

# Technology-assisted therapy for an adult with visual and intellectual impairments and separation anxiety: a single case study

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## Summary

Separation anxiety is highly prevalent among intellectually and visually impaired individuals, yet little research has been done into its treatment in this population. Due to delayed cognitive skills, these individuals struggle to develop the abstract concept of person permanence, which is necessary to diminish separation anxiety.

The first aim of this study was to investigate whether using technology alone or including caregivers was the most beneficial approach to developing person permanence using technology-assisted therapy. The caregivers received training in advance in an attachment-based protocol about securing attachment relationships with the participant. It was hypothesised that the inclusion of attachment figures in technology-assisted therapy would enhance the acquisition of the person permanence concept.

The second aim of this study was to determine whether technology-assisted therapy in tandem with the participation of caregivers consequently decreased separation anxiety and challenging behaviour in an adult with intellectual and visual impairment. It was hypothesised that the subject's anxiety and challenging behaviour levels would significantly decrease due to the intervention.

The final aim was to determine how the caregivers and the participant experienced this intervention. It was hypothesised that they would regard it as a positive experience.

This single-subject design used a pre-experimental quantitative approach. It was based on the familiar ABAB design and comprised six phases. Phase A served as baseline, giving the participants time to become acquainted with the technology. Phase B consisted of automated responses to the participant's messages. In phase C caregivers directed the active reply. The daily messages were discussed when the participant and caregiver reunited, incorporating the attachment-based protocol. Phase B and C were repeated. Phase D followed after the devices were handed in.

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The technology was a specially adapted touch iPhone with an application comprising coloured emoticons. When the participant was physically separated from the caregiver, he could send happy, sad, angry or scared emoticons, or request help. The caregiver, who had a similar device, responded by sending a pre-determined response such as acknowledging the participant's "I am angry" message with a "You are angry" message.

Due to the association between anxiety and challenging behaviour in this population, standardised instruments were used to measure changes in these behaviours. Repeated measure ANOVA and a non-parametric Friedman test were used to analyse the data, specifically comparing phase B and C. Overall, the results showed that behaviour did significantly change over the course of the intervention. The frequency of the various iPhone messages sent by the participant was recorded daily. ANOVA contrast results demonstrated significantly fewer anxious and angry messages sent during the C phases compared with the B phases. The professional caregivers recorded the frequency and intensity of anxiety and challenging behaviours. The ANOVA contrast results showed a significantly lower frequency and intensity of these behaviours in the C phases compared with the B phases.

A questionnaire was developed to evaluate the social validity of the intervention. The independent samples t-test demonstrated a significant difference between the mean scores rated by the caregivers at the beginning and the end of the invention. The participant and caregivers were positive about the intervention.

Although the results cannot be generalised, it can be concluded that the inclusion of caregivers in technology-assisted therapy can serve as an invaluable aid to developing the person permanence concept. The findings also indicate that the anxiety and challenging behaviour levels shown by the adult with ID and visual impairment decreased due to technology-assisted therapy applied by caregivers, while responses to the social validity of the intervention were positive.

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**KEY WORDS:** Separation Anxiety; Intellectual Disability; Visual Impairment; Self-controlled Technology; Single Case Study.



## Opsomming

Alhoewel skeidingsangs baie algemeen onder intellektueel- en visueel gestremde individue voorkom, is nog min navorsing oor die behandeling daarvan by sodanige individue gedoen. Weens verminderde kognitiewe vaardighede sukkel hierdie individue om die abstrakte konsep van “persoon-permanensie”, 'n konsep wat nodig is om skeidingsangs te verminder, te ontwikkel.

Die eerste doelwit van hierdie studie was om die die mees voordelige benadering tot die ontwikkeling van persoon-permanensie te bepaal: die gebruik van slegs tegnologie-gebaseerde metodes of tegnologie in samewerking met persoonlike versorgers. Die gekose versorgers het vooraf opleiding aangaande die protokol om 'n geneentheidsverhouding met die deelnemer op te bou, ontvang. Die hipotese is gehuldig dat die aanwesigheid van bekende versorgers in samehang met tegnologie-gesteunde terapie die verwerwing van die persoon-permanensie konsep sou vergemaklik.

Die tweede doelwit van hierdie studie was om te bepaal of die tegnologie-ondersteunde terapie in samewerking met die deelname van die versorgers verminderde voorkoms van skeidingsangs en uitdagende gedrag in 'n intellektueel- en visueel gestremde volwassene tot gevolg sou toon. Dit is veronderstel dat die deelnemer se ans en uittartende gedrag beduidend sou kon afneem as gevolg van die intervensie.

Die finale doelwit was om te bepaal hoe beide die versorgers en die deelnemer hierdie intervensie ervaar. Die hipotese was gehuldig dat hulle dit sou beskou as 'n positiewe ervaring.

Hierdie enkele-onderwerp ontwerp volg 'n pre-eksperimentele kwantitatiewe benadering. Dit is gebaseer op die bekende ABAB ontwerp en bestaan uit ses fases. Fase A dien as 'n basislyn, dit gee die deelnemers tyd om vertrouwd te raak met die tegnologie. Fase B behels outomatiese antwoorde op die deelnemer se boodskappe. Fase C is gerig op die

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versorgers se aktiewe respons. Die daaglikse boodskappe is bespreek tydens die hereniging van die deelnemer en versorger, met nakoming van die verhoudings-gebaseerde protokol. Fase B en C is herhaal. Fase D het gevolg nadat die toestelle ingehandig was. Die tegnologie bestaan uit 'n spesiaal aangepaste “touch iPhone” met 'n toepassing bestaande uit gekleurde “emoticons”. Wanneer die deelnemer fisies van die versorger geskei was, kon hy verskeie “emoticons”, byvoorbeeld gelukkig, hartseer, kwaad of bang “emoticons”, of versoek om hulp aan die versorger stuur. Die versorger, in besit van 'n soortgelyke toestel, het gereageer deur 'n voorafbepaalde reaksie, soos die erkenning van die deelnemer se "Ek is kwaad" boodskap, met 'n "Jy is kwaad" boodskap.

As gevolg van die assosiasie tussen angs en uittartende gedrag in die bepaalde bevolking, is gestandaardiseerde instrumente gebruik om veranderinge in hierdie gedrag te meet. “Repeated measure ANOVA” en 'n nie-parametriese Friedman toets is gebruik om die data te analiseer, spesifiek om fase B en C met mekaar te vergelyk. Algeheel beskou het die resultate getoon dat gedrag aansienlik verander het met die verloop van die intervensie. Die frekwensie van die verskillende iPhone boodskappe wat gestuur was deur die deelnemer is daaglik aangeteken. Die “ANOVA contrast” se resultate het getoon dat aansienlik minder angstig en kwaad boodskappe tydens die C fases in vergelyking met die B fases gestuur was. Die professionele versorgers het die frekwensie en intensiteit van angs en uitdagende gedrag aangeteken tydens die verloop van die intervensie. Die “ANOVA contrast” resultate het 'n aansienlike laer frekwensie en intensiteit van hierdie gedrag in die C fases in vergelyking met die B fases getoon.

'n Vraelys is ontwikkel om die sosiale geldigheid van die intervensie te evalueer. Die “independent t-test” het 'n beduidende verskil tussen die gemiddelde tellings toegeken deur die versorgers aan die begin en die einde van die intervensie getoon. Die deelnemer en versorgers was positief oor die intervensie.

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Alhoewel die resultate nie veralgemeen kan word nie, kan die afleiding gemaak word dat die insluiting van die versorgers in tegnologie-ondersteunde terapie kan dien as 'n waardevolle hulp om die konsep van persoon-permanensie konsep aan te leer. Die bevindinge dui ook aan dat die angs en protesterende gedragvlakke soos getoon deur 'n intellektueel- en visueel gestremde volwassene, afgeneem het as gevolg van tegnologie-ondersteunde terapie toegepas deur versorgers, terwyl die response op die sosiale geldigheid van die intervensie positief was.

**SLEUTELWOORDE:** Skeidingsang; Intellektuele Gestremdheid; Visuele Gestremdheid; Self-beheerde Tegnologie; Enkele Gevallestudie

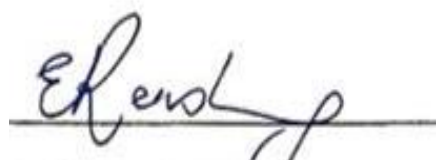
**Preface**

- This dissertation is in article format, complying with the requirements of rules A.5.4.2.7 as determined by the North-West University.
- The referencing and editorial style of this dissertation conform to the guidelines set out in the Publication Manual (6<sup>th</sup> edition) of the American Psychological Association (APA). The article will be compiled according to the guidelines of the journal to which the article will be submitted.
- The article will be submitted for possible publication in the Journal of Intellectual Disability Research.
- In order to present the dissertation as a unit, the page numbering is consecutive, starting from the introduction and proceeding to the references.
- Prof. Esmé van Rensburg, head supervisor, assisted with the peer review of this dissertation.
- Dr Paula Sterkenburg, co-supervisor, assisted in the analysis and interpretation of results as well as the peer review concerning the article.
- Prof. Esmé van Rensburg and Dr Paula Sterkenburg, co-authors of the article comprising this dissertation, have provided consent for the submission of this article for examination purposes for an MSc Research Psychology degree.

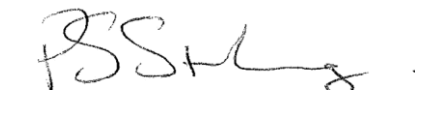
**Letter of permission**

Permission is hereby granted for the first author, D. Jonker, to submit the following article for examination purposes towards the attainment of an MSc degree in Research Psychology:

*Caregiver-mediated therapy for an adult with visual and intellectual impairment suffering from separation anxiety*

A handwritten signature in black ink, appearing to read 'E. van Rensburg', is written over a horizontal line.

Prof. E. van Rensburg  
Supervisor and co-author

A handwritten signature in black ink, appearing to read 'P. S. Sterkenburg', is written over a horizontal line.

Dr P. S. Sterkenburg  
Co-supervisor and co-author

**Proof of language editing**

**Michelle Coetzee** obtained the degree of Doctor of Philosophy in Theology from St Augustine College in Victory Park, Johannesburg, South Africa in 2014. A former actress and Amstel award-winning playwright (under her maiden name, Du Toit), she has 20 years' experience as a copy editor, rewrite sub-editor and mentor in the newspaper industry. She is also a published author – *Stories from the Prince of Mystery* (under her maiden name) and her master's thesis, *The Filioque Impasse – Patristic Roots*. Since obtaining her PhD, she has been working from home as a fulltime language editor, specialising in academic papers. She sources most of her work from the North-West University in Potchefstroom, South Africa, at which she appears on the list of approved language editors, as well as through an academic-editing online company, SCRiBBR, which is based in the Netherlands.

A handwritten signature in black ink. The first part is a large, stylized letter 'M' that loops back to the left. To the right of the 'M' is the name 'Coetzee' written in a cursive, handwritten style.

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Michelle Coetzee

# CAREGIVER-MEDIATED THERAPY FOR SEPARATION ANXIETY

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25 February 2015

Dear Deborah Jonker

## **Language editing**

This is to confirm that I edited your master’s dissertation, *Technology assisted therapy for an adult with visual and intellectual impairments and separation anxiety: a single case study*, and that I indicated the necessary grammatical corrections.

Although I took all reasonable precautions to ensure that all grammatical and stylistic corrections are indicated, you remain responsible for the final product. Therefore, please check these suggested corrections before applying them and, if possible, again perform a spell check after you have implemented them in order to eliminate typing errors.

Please contact me if there are any queries or if I can be of further assistance.

Yours sincerely

A handwritten signature in black ink, consisting of a large, stylized initial 'M' followed by the name 'Coetzee' in a cursive script.

---

Michelle Coetzee

## **Technology assisted therapy for an adult with visual and intellectual impairments and separation anxiety: a single case study**

### **SECTION 1: INTRODUCTION AND RATIONALE**

#### **1.1 Introduction**

This study investigated the use of technology-assisted therapy for an adult with visual and intellectual impairment. There is a high prevalence of separation anxiety in this population and one explanation for this is that it could be due to the absence or weak awareness of person permanence due to delayed cognitive development. The primary objective of this investigation was to evaluate the effectiveness of Technology-assisted Therapy for Separation Anxiety (TTSA) that was specifically developed for the purposes of this intervention. TTSA is an intervention aimed at reducing the anxiety and challenging behaviour levels of an adult with ID and visual impairment. More specifically, the objective was to determine the most effective means of facilitating the acquisition of the abstract concept of person permanence: by using technology alone or using technology to assist caregivers. The second aim was to determine whether TTSA decreased anxiety and challenging behaviour levels in an adult with intellectual and visual impairment. Finally, the last aim of the study was to determine how the caregivers and the participant experienced the intervention.

