petri Embregts (Tilburg University) en prof. dr. Heleen Riper (VU/Amsterdam UMC). De uitkomsten van de studies binnen dit promotieproject zijn beschreven in deze thesis. Momenteel is zij werkzaam als orthopedagoog/Gz-psycholoog, praktijkopleider voor de opleiding tot gezondheidszorgpsycholoog en inhoudelijk kwaliteitsbeleidsmedewerker bij ASVZ.

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