This section presents an introduction to the study. A gap in current research was identified, validating the need for the investigation into technology-assisted therapy. Since this study was done on secondary data, a brief overview will be given of the context of the study. The literature review comprises a survey of the existing research regarding the topic of intellectual and visual impairment, and the treatment of separation anxiety. A rationale for the



research paradigm that guides the study's methodology is also outlined. To conclude this section, the aims and hypotheses relevant to this study are formulated.

### **1.2 Contextualisation**

This study was done on secondary data that was collected in the Netherlands during the course of an intervention in which modern technology was used to enhance the individual's development towards independence. The title of the research project was: *Mobile technology to support relationship development, well-being and social participation*.

The primary objectives of the project were to test whether the implementation of the modern technology was effective in:

1. Reducing separation distress.
2. Reducing challenging behaviour.
3. Providing a positive experience of the intervention for both the caregivers and participant.

Six participants with visual and intellectual disabilities participated in the original study. All of them were under the care of an organisation that provides care for disabled persons. The main goal was to introduce the use of a specially developed mobile device during periods of separation from specific caregivers, and to thereby develop a sense of the mental presence of the caregivers that teaches the person that "out of sight" does not mean "out of heart".

Although six participants participated in the primary project, the current study involved a single subject design, thus reviewing one of the participant's data to investigate the use of technology-assisted therapy.

### 1.3 Problem statement and orientation

Intellectual disability (ID) in itself seriously affects psychosocial development and when it co-occurs with a visual impairment, it can be expected that the disability will be more severe (Evenhuis, Sjoukes, Koot, & Kooijman, 2009). One of these psychosocial problems is anxiety, identified to be often present in visually impaired persons with an intellectual disability. In particular, separation anxiety and panic disorders emerge frequently among children with ID (Došen, 2005; Emerson & Hatton, 2007). Nevertheless, studies on the treatment of these anxiety disorders have primarily focused on children without ID (Došen, 2005). Specifically, a void exists in the treatment of separation anxiety as studies relating to this population group focus mainly on phobic disorders. A review done by Hagopian and Jennett (2008) identified only 48 studies in 35 years concerning the treatment of persons with ID and anxiety, some being classified within the autism spectrum disorder, but none focussing on separation anxiety.

According to the stress-attachment model (Janssen, Schuengel, & Stolk, 2002), persons with ID are less equipped with coping skills and thus much more subject to psychopathologies such as anxiety than persons without ID (Greenberg, 1999). Research done by Došen (2005) indicated that clients with ID experience an impeded first phase of emotional development, which obstructs their cognitive development, and as such are more vulnerable to separation-anxiety. Separation anxiety is four times more prevalent among persons with an ID than among persons without ID (Emerson, 2003; Emerson & Hatton, 2007). Problematic behaviour resulting from separations can be understood as a failure to grasp the insight that separation from significant figures will be only temporary. The absence or weak awareness of person permanence among persons with ID can cause anxiety. The concept of person permanence is established when the child or dependant realises that valued persons, though not in close proximity, still exist (Schuengel & Van IJzendoorn, 2001).

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Attachment behaviour, that is, trying to achieve proximity to the caregiver, is a necessary skill used by the infant in times of distress. Denial of proximity to the caregiver in stressful situations might aggravate anxiety (Cassidy, 1999). Research has shown that persons with ID are more subject to insecure attachment relationships (Janssen et al., 2002; Schuengel & Janssen, 2006) than persons without ID. By building an attachment relationship with the therapist who provides psychological support, clients are enabled to regulate their emotional responses (Bowlby, 1969).

Various studies have shown the importance of developing an attachment relationship with clients with ID (De Schipper, Stolk, & Schuengel, 2006; Sterkenburg, Schuengel, & Janssen, 2008). However, it can be difficult for professionals to facilitate the development of secure attachment relationships (Clegg & Landsdall-Welfare, 1995), especially with clients with ID and visual impairment. The interactional relationship patterns between adults with ID and staff members are unspecified (De Schipper et al., 2006; Reuzel, Embregts, Bosman, Van Nieuwenhuijzen, & Jahoda, 2013) and caregivers are often not focussed on the attachment necessities of their clients (De Schipper et al., 2006; De Schipper & Schuengel, 2010).

A strong relationship exists between anxiety and challenging behaviour in persons with ID (Hagopian & Jennett, 2008; Pruijssers, Van Meijel, Maaskant, Nijssen, & Van Achterberg, 2014) and these challenging behaviours hamper social relationships, presenting a problem for professionals (Holden & Gitlesen, 2003; Matson, Neal, & Kozlowski, 2012). Such challenging behaviour can become draining and burdensome on the caregiving system (Matson & Shoemaker, 2009), obstructing attachment relationships from developing.

A systematic literature review by Den Brok and Sterkenburg (2014) proved that the use of technology in psychological interventions is becoming increasingly popular. Persons with ID are presented with greater independence when temporarily given access to technology that enables them to learn new skills (Den Brok & Sterkenburg, 2014). E-health is

a growing phenomenon (King et al., 2010; Mair et al., 2012) in which health information is mediated by digital technologies. It has the unique ability to influence behaviour and promote lifestyle changes via interactivity (Neuhauser & Kreps, 2003). However, a void still exists in making e-health accessible to persons with ID and visual impairment. The application of e-health to support persons with ID, more specifically persons with ID and visual impairment and separation anxiety, has not been explored.

With this backdrop in view, the researcher's first aim was to determine the efficacy of a tool intended to facilitate the grasping of the concept of person permanence and to specifically investigate the effect of including caregivers in the intervention. Secondly, the researcher wanted to verify if anxiety and challenging behaviour in an adult with ID and visual impairment decreased, and during what phase of the intervention this change in behaviour occurred. It was hypothesised that TTSA would be more effective when conducted in collaboration with a caregiver who had been building an attachment relationship with the participant. During the course of this intervention, the caregivers made use of an attachment-based protocol (Hoffman, Marvin, Cooper, & Powell, 2006). This protocol attempted to reduce separation anxiety by facilitating the acquisition of the person permanence concept. Furthermore, in this study the researcher wanted to investigate the social validity of the intervention. It was hypothesised that, overall, the participant and the caregivers that participated in the study would regard this intervention as a positive experience.

### **1.3.1 Intellectual disability**

Although various support mechanisms have been established, people with ID are still one of the most disadvantaged groups worldwide. It has been established that the majority of people with ID experience a poorer quality of life than individuals in the general population (Kozma, Mansell, & Beadle-Brown, 2009).

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ID is defined as a deficit in intellectual and adaptive development (Mash & Wolfe, 2013). Intellectual functioning refers to an Intelligence Quotient (IQ), which is usually tested by standardised, individually directed tests associated with various cognitive abilities (Foxcroft & Roodt, 2009; Shaffer & Kipp, 2007). IQ scores have a mean of 100 and roughly 95% of the population has scores within two standard deviations of the mean (an IQ between 70 and 130) (Mash & Wolfe, 2013; Shaffer & Kipp, 2007). A deficit in intellectual function refers to an IQ of 70 or below. Adaptive functioning refers to how effectively individuals manage their daily routine, and how capable they are of living independently and in accordance with community standards (Kearney, 2013; Mash & Wolfe, 2013).

According to the American Psychology Association (DSM-V, 2013) the following three criteria must be met to warrant the diagnosis of ID:

- A. Inadequate intellectual functioning that manifests when reasoning, solving problems, thinking abstractly and learning from experience, and confirmed by both clinical evaluation and individualised, standard intelligence testing.
- B. Inadequate ability to adapt to circumstances, and thus an inability to maintain personal independence and fulfil social responsibilities. Without ongoing support, the impediment limits functioning in one or more activities of daily life, such as communication, social participation and independent living.
- C. These intellectual and adaptive deficits manifest during the developmental period.

Criterion A refers to intellectual tasks comprising of reasoning, problem solving and understanding, abstract thinking and learning. Critical aspects generally lacking in this population are verbal comprehension, memory, abstract thought and cognitive effectiveness. Research done by Došen (2005) stated that individuals with ID experience an impeded first

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phase of emotional development, causing a delay in cognitive development. Persons with ID often struggle to comprehend new concepts or absorb new information (Blair, 2012).

Criterion B refers mainly to how well a person fulfils a community's expectations of independence and living a socially responsible life. Intellectually disabled people often present with communicative and social skill disorders predisposing them to behavioural problems (Carvill, 2001; De Ruiter, Dekker, Verhulst, & Koot, 2007; Didden et al., 2012). Children with ID have an increased risk of presenting with a comprehensive array of emotional and behavioural problems (Dekker, Koot, Van der Ende, Verhulst, 2002; Myrbakk & Van Tetzner, 2008) and display aggressive behaviour more often than children without ID. In a study done by Deb, Thomas and Bright (2001) it was demonstrated that up to 60.4% of adults with ID presented with at least one behavioural disorder.

Criterion C refers to the acknowledgment that certain deficits, as mentioned above, are present during childhood or adolescence, prior to the age of 18 years (Kail & Cavanaugh, 2007; Kearney, 2013; Mash & Wolfe, 2013). The age limit on the onset is twofold. Firstly, it recognises that ID is a childhood developmental disorder (Kail & Cavanaugh, 2007; Mash & Wolfe, 2013). Research has shown that individuals with ID do function at a level generally expected of people their age (Blair, 2012) and the inability to master new information is most likely to occur during this period of brain development (Haugaard, 2008; Mash & Wolf, 2013). Secondly, this age criterion rules out persons afflicted by adult-onset degenerative diseases (Mash & Wolfe, 2013).

Four levels of severity of ID are distinguished: (1) profound (IQ 0–20), (2) severe (IQ 20–35), (3) moderate (IQ 35–50), and (4) mild (IQ 50–70) (Didden et al., 2012). However, according to the DSM-V (2013) the different levels of severity are not based on IQ scores, but are premised on the foundation of adaptive functioning because this determines the level of support required. The three domains specified are conceptual, social and practical (Table

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1). If the deficit persists after early childhood, the disorder is generally permanent, although severity levels might change over time (American Psychology Association, 2013). The participant in this study had been diagnosed with a moderate ID.

Table 1  
*Severity levels of intellectual disability as stated by DSM-V*

Level of severity	Conceptual domain	Social domain	Practical domain
Mild	A struggle to learn academic skills might be present in schoolchildren and adults. Usually requires assistance to meet age-related expectations.	Might lack competency to communicate and interact socially in comparison to peers, presenting as a difficulty to perceive social cues.	The individual can independently accomplish daily tasks. Support might be needed with complex activities such as transportation and financial management.
Moderate	Intellectual abilities lag behind peers.	A clear communication difference compared with peers throughout development.	The individual can master daily tasks such as dressing and hygiene, although sufficient time and training is needed to teach the individual how to do these tasks independently.
Severe	Accomplishment of abstract skills is limited. Caretakers need to offer support for problem solving throughout lifespan.	Communicates with single words/phrases.	The individual needs support and supervision of daily activities such as feeding and bathing.
Profound	Abstract abilities limited to the physical world rather than symbolic processes. Co-existence of motor and sensory impairments might inhibit the practical use of objects.	Limited understanding of figurative communication in speech or gesture. The individual communicates with gestural and emotional cues. A co-occurrence of sensory and physical impairments can prevent social activities.	The individual is completely dependent on others to meet daily needs such as health and safety. It might be possible for the individual, if not physically impaired, to assist with certain daily tasks at home, for example carrying dishes to the table.

### **1.3.2 Visual impairment**

Visual acuity (VA) is normally measured by the smallest letter that is recognisable at a distance of six metres. The letters are constructed in such a way that they represent a specified visual angle; such letters are called optotypes. According to the WHO criteria, moderate visual impairment is defined as  $VA < 0.3$  in the best eye with the best correction, severe visual impairment as  $VA < 0.10$  and blindness as  $VA < 0.05$ . People with ID often have to be assessed at three metres and the fraction is given as a decimal. Many adults with ID are illiterate and picture charts showing culturally recognisable icons are therefore often used (Warburg, 2001).

Visual impairment has a significantly negative impact on the quality of life (Langelaan et al., 2007) of an individual. Emotional and behavioural problems have a higher incidence among children with a visual impairment than among those with normal vision (Sharma, Sigafos, & Carroll, 2002). Visually impaired infants experience a restraint in the normal developmental phase of exploring and discovering the world around them, and their development of the concept of self is usually impaired (Kitson & Thacker, 2002). This prevalence of poor self-awareness might lead to the notion that visually impaired individuals are unmotivated and “schizoid” (Carvill, 2001; Kitson & Thacker, 2002).

### **1.3.3 Visual impairment in the ID population**

Intellectual and visual impairment often co-occur (Evenhuis, 1995; Evenhuis et al., 2009; Van Splunder, Stilma, Bernsen, & Evenhuis, 2006; Warburg, 2001). ID has a critical impact on psychosocial development and when it co-occurs with a visual handicap, the impediment is generally more profound (Carvill, 2001; Evenhuis et al., 2009). Visual impairment severely handicaps a person who already has the diminished functioning, skills and communication abilities associated with ID (Evenhuis et al., 2009).



### **1.3.4 Anxiety disorders**

Anxiety as a chronic condition can be described as a fear response disproportionate to the real danger. In its most acute form it causes a significantly inhibited quality of life. Coping mechanisms often include avoidance of the feared situation in an attempt to minimise episodes of expected fear, panic and conditions of severe physiological arousal. Anxiety disorders are mostly categorised in the DSM–V according to the provoking stimuli and/or the nature of the response (Hagopian & Jennet, 2008; Kail & Cavanaugh, 2007), such as separation anxiety. Anxiety can be regarded from a behavioural analytic perspective as an escape-maintained behaviour, and can present as overt behaviour (behaviour that can easily be observed such as tantrums) or covert behaviour (more difficult to observe, for instance increased heart rate) (Kail & Cavanaugh, 2007; Lang et al., 2011). Untreated anxiety disorders have a negative impact on the person's and the family's quality of life and can be regarded as a risk factor for developing psychopathology at a later age (Greenberg, 1999; Lewinshohn, 2008; Nauta & Emmelkamp, 2012).

The stress-attachment model (Janssen et al., 2002) indicates that the ID population is not well enough armed with coping skills and is consequently at risk for pathologies such as anxiety (Greenberg, 1999). Bradley (2000) has proposed that the progression to psychopathology might be linked to a person with ID's inability to control stress. If they are not empowered to cope with the impact of stress, people with ID might experience grave physiological impediment (Janssen et al., 2002).

### **1.3.5 Separation anxiety disorder (SAD) in the ID population**

The prevalence of anxiety disorders is significantly higher among children with ID than among children without ID (Emerson, 2003; Emerson & Hatton, 2007), especially separation anxiety. The incidence of separation anxiety among intellectually disabled persons

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tends to be four times higher than among persons without intellectual impairment (Emerson, 2003; Emerson & Hatton, 2007) and, according to a study done by Emerson (2003), separation anxiety is the most prevalent psychiatric disorder diagnosed in children with a mild to moderate ID.

Separation anxiety in children without ID usually presents at between eight and 12 months of age and will usually diminish at between 20 to 24 months (Louw & Louw, 2007; Shaffer & Kipp, 2007). According to the American Psychology Association (2013), the DSM-V diagnostic criteria for SAD are as follows:

- A. SAD is characterised by extreme anxiety when separated from those to whom the individual is attached, as substantiated by at least three of the following:
1. Persistent intense distress when expecting or experiencing separation from an attachment figure.
  2. Endless fear that something bad will happen to an attachment figure.
  3. Permanent, intense concern about potential incidents that might cause separation from an attachment figure.
  4. Due to the fear of separation, the individual presents with continuous unwillingness to leave the home.
  5. Intense fear of or hesitancy about being alone or separated from an attachment figure.
  6. Refusal or unwillingness to sleep out or to go to sleep without a nearby attachment figure.
  7. Repetitive nightmares about the topic of separation.
  8. Constant physical discomfort (e.g. headaches, nausea) when separated from those to whom the individual is attached or when separation is expected.

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- B. The irrational fear or anxiety is chronic and of long duration (at least four weeks in children and adolescents, and typically six months or more in adults).
- C. The disorder is responsible for diminished functioning secondary to clinically significant distress.
- D. The condition is not the result of an alternative mental disorder.

Separation anxiety is expected to be a normal response for persons with ID with a developmental level of between 0 and 48 months (Došen, 2005). However, when the individual with ID with a cognitive functioning level higher than 48 months has not learned that “out of sight” is not equivalent to “permanently lost”, separation anxiety can be regarded as developmentally inappropriate, and this scenario applies to a significantly large number of children and adults with a moderate to mild intellectual disability (Emerson & Hatton, 2007).

### **1.3.6 Person permanence**

The concept of person permanence is grasped when the child understands that a person continues to exist when the latter is removed from the child’s perceptual field (Schuengel & Van Ijzendoorn, 2001). According to Piaget, the concept of person permanence gradually develops during the first phase of a normal child’s cognitive development, namely the sensory-motor phase. As it is a gradual process, the concept will be fully developed only after 18 months (Louw & Louw, 2007, Shaffer & Kipp, 2007).

However, the ability to understand that persons continue to exist when they are no longer in the vicinity or in physical contact might be very abstract and children with ID and visual impairment can experience great difficulty in learning this abstract concept (Cassidy, 1999). The developmental and cognitive impairment of individuals with ID can profoundly limit their concept of person permanence (Cassidy, 1999). The lack or inadequate awareness

of person permanence among persons with an intellectual and visual impairment can in turn lead to experienced anxiety (Došen, 2005).

### **1.3.7 Attachment**

Mahler, Pine, and Bergman (1975) hypothesised that the need for bonding with other people is intrinsic to human nature and this process provides a psychologically secure base for a child from which to explore and achieve self-confidence. Attachment refers to actively seeking and maintaining proximity to an attachment figure, which enables the individual to regulate behaviour, particularly under conditions of distress (Haugaard, 2008; Mash & Wolfe, 2013; Shaffer & Kipp, 2007). The attachment process is an essential skill obtained by the infant to cope during times of distress by trying to retain immediacy to the caregiver (Cassidy, 1999; Haugaard, 2008). By constructing a secure attachment relationship with an attachment figure who offers psychological support, individuals are enabled to regulate their emotional responses (Bowlby, 1969). On the other hand, the absence of an attachment figure could aggravate anguish and anxiety, increasing the potential to present with psychophysical imbalance (Cassidy, 1999). Table 2 gives an indication of the four different attachment styles (Kail & Cavanaugh, 2007; Mash & Wolfe, 2013; Shaffer & Kipp, 2007). There is evidence that infants from as early as the age of four months respond in a unique way to an attachment figure, although attachment behaviour is established only when the infant's behaviour is directed towards maintaining proximity to the attachment figure. Attachment behaviour in adults can be regarded as merely a straightforward perpetuation of attachment behaviour during childhood (Bowlby, 1969).

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Table 2

*Different types of attachment styles and how general behaviour, the impact of relationships and the possibility of deficits/disorders can be perceived*

Type of attachment style	General behaviour	Impact on relationships	Deficits/ Disorders
Secure	Child willingly separates from attachment figure and is at ease to explore freely. The child actively strives for proximity to the attachment figure when upset or feeling threatened by strangers.	Individuals tend to seek out others. Individuals rely on supportive relationships as a secure base. By fulfilling the needs of the individual, the attachment figure teaches the individual how to react in the near future during stressful situations.	Even though the individual might become psychologically distressed, the nature of the secure attachment relationship serves as a protective factor against disorders.
Insecure (anxious-avoidant)	The child participates in exploration, but displays slight interaction with the attachment figure. Child shows little distress when aware of strangers.	Individuals disguise emotional signalling.	Conduct disorders Aggressive behaviour Depressive symptoms
Insecure (anxious – resistant)	Child displays resistance to exploration. Child is very cautious of strangers. Child displays difficulty settling down when reunited with the caregiver, and combines contact seeking with crying and obsessiveness.	Individuals struggle to manage anxiety. Individuals have a habit of amplifying emotions and uphold negative beliefs about the self.	Phobias Anxiety Psychosomatic symptoms Depression
Disorganized/ Disoriented	There is no sign of a consistent strategy to seek out proximity. Displays disorganised behaviour when in an unknown environment.	Individual is incompetent to form intimate attachments to others.	Broad range of personality disorders.

Louw and Louw (2007) highlighted six contributing factors that might influence attachment behaviour in infants. The attachment behaviour of the infant, for example crying or friendliness, evokes a response from the mother and if the mother positively responds to the needs of the infant, it facilitates the feeling of security and proximity. The mother's personality and relationship with the infant plays a crucial role in the development of an attachment relation – if the mother displays a positive attitude towards the infant, the process of attaching will be secured. The temperament of the infant has a direct influence on the

caregiver. Psychosocial factors, for example a bad marriage, poverty and inadequate social support, can hinder attachment relationships from forming. Post-partum depression presenting after delivery can have problematic consequences on the child-caregiver relationship. There is contradictory evidence as to whether a mother preferring to continue with her profession could have an effect on the development of attachment. However, if the mother establishes a supportive relationship with the infant, the fact that the mother is working should not have a negative effect on the infant.

### **1.3.8 Insecure attachment in this population**

Individuals with ID are more prone to developing insecure attachment relationships (Janssen et al., 2002; Schuengel & Janssen, 2006) than non-intellectually disabled persons. Janssen and colleagues (2002) nominated the contributing factors for the development of an insecure attachment relationship in children with ID as parental stress, ineffective parenting, children's limited cognitive skills and institutionalisation.

Various studies have stated that the parents of children with ID are more vulnerable to experiencing profound levels of parental stress compared to parents of non-disabled children (Hassall, Rose, & McDonald, 2005; Marvin & Pianta, 1996; Smith, Oliver, & Innocenti, 2001). A study done by Saloviita, Itälä, and Leinonen (2003) identified the most significant contributory factors to parental stress: mothers linked it to the child's behaviour patterns and for fathers it was usually the inability to socially accept the child. Other common factors influencing parental stress include environmental characteristics (for example the family's mode of functioning/support), parents' cognitive states and the severity of the child's disability (Hassall et al., 2005; Smith et al., 2001).

Due to the complex character of children with ID, parenting can be seen as a demanding task (Baxter, Cummins, & Yiolitis, 2000). Children with ID are not explicit in

their signalling behaviour and incredible sensitivity is required for parents to overcome this difficulty. Consequently, it is problematic for parents to interact with the child, especially when bestowing affection (Janssen et al., 2002).

As mentioned above, the ability to experience the person even when he or she is not physically present can be lacking in persons with ID (Schuengel & Van Ijzendoorn, 2001). Due to their inability to grasp the concept that separation from supporting figures is only temporary, persons with ID often present with problematic behaviour. Consequently it severely limits their ability to identify and select attachment to suit the situation (Cassidy, 1999).

Institutionalisation is regarded as an intensely stressful event for individuals with ID and has a negative impact on the attachment need (Cassidy, 1999). In institutions caregivers can fulfil a similar attachment figure role to that of parents (De Schipper & Schuengel, 2010). However, facilitating and establishing secure attachment relationships might be a difficult task for professionals (Clegg & Landsdall-Welfare, 1995), especially with clients with ID and visual impairment. How the client experiences the exposure to opportunities and even the client's behaviour might be directly linked to the level of assistance the caregivers provide (Mansell et al., 2002). The level of success achieved can be based upon the quality of the relationship established with the support staff, as each individual's relationship with support staff members presents itself uniquely (De Schipper & Schuengel, 2010). A greater level of sensitivity might be required from caregivers to overcome the difficulty that children with ID often have expressing their attachment signals (Schuengel & Janssen, 2006). The interpersonal relationship profiles of clients with ID and other staff members are not well documented (De Schipper et al., 2006, Reuzel et al., 2013) and caregivers often do not focus on the attachment needs of their clients (De Schipper et al., 2006; De Schipper & Schuengel, 2010). The framework of professional day care might also not always be advantageous to the

development of attachment relationships, depending on the availability and turnover of staff and work schedules (De Schipper & Schuengel, 2010).

A study done by Clegg and Sheard (2002) supports research identifying insecure attachment as the foundation of challenging behaviour in the ID population. De Schipper and Schuengel (2010) pointed out the correlation between challenging behaviour and inadequate attachment relationships in intellectually disabled persons, which implies that healthy attachment behaviour can decrease challenging behaviour displayed by persons with ID.

### **1.3.9 Challenging behaviour**

Numerous studies use the following definition of challenging behaviour: On a daily basis the individual's behaviour prevents him or her from participating in events. This behaviour can also lead to injury to the self and/or others, usually requiring two or more professionals to regulate the individual (Holden & Gitlesen, 2006). A study done by Janssen and colleagues (2002) indicated that 30 to 60 % of children with ID present with challenging behaviour. Challenging behaviour has been categorised mainly into four groups, namely: (1) self-injury, (2) aggression, (3) destruction and (4) other behaviour (Emerson et al., 2001; Holden & Gitlesen, 2006). Most individuals with ID usually present with two or more forms of challenging behaviour.

An association between challenging behaviour and psychiatric disorders has been confirmed (Holden & Gitlesen, 2003; Myrbakk & Von Tetzchner, 2008) and the co-existence of psychiatric disorders will aggravate unmanageable behaviour (Emmerson et al., 1999). Challenging behaviour goes hand and hand with anxiety in the ID population (Hagopian & Jennett, 2008; Larson, Alim, & Tsakanikos, 2011). A literature review done by Pruijssers and colleagues (2014) confirmed the complex relationship between anxiety and challenging behaviour in adults as well, raising the question of whether the unmanageable conduct was



responsible for an increase in anxiety and the resultant psychopathology or vice versa. We have only a limited understanding of the reasons for challenging behaviour.

Challenging behaviour is detrimental to the quality of life of the individuals with ID and often contributes to treatment dilemmas (Janssen et al., 2002). Challenging behaviours obstruct the development of social relationships, placing a therapeutic challenge on parents and professionals (Holden & Gitlesen, 2003; Matson et al., 2012). This behaviour not only handicaps attachment relationships with caregivers, but also becomes exhausting and burdensome on the healthcare system, resulting in an increase in expenditure (Felce, Lowe, Beecham, & Hallam, 2000; Matson & Shoemaker, 2009).

### **1.3.10 Treatment**

Research focussing on the successful therapy of individuals with ID is limited (Strauser, Lustig, & Donnell, 2004, Sturmey, 2012). A review done by Brown and colleagues (2011) notes, more specifically, that there is a lack of evidence-based information regarding psychological interventions for people with ID. They argue that the lack of access to psychotherapies for people with ID has led to their exclusion from mainstream research, thereby limiting evidence-based information on effective interventions and treatment approaches. This has had significant consequences for research, policy, education and clinical practice (Brown, Duff, Karatzias, & Horsburgh, 2011). Against this backdrop, Schuengel, De Schipper, Sterkenburg, and Keff (2013) suggested that interventions effective for treating non-intellectually disabled developing children and adults might also be used as a foundation for the development of new therapy methods for persons with ID.

Three main approaches, namely behaviour interventions, attachment-based interventions and psychotropic medication, have been used as therapy methods among people with ID.

### **1.3.11 Behaviour interventions**

Behaviour interventions that include the reinforcement of alternative behaviours are still regarded as the primary treatment option when managing challenging behaviour (Matson et al., 2012). However, behaviour modification has not always been an effective option when treating seriously intellectually and visually impaired children – they often appear to be insensitive to society’s disapproval of their behaviour, thus limiting the therapeutic value of reinforcing alternative behaviour. Relaxation and desensitisation methods might be used to lessen symptoms of anxiety and phobias, but it must be emphasised that more complex disorders still lack adequate intervention options (Didden et al., 2012).

A review done by Cartwright-Hatton and colleagues (2004) indicated that Cognitive Behaviour Therapy (CBT) could be a promising treatment intervention for managing childhood and adolescent anxiety. However, the review did not indicate whether CBT was effective in the long term. It has also been confirmed that individuals with ID might not be capable of forming the traditional therapeutic relationship sought during CBT and might struggle with the abstract concepts (Lang et al., 2011). It is recommended that this gap in the research be investigated by using controlled and randomised experimental research designs (Sturmey, 2004).

### **1.3.12 Attachment-based interventions**

Research has confirmed the importance of regulating attachment behaviour to prevent challenging behaviour due to emotional distress (De Schipper & Schuengel, 2010; Janssen et al., 2002; Sterkenburg et al., 2008). Because individuals with ID are not adept at dealing with stressful situations on their own, the presence and/or support of an attachment figure might be especially important (De Schipper & Schuengel, 2010). Only a few studies have been undertaken to evaluate the interaction between young adults with ID and their caregivers

(Reuzel et al., 2013). The positive interaction that follows from this position of trust is necessary for the professionals to gain adequate insight into the needs of their clients (Reinders, 2010).

### **1.3.13 Psychotropic medication**

Studies done over the last 20 years showed that nearly 50% of people with ID receiving care have been treated with psychotropic medication. The most common reason for the use of psychotropic drugs for people with ID is to manage challenging behaviours (Matson et al., 2000). A review done by Deb and colleagues (2008) investigated the use of psychotropic medications to control challenging behaviour in persons with ID. The conclusion was that mood stabilisers can benefit the person with ID who suffers from challenging behaviour, but a warning was issued for cautionary interpretation due to methodological flaws in some of the articles included in the review.

Research has shown that people with mental retardation constitute an overmedicated population (Matson et al., 2000; Reiss & Aman, 1997). It has been established that community service providers are not well equipped to deal with individuals who have challenging behaviour and who then present with side effects caused by the overuse of medication (Kozma et al., 2009). Although diagnostic instruments have improved over the years, correctly diagnosing persons with ID might be a difficult task (Sturmey, 1995). Prescriptions frequently violate current guidelines, especially when conducted by general practitioners. A study done by Holden and Gitlesen (2004) on the use of psychotropic medication for persons with ID indicated that a lot of prescriptions had not been indicated by a diagnosis, alternatives to medications had rarely been explored, and effects and side effects were not evaluated. Also, studies of psychotropic treatment of psychiatric disorders and problem behaviour in mentally retarded people have critical methodological flaws (Matson et

al., 2000). Important shortcomings identified were a lack of behavioural assessment and treatment prior to being medicated, which calls into question whether medications were necessary at all or could be combined with behavioural interventions. The scientific foundation for prescribing psychotropic medication for persons with ID has not been thoroughly researched and the irrational use of these drugs should be restricted due to limited effectiveness, potential side effects and the option of therapeutic alternatives (Holden & Gitlesen, 2004). A systematic review of randomised trials done by Brylewski and Duggan (1999) showed that there is no trial-based evidence regarding the effectiveness or ineffectiveness of antipsychotic medication for adults with ID and challenging behaviour.

### **1.3.14 E-Health**

E-health is a growing phenomenon (Chan, Ray, & Parameswaran, 2008; Hsu et al., 2005; King et al., 2010) and research on the impact of E-health has increased rapidly since 2008 (Mair et al., 2012). “E-health communication” and health promotion efforts that are facilitated by computers and other technologies have the ability to promote preferred behaviour changes through unique features such as interactivity and convenience (Neuhauser & Kreps, 2003). The barriers to communication between healthcare providers and their patients are time and space. Telecommunication technology is a powerful tool for combating this problem (Tachakrax et al., 2003). Healthcare providers are systematically focussing on using e-health systems that utilise communications technologies to improve access to quality services and to enhance service efficacy (Mair et al., 2012).

There is growing initial evidence that e-health communication can positively influence behaviour-related issues (Neuhauser & Kreps, 2003). Studies support the evidence that a range of objective quality of life indicators, especially autonomy, are positively related to adaptive behaviour (Perry & Felce, 2005; Stancliffe et al., 2000). A systematic literature

review by Den Brok and Sterkenburg (2014) proved the positive outcome when applying technology in psychological interventions. Intellectually disabled persons can obtain greater independence when they have access to and are being taught to use technology (Den Brok & Sterkenburg, 2014). Studies also showed that technology can improve the independence and autonomy of visually impaired students (De Freitas Alves, Monteiro, Rabello, Gasparetto, & Carvalho, 2009) and when technology is adapted to meet a consumer's specific needs, the best outcome is experienced (Scherer & Glueckauf, 2005).

Cellular technology as a form of information and communications technology (ICT) is being used extensively in modern civilisation (García-Montes, Caballero-Muñoz, & Pérez – Álvarez, 2006). Yet the number of people with ID utilising cellular technology is tiny in comparison to the number of persons without ID who use it (Stock et al., 2008). This is often due to complexity of the software and the physical attributes of the hardware of the modern cell phone. A study done by Bryan and colleagues (2007) indicated that 58% of participants with ID had never used a cell phone and only 28% regularly used one. Although the use of computers by persons with ID has become more established since the late 1900s, the use of other technologies has not followed a similar pattern (Palmer et al., 2012).

### **1.3.15 Technology-assisted therapy**

Studies done by Lancioni and colleagues led to the conclusion that modern technology can be used in the treatment of persons with visual and intellectual disabilities. The positive outcome of the use of technology is supported by numerous studies (Lancioni, Van den Hof, Furniss, O'Reilly, & Cunha, 1999; Lancioni et al., 2009). In a study done by Stock and colleagues (2008) it was ascertained that individuals with ID were able to operate a specially adapted cell phone system more confidently (e.g. making fewer errors) than when using a traditional cell phone handset. It is evident that people with ID can benefit from the

use of cell phone technology, particularly when it is equipped with features that ensure cognitive access. Such endeavours might considerably increase the percentage of people with ID who use cell phone technology for a wide array of potentially beneficial purposes. However, studies do not discuss the possible link between the uses of e-health to address mental illnesses in persons with ID in general, or more specifically in persons with ID and attachment-related disorders such as separation anxiety, especially when combined with visual impairment.

### **1.4 Research paradigm**

This study was done on secondary data that was gathered in the Netherlands during the period June 2011 to August 2012. The main goal of the research project was to test a specific intervention, endeavouring to alleviate problematic anxiety in visually and intellectually disabled participants when being separated from their caregivers, thus diminishing the caregivers' burden and improving the quality of life of the handicapped participants. The study followed a quantitative approach where the research methodology is directed upon deductive measurement, analysis and interpretation of a stipulated hypothesis (Bless, Higson-Smith, & Kagee, 2007; Creswell, 2003).

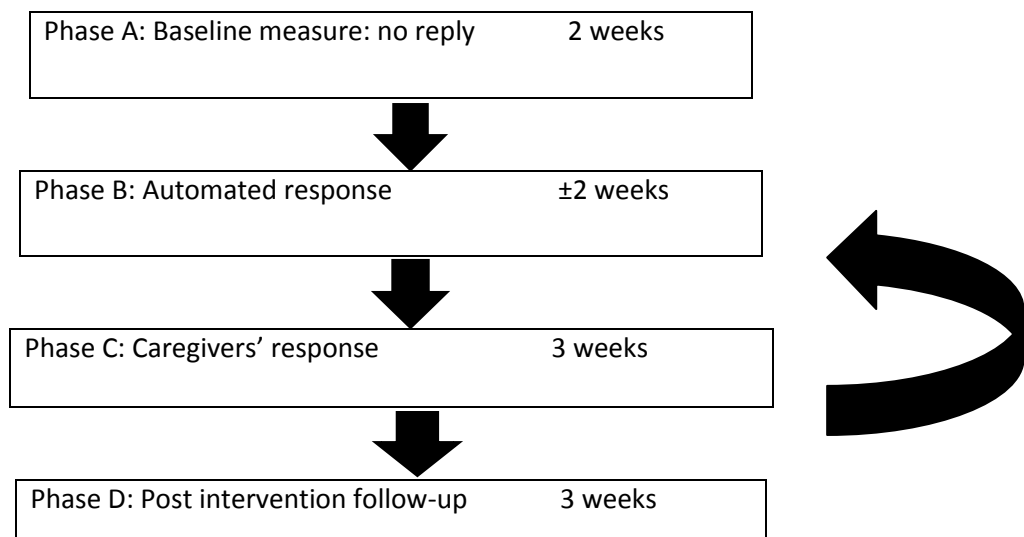
### **1.5 Research Design**

This single-subject design study followed a pre-experimental ( $AB_1C_1B_2C_2D$ ) quantitative research approach (Campbell, 1957). Experimental research (e.g. single-subject research) is uniquely designed to ascertain the effect of an intervention on a particular population (Cook, Cook, Landrum, & Tankersley, 2008). Single-subject studies have also been recommended as a useful method to examine clinical liability (Gonnella, 1989). The design is a variation of the familiar ABAB design for single-case experimentation (Figure 1). The repeated recordings of

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the target behaviour help to prove the validity of the study (Zhan & Ottenbacher, 2001). The four-phase ABAB design is now universally accepted as a scientifically valid and clinically convincing single-case design (Kratochwill & Levin, 2010). This study consisted of the following phases:

- Phase A (provides a baseline measure): This phase consisted of a two-week period in which the technology was used without a response in return.
- Phase B: Mobile device with an active reply function, which provided automated responses to messages sent by the participant.
- Phase C: Mobile device with an active reply function that was operated by the caregivers; the caregivers were instructed to follow-up on the messages when they returned to the participant.
- Phase D: A follow-up discussion between the caregivers and the participant. The mobile device was returned.



*Figure 1:* The design of the intervention

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The rationale for the current application of the design was as follows:

- Phase A (baseline): The two-week training period (Phase A) was intended to be a precursor that set phase B1 in motion. This precursor phase served as a baseline quantification of the client's anxiety and challenging behaviour. It also verified that the participant was familiar with the technology. During this phase the participant might have presented reduced anxiety levels due to the stimulating effect of the technology. The inclusion of the technology during this phase was therefore necessary to prove that the origin of change during the intervention was not due to the distractive nature of the instrument.
- Phase B<sub>1</sub>: automated replies to messages sent by the participant were unlikely to have the same meaning for the client as replies sent by caregivers, and should not have had the same impact as being physically together with the caregiver. As a result, the participant should not have experienced that the relationship persisted during physical separations. To test this hypothesis, condition B was a control condition for condition C, in order to eliminate the alternative hypothesis that the effect of the intervention might be due to distraction and stimulation by the mobile device.
- Phase C<sub>1</sub>: this condition tested the intervention as developed against the control conditions A and B.
- Phase B<sub>2</sub>: removing the caregivers' response made it possible to test whether the intervention effect disappeared, versus the possibility that a decrease in anxiety from A and B to C could be ascribed to the effect of natural changes over time.
- Phase C<sub>2</sub>: by reintroducing the caregivers' responses, the deterioration from C<sub>1</sub> to B<sub>2</sub> should have been reversed to an improvement, proving association between the intervention (C) and the supposed effects.



### 1.6 Participants and context

The study was conducted in the Netherlands and at the premises of an organisation that provides long-term care for intellectually and visually disabled adults and children. This organisation endeavours to improve the quality of life for blind and visually impaired persons by empowering them. Purposive sampling was done to select the participant. The participant suffered from separation anxiety and had requested help; as such he qualified to participate in this study. The participant lived at a residential home for people with visual and intellectual disabilities, at which caregiving was provided by a specialised care service provider. He also complied with the following inclusion criteria of the study:

- Having a visual disability in accordance with WHO criteria, but still able to read.
- Having an IQ between 40 and 70 (moderate to mild) and having acquired the disability before adulthood.
- Regularly becoming distressed when left alone, as shown on the PIMRA (see instruments).
- The capacity to physically use the touch-screen of the mobile device.

The exclusion criteria of the study were:

- Adults diagnosed within autism spectrum disorder.
- Persons who are deaf.

Twelve caregivers participated in the study. Each one was from the Netherlands and spoke Dutch. Six of them were between 20 and 30 years of age; five were between 40 and 50 and one of them was between 50 and 60 years of age. They were well known to the participant. Ten of the 12 had known him for more than three years and the other two had known him for less than a year.

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The primary objective of Technology-assisted Therapy for Separation Anxiety (TTSA) is to reduce separation anxiety experienced by persons with an intellectual and visual impairment. An adapted cell phone (iPhone touch) onto which a specialised application had been uploaded was used in conjunction with discussions between the participant and caregivers. The participant, when physically separated from the caregivers, could choose between four options to express his emotions (happy, sad, angry, or scared). He could also send a message to request help when needed. The caregiver replied to each message sent by the participant by sending a predetermined response on a device similar to that of the client. For instance, when the participant expressed a happy emotion by sending a “I am happy” emoticon, the caregiver acknowledged the message by replying with “You are happy” (Figure 2). When the participant and the caregivers were reunited, the messages traded between them were discussed. The conversation was directed through the use of an attachment-based protocol. At the beginning of the intervention the “Circle of Security Graph” designed by Hoffman et al. (2006) was explained and taught to the caregivers. A child lock-function prevented the participant from accidentally exiting the application. The device was attached to the participant’s wheelchair to enable independent usage.

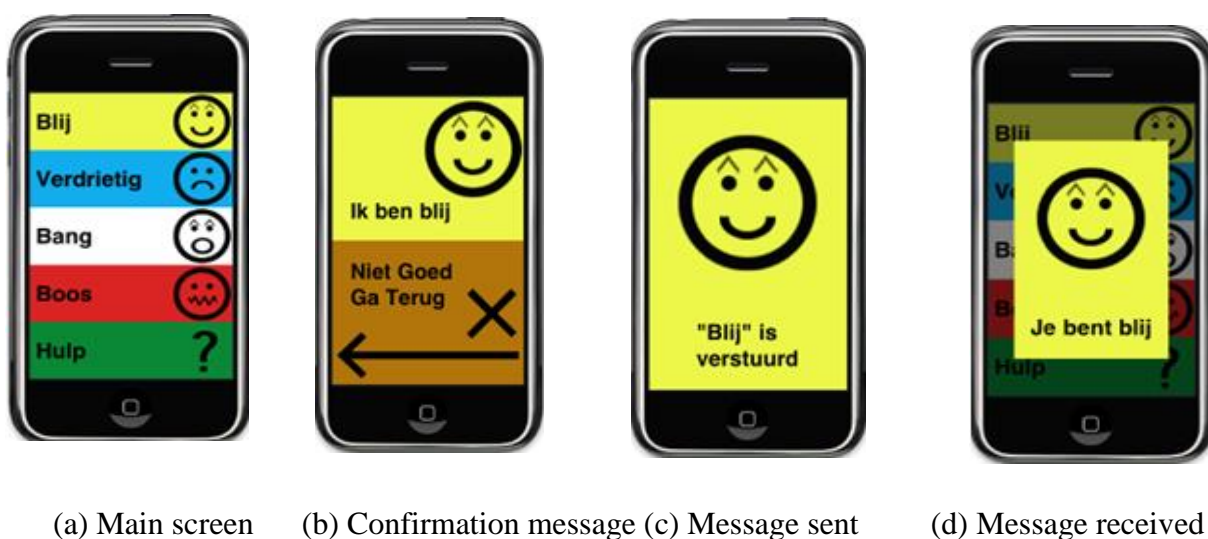


Figure 2: A specially adapted cell phone (I-phone touch) containing a specific application

### 1.7 Data collection

Various standardised instruments were used in the study to monitor changes in anxiety and challenging behaviour at the end of every phase.

***The Psychopathology Inventory for Mentally Retarded Adults (PIMRA) (Kazdin, Matson, & Senatore, 1983):***

This is one of the most widely administered and researched instruments used for assessing psychopathology in individuals with developmental disabilities. This scale consists of 56 true/false items within eight subscales: schizophrenia, affective disorder, psychosexual disorder, adjustment disorder, anxiety disorder, somatoform disorder, personality disorder and inappropriate adjustment. The anxiety subscale of the PIMRA was used to measure change in anxiety levels by requesting the caregivers to complete the questionnaire. The anxiety scale presents modest to adequate internal consistency ( $\alpha = .63$ ) (Van Minnem, Savelsberg, & Hoogduin, 1994). Only the seven items on “anxiety disorder” were used with a scoring time of approximately three minutes.

***The Dutch version of the Adult Behaviour Checklist (ABCL) (Achenbach & Rescorla, 2003):***

The changes in anxiety and challenging behaviour were monitored by the caregivers completing the observer rating scale, specifically the anxious/depressed, aggressive behaviour, intrusive syndrome scales. Tenneij and Koot (2007) proved that the ABCL was a reliable and valid measure for assessing psychopathology in persons with a mild intellectual disability. The anxious/depressed- and the aggressive behaviour scale both displayed a good inter-rater reliability with a Cronbach alpha correlation of .89. Both of these results are considered to indicate fair inter- rater reliability. The ICC showed the following results: .62 (good), .75 (excellent), .56 (fair) and .75 (excellent) for the above-mentioned subscales respectively. The scoring time was between five and 20 minutes.

### ***The Brief Symptom Index (BSI) (Derogatis & Spencer, 1982):***

The *BSI*, often used to measure therapy effect, was used to measure anxiety throughout the intervention. The participant was helped to complete the anxiety subscale by an impartial guide. The results indicated changes in anxiety symptoms. Wieland, Wardenaar, Fontein and Zitman (2012) found that the anxiety subscale presented good internal consistency ( $\alpha = .82$ ). The *BSI* also showed adequate discriminant validity, an indication of the instrument's ability to classify and differentiate between different psychopathology diagnoses (Wieland et al., 2012). The 53-item list was scored by the participant assisted by an independent researcher. The scoring time was approximately 15 minutes.

### ***The Social Validity Scale (Seys, 1987):***

The caregivers reported how they experienced the use of the mobile device in daily care. The questionnaire was based on the Social Validity Scale used by Seys (1987), similarly to the way it was done by Janssen, Riksen-Walraven, and Van Dijk (2002). This questionnaire was specially designed to evaluate the intervention and used 5-point Likert-type ratings. The different themes were: preparation of the intervention, the intervention itself, practicability, efficiency, the usefulness of collecting data, subjective evaluation of skills by the caregiver and the subjective evaluation of the client's skills. The caregivers reported how they experienced the different themes on 32 items with answers that could range from very difficult to very easy. Completing the questionnaire took 20 to 30 minutes. This Social Validity Scale (Seys, 1987) was also adapted for the participant. The questionnaire was constructed in a similar way to the Social Validity scale for caregivers (see above), but was shorter and used different themes and easier wordings via graphic rating scales, thus simplifying the scoring. The different themes were: the training, the intervention itself, usability and the subjective evaluation of the participant. Completing the questionnaire took approximately 15 minutes.

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The merits of the intervention were evaluated by analysing the levels of anxiety and presenting challenging behaviour, specifically by comparing phases B and C. The frequency of the different types of messages (happy, sad, angry, anxious and help) sent by the participant was recorded throughout the intervention. The messages sent by the mobile device were registered in a web-based data collection system. The behavioural patterns of the participant at the residential home and at work were recorded by the professional caregivers. A user-friendly web-based computerised data collection system, “Qualtrics”, was used for the daily reporting of behavioural patterns. A computerised reminder for filling out the lists was programmed into and visible on the computers on which caregivers checked their e-mails daily. The daily scoring time was approximately five minutes.

### **1.8 Data analyses**

The first aim of this study was to determine an effective aid for acquiring the abstract concept of person permanence: technology alone versus the inclusion of caregivers in technology-assisted therapy. The second aim of this study was to determine whether technology-assisted therapy, as applied by caregivers, decreases separation anxiety and challenging behaviour in an adult with a visual and intellectual disability. Sequential analysis was done by using Noldus’ The Observer, a computer software package (Wageningen, the Netherlands). Sequential analysis is a statistical procedure whereby patterns in a data set can be revealed (Shriver, Frerichs, Williams, & Lancaster, 2013). The variations in the probability of the developing pattern can be examined over time and provides a probability statistic of the dependent variable following the observed variable (Munde, Vlaskamp, Maes, & Ruijsenaars, 2012). The current study used Noldus’ The Observer computer program to determine the probability of the happy, sad or angry message pattern (observed variable) after an anxious message (dependent variable) with a two-second interval. If the probability of the

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patterns arising increased during the course of the intervention, it would show that the response by the caregiver during phase C contributed to decreasing the anxiety levels experienced by the participant. In theory, a Yule's Q (Bakeman & Gottman, 1997) can be used to examine whether observed probabilities differ significantly. However, Yule's Q can only be analysed when the marginal sums of the frequency of the two messages are larger than five (Bakeman & Gottman, 1997). ANOVA contrasts were used to measure the frequency of the anxiety messages sent by the participant in phases B and C. Repeated measure ANOVA and a non-parametric Friedman test were used to compare the results of the various instruments that measured anxiety and challenging behaviour. While evaluating the daily behaviour of the participant in the residential homes, a distinction was made between anxiety and challenging behaviour. The numerous behaviour options in the daily observation lists were arranged according to anxiety (comprises stress, anxiety and clinging behaviour) and challenging behaviour (anger, yelling and hitting). ANOVA contrasts were used to compare the frequency and intensity of the challenging and anxious behaviour in the residential home in phases B and C. The effect of the intervention was examined using the mean frequency and intensity of all the behaviours scored on the residential lists. The third aim of this study was to determine how the caregivers and the participant experience technology-assisted therapy. The caregivers were instructed to evaluate the mobile device by filling out a Social Validity Scale (Seys, 1987) questionnaire. This Social Validity Scale was also adapted for the participant. To test whether the participant and the caregivers had a positive experience using this intervention during daily caregiving, descriptive statistics and t-test analyses were used to study the social validity of the Technology-assisted Therapy for Separation Anxiety (TTSA) before and after the intervention. The independent samples t-test would indicate whether there was a significant

difference between the mean scores rated in the beginning and again at the end of the intervention, as evaluated by the caregivers as well as the participant.

### **1.9 Research hypotheses and research questions**

The following research hypotheses were formulated for this study:

- Regarding the first aim of this study, it was hypothesised that the inclusion of caregivers in technology-assisted therapy would be more likely to facilitate the development the concept of person permanence than technology alone.
- Regarding the second aim of this study, it was hypothesised that the anxiety and challenging behaviour levels displayed by a visually and intellectually disabled participant would significantly decrease due to technology-assisted therapy applied by caregivers.
- With regard to the second aim, it was hypothesised that the caregivers and the participant would regard the technology-assisted therapy as a positive experience.

Based on the background information given, the following research questions were formulated for this study:

- Does the inclusion of caregivers in technology-assisted therapy serve as a more efficient aid to developing the abstract concept of person permanence in an adult with intellectual and visual impairment than technology alone?
- Can technology-assisted therapy, as applied by caregivers, decrease separation anxiety and challenging behaviour in an adult with intellectual and visual impairment?
- How do the participant and the caregivers experience technology-assisted therapy?

### **1.10 Ethical considerations**

The Vrije University Medical Centre's Medical-Ethical Review board endorsed ethical approval for this study (NL33646.029.11). Please refer to the attached Addendum. This board is certified by the Central Committee on Research pertaining to Human Subjects (CCMO) to evaluate and oversee Dutch prevailing medical research.

Written informed consent was obtained from all the participants. The moderately to mild intellectually disabled participant (IQ 47) was capable of giving written consent. The document was read and explained to him, and he was encouraged to take it home to evaluate. The data gathering process took place from June 2011 to August 2012. To warrant the nature of confidentiality, a pseudonym was used to hide the participant's identity.

### **1.11 Outline of the study**

Section I presents an overall introduction to technology-assisted therapy for an adult with visual and intellectual impairment, followed by the problem statement, which includes the rationale for investigating technology-assisted therapy in this population. In section II the guidelines used by the author, as required by the Journal of Intellectual Disability Research, are outlined. This is followed by the author's article: *Caregiver-mediated therapy for an adult with visual and intellectual impairment suffering from separation anxiety*. Section III is a critical reflection by the researcher on the current study. Finally, the complete reference list is outlined.



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**SECTION 2: ARTICLE**

Caregiver-mediated therapy for an adult with visual and intellectual impairment suffering from separation anxiety



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# CAREGIVER-MEDIATED THERAPY FOR SEPARATION ANXIETY

Caregiver-mediated therapy for an adult with visual and intellectual impairment suffering  
from separation anxiety

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## 2.2 MANUSCRIPT

### **Abstract**

*Background* There is a high prevalence of separation anxiety among intellectually disabled (ID) persons, yet treatment options are few. One explanation for separation anxiety is that it could be rooted in a weakly developed sense of person permanence. In this study, a specially adapted mobile phone, to which a specific application had been uploaded, was used in conjunction with dialogue between a client and his caregiver as a means of addressing this problem. The primary aim of this research was to evaluate the efficacy of a Technology-assisted Therapy for Separation Anxiety (TTSA) that was specifically developed for the purposes of this study. Furthermore, there were three underlying aims. The first was to determine the best use of an operative aid for acquiring the abstract concept of person permanence: technology alone versus the inclusion of caregivers in technology-assisted therapy. The second objective was to determine whether technology-assisted therapy decreased separation anxiety and challenging behaviour in adults with visual and intellectual disability. The last aim of the study was to determine how the caregivers and the client experienced technology-assisted therapy.

*Methods* A pre-experimental, quantitative approach (AB<sub>1</sub>C<sub>1</sub>B<sub>2</sub>C<sub>2</sub>D) was used for this single-subject study. The frequency of the client's different types of messages (happy, sad, angry, anxious and help) sent using the technology was recorded daily throughout the intervention. The Adult Behaviour Checklist (ABCL), Brief Symptom Inventory (BSI) and Psychopathology Inventory for Mentally Retarded Adults (PIMRA) were used during the course of the intervention to measure changes in the client's behaviour (specifically levels of anxiety and challenging behaviour). Caregivers also used observation lists to rate the intensity and frequency of the client's anxiety and challenging behaviour. The social validity of the technology was evaluated by both the client and the caregivers.

## CAREGIVER-MEDIATED THERAPY FOR SEPARATION ANXIETY

*Results* There was a significant decrease in the anxious and angry messages sent in the C phase (inclusion of caregivers in technology), compared to the B phase (technology alone). During the intervention there was also a decrease in both anxious and challenging behaviour in the C phase compared to the B phase. Overall, both the client and the caregivers were positive about the Social Validity Scale of the intervention.

*Conclusion* The findings suggest that TTSA, when conducted in collaboration with caregivers, is a valuable intervention technique to reduce levels of anxiety and challenging behaviour among a person with intellectual disability and a comorbid visual impairment. Additionally, although this intervention was directed towards treating separation anxiety, the TTSA together with the inclusion of caregivers who had been reacting sensitively and responsively to the emotional needs of the client, may be a feasible aid to facilitate or reinforce an acquisition of the abstract concept of person permanence, especially in circumstances where such a deficit has been identified.

**Keywords** separation anxiety, intellectual disability, visual disability, technology, treatment, single case study

### **Introduction**

Intellectually disabled (ID) children with a co-existing visual impairment are more predisposed to developmental problems than children with a single impairment (Alimovic 2013). Intellectual and visual impairment often co-exist, and in such cases it could be expected that the disability will be more severe (Evenhuis 1995; Evenhuis *et al.* 2001; Warburg 2001; Van Splunder *et al.* 2006; Evenhuis *et al.* 2009). Developmental and cognitive impairment can severely limit an individual with ID's concept of person permanence (Cassidy 1999), which can in turn indicate a prognosis of developing separation anxiety (Došen 2005). The concept of person permanence is created when the child or

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dependant appreciates that valued persons, though not present in the close vicinity, still exist (Schuengel & Van IJzendoorn 2001). One of the objectives of the study was to determine the efficacy of an operational aid for acquiring the abstract concept of person permanence in an adult with intellectual and visual impairment: technology alone versus the inclusion of caregivers in technology-assisted therapy.

According to the stress-attachment model (Janssen *et al.* 2002), the ability of persons with ID to manage stressful situations is inadequate and thus they are much more predisposed to psychopathologies such as anxiety than persons without ID (Greenberg 1999). Separation anxiety also appears frequently among ID children (Došen 2005; Emerson & Hatton 2007). Research has shown that the incidence of separation anxiety among persons with ID is four times more prevalent than among persons without ID (Emerson 2003; Emerson & Hatton 2007). When measured against the DSM-IV symptom criteria for anxiety disorder, 21.9% of children with a mild to moderate intellectual disability meet the criteria for anxiety disorder (Dekker & Koot 2003). Nonetheless, studies on the treatment of anxiety disorders focus mainly on phobic disorders among children without an intellectual disability (Došen 2005). This is remarkable, as reliable therapy techniques used for treating anxiety in non-intellectually disabled persons can be applied to the ID population (Hagopian & Jennett 2008).

The incapability of acquiring the understanding that being separated from emotionally significant persons will only be temporary is often considered to be the origin of challenging behaviour. The skill to realise that persons exist even when they are no longer in the adjacent area or in physical contact is very abstract, and ID and visually impaired children might experience pronounced difficulty in learning this abstract concept (Cassidy 1999). The

absence or weak development of the concept of person permanence can cause anxiety (Došen 2005).

Attachment refers to actively seeking and maintaining immediacy to a trusted figure, allowing the individual to control behaviour, particularly when he or she is anxious (Bowlby 1969; Cassidy 1999). Several studies have shown the significance of developing an attachment relationship with ID clients (De Schipper *et al.* 2006; Sterkenburg *et al.* 2008). By constructing an attachment relationship with the therapist who provides psychological support, clients are empowered to manage their emotional responses (Bowlby 1969). Conversely, the absence of an attachment figure can foster distress and psychophysical disequilibrium. Persons with ID are much more prone to insecure attachment relationships (Janssen *et al.* 2002; Schuengel & Janssen 2006) than non-intellectually disabled persons and it can be a challenging task for professionals to create and facilitate secure attachment relationships with members of this population (Clegg & Landsdall-Welfare 1995). Research has shown that the interactional relationship patterns between ID clients and staff members are not well recognised (De Schipper *et al.* 2006; Reuzel *et al.* 2013) and caregivers are not focussed on the attachment needs of their clients (De Schipper *et al.* 2006; De Schipper & Schuengel 2010).

E-health is an emerging phenomenon (King *et al.* 2010; Mair *et al.* 2012), in which health promotion and information are facilitated by computers and other modern technologies. It has an exceptional ability to influence behaviour and encourage lifestyle adjustment via interactivity (Neuhauser & Kreps 2003). E-health also has the potential to remove the time and space barrier between clients and professionals (Tachakrax *et al.* 2003). A systematic literature review by Den Brok and Sterkenburg (2014) verified that the use of technology in psychological interventions is increasingly in demand. Persons with ID are offered greater

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independence when given access to technology (Den Brok & Sterkenburg 2014). Studies also show that technology can encourage independence and autonomy among students (De Freitas Alves *et al.* 2009). However, a void still exists with respect to applying e-health to clients with ID and visual impairment. The use of e-health to support persons with ID, more specifically persons with intellectual and visual impairments and separation anxiety, has not been explored. The number of people with ID using mobile technology is tiny compared to persons without ID (Stock *et al.* 2008). A study done by Bryan *et al.* (2007) established that 58% of the participants with ID had never used a mobile phone and only 28% regularly used one. Although Palmer *et al.* (2012) indicated that the use of computers by persons with ID is more widespread these days, their use of additional modern technology has not altered since the late 1990s.

The aim of this study was to determine the efficacy an operational aid for acquiring the abstract concept of person permanence and to specifically investigate the effect of including caregivers in the use of the technology. It was expected that a virtual connection with the caregiver via the use of a mobile device would improve the client's awareness of person permanence. Previous research emphasises the importance of personalised feedback as a counterweight to the lack of personal contact in computerised health interventions (Musiat *et al.* 2012). The most effective use of technology occurs when created to meet and augment a consumer's particular functional and social needs (Scherer & Glueckauf 2005). During the intervention the caregivers made use of an attachment-based protocol that attempted to facilitate the development of the person permanence skill, which is necessary to overcome the separation anxiety.

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In addition to the impact of the virtual connection with the caregiver, this study also aimed to investigate the effect of TTSA on separation anxiety and challenging behaviour in an adult with a visual and intellectual disability, and to ascertain during which phase of therapy this change in behaviour occurred. There is a close association between anxiety and challenging behaviour in persons with ID (Hagopian & Jennett 2008; Pruijssers *et al.* 2014) and these challenging behaviours obstruct social relationships, presenting an inconvenience to professionals (Holden & Gitlesen 2003; Matson *et al.* 2012). TTSA used as an intervention to reduce anxiety and challenging behaviour was expected to be more effective when conducted in collaboration with a caregiver who had been building an attachment relationship with the client.

Regarding the social validity of the self-controlled technology, it was necessary to define to what extent the inclusion of technology contributed to the lowering effect of TTSA on separation anxiety. It was expected that the caregivers would be positive about using this technology to support their daily caregiving and that the device would be easy to understand and to operate for both the client and the caregivers.

### **Method**

#### **Participant and caregivers**

John<sup>1</sup> is a 27-year-old male who is moderately intellectually disabled with an IQ of 47. He is visually impaired but able to read, wheelchair bound and in need of constant supervision. During the week John lives at a residential group home run by a care service that provides care for people with visual and intellectual disabilities. His occupation is delivering mail at the residential home during the week and he visits his family during the weekends.

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<sup>1</sup> Pseudonym

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The researchers informed the residents about the proposed study regarding separation anxiety. The caregivers nominated John to the researchers and, as he met the DSM-IV criteria for separation anxiety, he was invited to participate in the study. John describes himself as tense, dislikes contact with unfamiliar people and experiences anxiety at separation from his caregiver. John explains that he can tolerate being alone, but becomes anxious when left alone for extended periods. When left alone – especially when in his bed – John tends to be preoccupied by thoughts of abandonment by his caregivers. He attempts to cope with the anxiety by listening to music and actively seeking interaction with others.

During this study, John received care from 12 caregivers. The 10 caregivers working shifts during the day at his home facility as well as the two caregivers at his work were trained in the use of the intervention. Due to the fact that John also has a physical disability, the caregivers attended to his attire, bathroom requirements and meal preparations. Since the caregivers were also allocated to other duties, physical separations were unavoidable. All 12 of the caregivers were of Dutch origin and spoke Dutch. The caregivers varied in age: 50% were between 20 and 30 years old, 40% were between 40 and 50 years old and 10% were between 50 and 60. Their levels of education ranged from middle vocational education (60%) to higher vocational education (30%) and university education (10%). The caregivers were well acquainted with John; 10 of them had known him for more than three years and only two caregivers had known him for less than a year.

The VU University Medical Centre's Medical-Ethical Review board evaluated the medical-ethical merits and granted permission for this study (NL33646.029.11). This board has been licensed to approve research by the Central Committee on Research involving Human Subjects, which is responsible for monitoring submissions in light of Dutch legislation

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governing medical research. The care organisation employing the caregivers received compensatory funding for completing the questionnaires. John also received a gift voucher for participating in the study. The caregivers and John gave written, informed consent for their involvement in the study. The consent document was read and explained to John and the caregivers, and it could be assessed at home. Data was collected from June 2011 until August 2012.

### **Intervention**

Technology assisted Therapy for Separation Anxiety (TTSA) aims to lower the separation anxiety experienced by persons with a visual impairment and a mild to moderate intellectual disability. A specially adapted mobile phone (iPhone touch), onto which a specific application had been uploaded, was used in conjunction with dialogues between the client and caregivers. The client, when physically separated from the caregiver on duty, could choose between four different options to convey his emotions (happy, sad, angry or anxious). He could also send a message to request help when needed. The caregiver replied to each message sent by the client by sending a pre-determined response on a device similar to that of the client. For example, when the client conveyed a happy emotion by sending the message “I am happy”, the caregiver recognised the message by responding with “You are happy”. All the messages exchanged by the client and caregiver were then discussed at daily follow-up gatherings attended by the client and the relevant caregiver. This discussion was guided by an attachment-based protocol, based on the Circle of Security, in which the caregivers received training (Marvin *et al.* 2002). The attachment-based protocol is based on attachment theory (Bowlby 1969) and endeavours to establish a secure relationship between the caregiver and the client, creating an environment in which the client dares to speak about his emotions (see Appendix A for protocol). The iPhone was secured with a child lock function to block the



client from exiting the application. To enable independent use, the device was mounted onto his wheelchair.

### **Design**

This single-subject design study followed a pre-experimental quantitative research approach (AB<sub>1</sub>C<sub>1</sub>B<sub>2</sub>C<sub>2</sub>D). Two weeks prior to the intervention, John was taught by one of the researchers how to send a message and how to associate each button with a specific emotion, and how the iPhone needed to be charged. The 12 caregivers also received training during two team meetings. An introductory meeting was first held that focused mainly on problem mapping and identifying the client's handicaps and behavioural problems. The caregivers were told that an application was being investigated and asked whether they wanted to participate in the study, without mentioning the exact nature of the intervention. The second meeting included training in the procedure involved in using the mobile phone and explaining the purpose of the phone. The attachment-based protocol was introduced and discussed. Throughout the intervention the caregivers were required to act accordingly to the set protocol. The protocol was reviewed and posted on a notice board (see Appendix A regarding attachment-based protocol). A manual was set for each task. During the third meeting this information was revised. The caregivers were provided with the telephone number of the researcher responsible for the data collection in case they needed assistance with the mobile phones or protocol.

Phase A consisted of a two-week training period. This precursor phase provided a baseline measurement and ensured that the client was familiarised with the technology. The technology comprised an iPhone touch that was specially modified for ID and visually disabled persons. During this phase, the client might have presented reduced anxiety levels due to the stimulating effect of the technology, which, on a short-term basis, could have

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lessened his feelings of anxiety. The inclusion of the technology during this phase was necessary to prove that the origin of change during the intervention was not the distractive nature of the instrument. During this two-week period the technology was used without response in return. During phase B<sub>1</sub>, which lasted 11 days, an automated response from a computer was received by the client. Phase C<sub>1</sub> lasted three weeks and contained two new components. Firstly, a response from the caregiver on duty that specific day was received instead of an automated computer response. Secondly, a set attachment-based protocol was used to reflect on the sent messages. This conversation took place at any available time when the caregiver and the participant were reunited.

Phases B<sub>2</sub> and C<sub>2</sub> were executed identically, if compared to phases B<sub>1</sub> and C<sub>1</sub>, except for the time allocation – the former lasted for three weeks. The repetition is purposefully included in the design to exclude arguments that the changes in separation anxiety levels are due to natural change over time. Furthermore, the repetition allowed for the examination of changes in the separation anxiety levels between phases C<sub>1</sub> and B<sub>2</sub>. Changes in behaviour could therefore be accredited to the impact of the intervention only. The mobile devices were handed in at the commencement of phase D. This final phase, consisting of follow-up discussions between each caregiver and the participant, took three weeks. During this phase, the participant was given the opportunity to share his experiences regarding the intervention, while the caregivers conveyed their perceptions by completing a questionnaire.

### **Instruments**

#### *Frequency of different type of messages from the iPhone*

The frequency of the different types of messages (happy, scared, angry, anxious and help) sent by the client was recorded daily throughout the intervention. The messages sent via the mobile device were registered in a web-based data collection system.

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### *Standardised instruments used to measure change in anxiety and challenging behaviour*

Adult Behaviour Checklist for ages 18-59 (ABCL): The changes in anxiety and challenging behaviour were monitored by requesting two caregivers, one caregiver at his home and one caregiver at his work, to complete the observer rating scale. The same persons scored the ABCL at the end of each phase of the intervention. The anxious/depressed, attention-seeking behaviour and aggressive behaviour scales were used. Tenneij and Koot (2007) proved that the ABCL is a reliable and valid measure for assessing psychopathology in persons with a mild intellectual disability. The anxious/depressed- and the aggressive behaviour scale both displayed a good inter-rater reliability with a Cronbach alpha correlation of .89. Both of these results are considered to indicate fair inter-rater reliability. Based on Tenneij and Koot's (2007) study, the ICC also showed the following results: .62 (good), .75 (excellent), .56 (fair) and .75 (excellent) for the above-mentioned subscales respectively.

Psychopathology Inventory for Mental Retarded Adults (PIMRA): The PIMRA – I (informant version) was scored in the same way as the ABCL by using the anxiety scale. Rush *et al.* (2004) note that the PIMRA can appropriately detect psychopathology in persons with intellectual disabilities, but for diagnosis the PIMRA should not be used in isolation. Therefore, different standardised instruments were used to measure anxiety to contribute to the reliability of the results. A study done by Van Minnen and colleagues (1994) found that the PIMRA displays low to modest inter-rater reliability. The Cohen's kappas by the two independent informants for the items ranged from .01 to .74, with a mean of .40. The Cronbach's alpha for the internal consistency of the PIMRA-I subscale Anxiety disorder was .63, indicating a modest to adequate internal consistency (Van Minnen *et al.* 1994).

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Brief Symptom Inventory (BSI): At the end of each phase of the intervention the client was assisted by an independent researcher who was experienced in supporting persons with ID to complete the anxiety subscale questionnaire. The researcher read the questions to the client and noted his reply. Different standardised instruments were used to measure anxiety, contributing to the reliability of the results. Wieland *et al.* (2012) found the internal consistency of the anxiety subscale to be  $\alpha = .82$ . The BSI presents an adequate discriminant validity, which is an indication of the instrument's ability to identify and distinguish between different psychopathology diagnoses (Wieland *et al.* 2012).

### *Residential daily observation lists*

The 12 professional caregivers were asked to record the frequency and intensity of the anxiety and challenging behaviour of the client both at work and at home. The daily observation list was completed by the caregiver on duty who took responsibility for the client. A web-based computerised data collection system, "Qualtrics", which is consumer friendly and fitted into the caregiver's daily reporting routine, was used for the daily reporting of challenging behaviour. It contained a computerised reminder for completing the list and was visible on the computer used by the caregivers for checking their e-mails daily. It took about five minutes to complete the daily scoring.

### *Social Validity of the intervention*

The same two caregivers, one at the client's home and one at the client's work facility, were also requested to complete the Social Validity questionnaire before and at the end of the intervention. This questionnaire was based on the Social Validity Scale used by Seys (1987), similarly to the way it was done by Janssen *et al.* (2002). This questionnaire was specifically designed to evaluate the intervention and used 5-point Likert-type ratings. The different

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themes were: the type of intervention and its desirability, the efficacy of the intervention, the subjective evaluation of the caregiver and the subjective evaluation of the client. To measure the desirability of the intervention, questions such as “What do you think of the idea to use a mobile phone to improve the interaction between clients and their caregivers?” were included. The intervention itself was measured against questions such as “How do you find the design of the intervention?” Regarding the practicability and efficacy of the intervention, questions such as “How do you experience the presence of a mobile phone?” was asked and to measure the subjective skills of the caregiver, e.g. “Did your skills in dealing with unwanted behaviours of the client change?” The subjective evaluation of the client was measured with questions such as “How did the client’s attitude towards others changed?” The caregivers reported on 32 items relating to how they experienced the different themes.

The questionnaire was constructed in a similar way to measure the social validity for the client, but the social validity scale (Seys 1987) adapted for the client was shorter, and used different themes and easier wordings via graphic rating scales, thus simplifying the scoring. The different themes were: the training, the intervention itself and its usability, and the subjective evaluation by the client. Regarding the training, the questionnaire included questions such as “How did you experience learning to use the mobile phone during the first few weeks?” The intervention itself was measured with e.g. “How do you find the mobile phone as a tool?” and the usability of the intervention, e.g. “How did you find the colours on the phone?” The client completed the questionnaire before and at the end of the intervention.

### **Data analyses**

#### *Anxiety and challenging behaviour*

Sequential analysis, done by using Noldus’ The Observer computer software package

(Wageningen, the Netherlands) provided insight into the contribution of phase C. Sequential

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analysis is a statistical procedure through which patterns in a data set can be discovered (Shriver *et al.* 2013). The changes in the probability of the pattern occurring can be monitored over time, which provides a probability statistic of the dependent variable following the observed variable (Munde *et al.* 2012). In the current study Noldus' The Observer computer programme was used to calculate the probability of the pattern of a happy, sad or angry message following an anxious message, with a two-second interval. The two-second interval was chosen randomly as a time slot to ignore inadvertent messages. It was expected that the probability of the patterns occurring would increase over time, which would indicate that the response by the caregiver during phase C actively operated to decrease the levels of anxiety experienced by the client. A Yule's Q (Bakeman & Gottman 1997) can be used to analyse whether observed probabilities differ significantly, but can only be calculated when the marginal sums of the frequency of the two messages are larger than five (Bakeman & Gottman 1997).

ANOVA contrasts were used to compare the frequency of the anxiety messages sent by the client in phases B and C. It was expected that the frequency of the anxiety messages sent by the client would be significantly lower in phase C than in phase B, indicating a reduced level of anxiety experienced by the client. The data on messages sent was inspected visually on outliers first. An outlier in a data collection is a point that is considerably dissimilar with the remainder of the data (Pallent 2010). Only one data point was considered to be an outlier and was changed into a missing value. This was due to the fact that on the 14<sup>th</sup> day of the C1 phase the client sent 115 "I am happy" messages.

In this study it was anticipated that the levels of anxiety experienced and challenging behaviour exhibited by the client would significantly decrease due to the inclusion of the

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caregiver response phase. Non-parametric Friedman tests were done to measure the change in anxiety and challenging behaviour levels over time. It was expected that the anxiety and challenging behaviour levels, as measured with a battery of standardised instruments, would be significantly lower in phase C than in phase B. If more than two scores were missing on one item, the item was removed; otherwise the mean score of the last and upcoming score was taken.

The various behaviour options in the daily observation lists of the client were grouped according to anxiety (includes stress, anxiety and clinging behaviour) and challenging behaviour (includes anger, yelling and hitting). ANOVA contrasts were used to compare the daily frequency and intensity of the anxious and challenging behaviour of the client while the client was at home and at work. The effect of the intervention on the client's anxious and challenging behaviour in the residential setting was studied using the mean frequency and intensity of all the behaviour scored on the residential lists. It was expected that a decrease in both anxious and challenging behaviour would be experienced in the C phase compared to the B phase.

### *Social Validity*

Descriptive statistics and t-test analyses were used to determine the social validity of the Technology-assisted Therapy for Separation Anxiety (TTSA) both before and after the intervention. It was expected that both the client and the caregivers would be positive about using this intervention during daily caregiving.

## Results

Figure 1 shows the probability of an angry, sad or happy message following an anxious message, with a two-second interval. The probability of an angry message following an anxious message decreases from phase B<sub>1</sub> ( $M = .06$ ) to phase C<sub>1</sub> ( $M = .00$ ). Thereafter the probability stays low. The probability of a sad message following an anxious message decreases from phase B<sub>1</sub> ( $M = .05$ ) to B<sub>2</sub> ( $M = .00$ ). The probability of a happy message following an anxious message decreases from phase B<sub>1</sub> ( $M = .02$ ) to phase B<sub>2</sub> ( $M = .00$ ), with an increase in the probability from phase B<sub>2</sub> ( $M = .00$ ) to phase C<sub>2</sub> ( $M = .01$ ). In this study the frequencies of the consecutive messages were smaller than five and the Yule's Q could thus not be used.

[Insert Figure 1 here]

The ANOVA contrast results (Table 1) indicate that there was a significant difference between the automated computer response phase (phases B<sub>1</sub> and B<sub>2</sub>) and the caregiver response phase (phases C<sub>1</sub> and C<sub>2</sub>). There were significantly fewer anxious messages in the C phases compared with the B phases ( $F = 4.348$ ,  $df = 1$ ,  $p < .05$ ). There were also significantly fewer angry messages in the C phases compared with the B phases ( $F = 8.626$ ,  $df = 1$ ,  $p < .001$ ). However, no significant differences were found between the B and C phases with regard to the happy, sad or help messages.

[Insert Table 1 here]

The non-parametric Friedman test on the ABCL anxiety subscale showed that there was a significant change over the course of the intervention from phase A to phase D ( $X^2(5, N=14)$



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= 11.49,  $p = .042$ ) and the BSI anxiety levels of the client significantly decreased over the course of the intervention ( $X^2(5, N=6) = 15.67, p = .008$ ). The Friedman test results of the PIMRA showed that the anxiety levels of the client did not significantly change over the course of the intervention. The Friedman test results of the ABCL aggression subscale showed that the challenging behaviour levels of the client did significantly change over the course of the intervention ( $X^2(5, N=12) = 11.78, p = .038$ ) and on the ABCL attention-seeking subscale there was a significant decrease over the course of the intervention ( $X^2(5, N=17) = 26.87, p = .000$ ).

The ANOVA contrast results indicated that there was a significant difference between the automated computer response phase B (phases B<sub>1</sub> and B<sub>2</sub>) and the caregiver response phase C (phases C<sub>1</sub> and C<sub>2</sub>). Figure 2 shows the sum frequency and intensity of the anxious and challenging behaviours that were recorded by the caregivers in the residential home throughout the intervention. The frequency of the anxious behaviour was significantly less in the C phases compared with the B phases ( $F = 8.593, df = 1, p < .005$ ). The intensity of the anxious behaviour was also significantly less in the C phases compared with the B phases ( $F = 4.470, df = 1, p < .05$ ). The frequency of the challenging behaviour was significantly less in the C phases compared with the B phases ( $F = 9.298, df = 1, p < .005$ ). The intensity of the challenging behaviour was also significantly less in the C phases compared with the B phases ( $F = 4.236, df = 1, p < .05$ ). Figure 3 shows the sum frequency and intensity of the challenging behaviours that were recorded by the caregivers in the residential home throughout the intervention.

[Insert Figures 2 and 3 here]

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Descriptive statistics for the items on the social validity scale scored by the caregivers are presented in Table 2. The independent samples t-test indicates that there was a significant difference between the mean scores rated by the caregivers during daily care in the beginning and at the end of the intervention ( $t = 1.718$ ,  $df = 30$ ,  $p = < .05$  one-tailed). The highest mean value was reached by the intervention itself (theme 3,  $M = 4.00$ ) at the end of the intervention. There was no difference between the onset and end scores for the desirability of the intervention (theme 1,  $M = 3.50$ ), the preparation for the intervention (theme 2,  $M = 3.00$ ) and the usefulness of collecting data (theme 6,  $M = 3.67$ ). Both the practicability (theme 4) and effectiveness (theme 5) of the mobile device were scored lower at the end of the intervention. There is no data reflecting the onset scores obtained from the caregivers at the work facility; thus only the end scores are presented in Table 2. Overall, the client rated the instrument higher at the end of the intervention ( $M = 4.64$ ) than at the beginning ( $M = 4.09$ ), although the independent samples t-test indicated that this difference was not significant.

[Insert Table 2 here]

### **Discussion**

This study complements another study on the effect of TTSA (Hoffman *et al.* 2015). Six participants with visual and moderate to mild intellectual disabilities participated and results were that TTSA can serve as effective intervention to address separation anxiety in adults with intellectual and visual impairment. In this study the researchers wanted to determine the best use of an operative aid for overcoming separation anxiety: technology alone or the inclusion of caregivers in technology-assisted therapy.

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TTSA proved to be an effective tool to help reduce anxiety and challenging behaviour levels in a client with ID who is visually impaired, particularly in the caregiver response (C) phases compared with the computer response (B) phases.

Persons with ID often present limited awareness or an absence of the concept of person permanence (Schuengel & Van IJzendoorn 2001), particularly if they have a comorbid visual impairment (Rogers & Pulchalski 1988; Bals *et al.* 2002). According to the stress-attachment model (Janssen *et al.* 2002), the coping skills of persons with ID are generally not well developed and their attachment relationships are often insecure. This could explain the anxiety and challenging behaviour exhibited by people with ID, including those with a visual impairment. This study consequently aimed to modify the client's emotional responses by utilising technology. The caregivers, using the set attachment-based protocol, responded sensitively to the emotional needs of the client. Moreover, they always provided him with feedback and talked to him about his emotions.

The client now recognises that the caregiver is still there, although he does not see or hear him/her and is less inclined to demand the caregiver's attention. This, along with the reduction of anxiety and challenging behaviour, seems to suggest that the use of the technology in conjunction with the involvement of the caregivers contributed to the client's sense of person permanence. These findings are supported by the literature, which suggests that establishing a secure attachment relationship with the therapist will help to modify the client's emotional responses (Bowlby 1969) and he/she could consequently present with fewer anxiety episodes (Cassidy 1999). The quality of assistance they provide might also modify the client's behaviour and contribute to a more positive attitude towards life (Mansell *et al.* 2002).

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However, a limitation of the data gathering was that there was no data reflecting the social validity onset scores obtained from the caregivers for using the instrument when the client was at the work facility. Only the onset and end scores measuring the use of the technology in daily care could be evaluated. Thus, although high scores were obtained at the end of the intervention for using the technology when the client was at the work facility, we cannot evaluate the onset and end scores of the intervention. Nevertheless, our findings suggest that the caregivers were, overall, positive about the social validity of the technology. The client was also positive about using the instrument.

In addition, as this was a single case study, the findings cannot be generalised to all persons with ID. A client's attachment behaviour might also vary, depending on the relationship with the caregiver (De Schipper & Schuengel 2010). Moreover, further research must be done on the distinctive characteristics of caregivers and the effect these might have on the results.

This study also has limitations regarding its methodology. As a precautionary measure, in case the perspectives of the independent researchers had a bearing on the ratings of the standardised instruments measuring the anxiety and challenging behaviour at the end of each phase of the intervention, an additional standardised instrument to measure anxiety levels, the BSI, was included in the study. The client's mentor, experienced in working with adults with visual and intellectual impairment, assisted the client to complete the lists. To reduce the possibility that the caregivers might simply be observing in line with the expectations of the study, the caregivers were not informed when the different phases of the intervention began. Notwithstanding, the assumption can be made that when the caregivers did not receive any messages on the mobile phone, they might have deduced that a new phase has started. Furthermore, while the caregivers made adequate use of return messages to reply to the

messages sent by the client, the exact reaction at reunion was not controlled to ascertain whether the caregivers reacted strictly accordingly to the set protocol. To guarantee objectivity, the study has combined various instruments to test the effect of the intervention, namely monitoring the frequency of sent messages, standardised questionnaires and observation lists.

In summary, the findings indicate that the technology as well as the reaction of the caregivers compared to the use of technology without the reaction of the caregivers is the most effective method to reduce anxiety and challenging behaviour in an adult with ID and visual impairment. Additionally, although this intervention was directed towards treating separation anxiety, TTSA might be a feasible aid to facilitating or reinforcing the acquisition of the abstract concept of person permanence. Overall, both the client and the caregivers were positive about the Social Validity Scale of the intervention. However, for this N=1 study it is apparent, as mentioned in other single case design studies that followed a quantitative approach (Sterkenburg *et al.* 2008; Damen *et al.* 2014), that the results cannot be generalised to the greater population due to the nature of the design and purposeful sampling (Bless *et al.* 2007; Coolican 2014). Further research is needed to study TTSA when applied to a larger population.

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## Tables

**Table 1** ANOVA contrast results for different type of messages sent by the client: mean, standard deviation error, *F*- and *p*-values

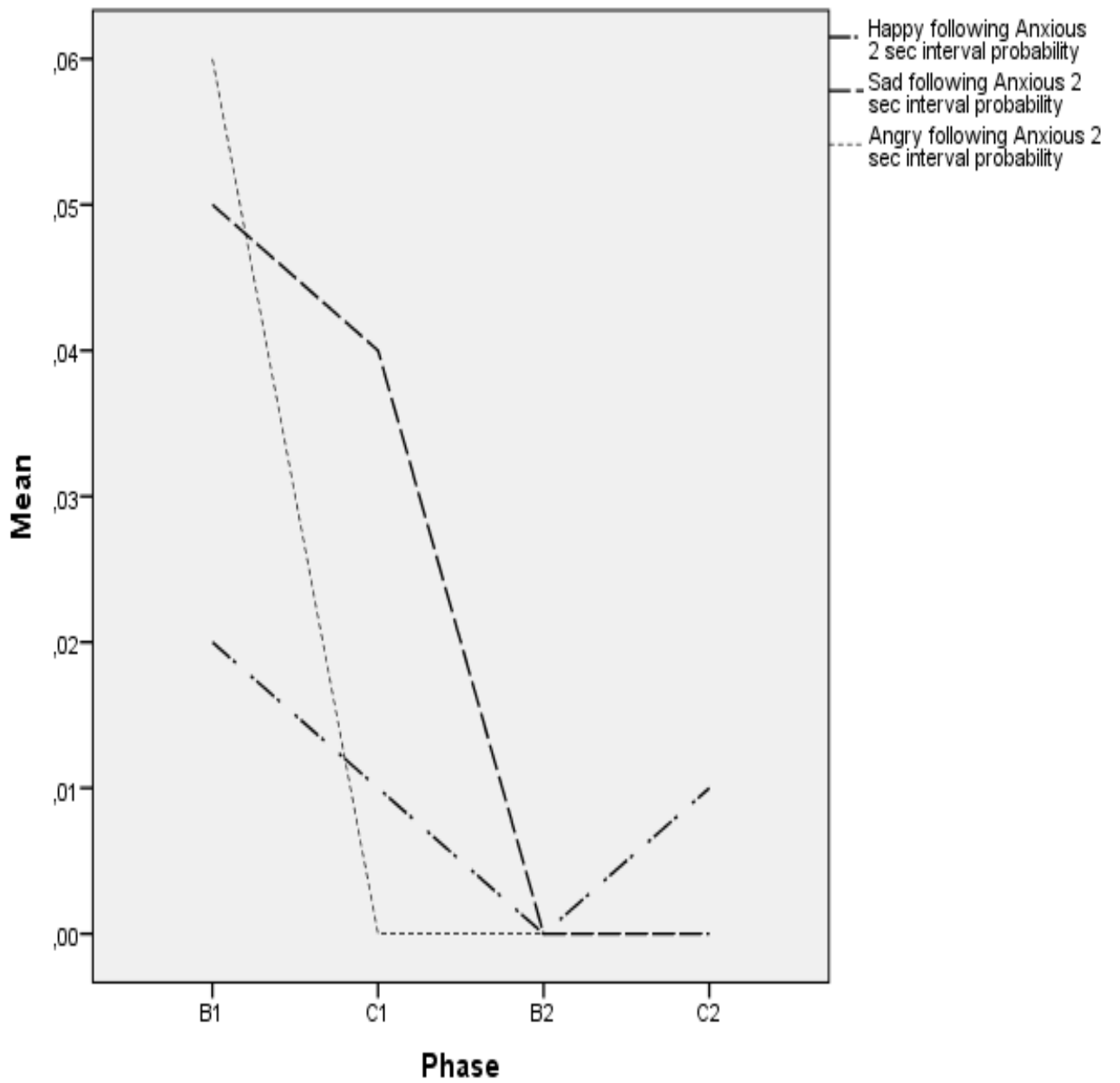
Type of message	Mean	SD error	<i>F</i> -Value	<i>p</i> -Value
Happy	11.60	1.58	2.03	.16
Angry	.82	.13	8.62	.00**
Anxious	1.15	.17	4.35	.04*
Sad	1.35	.22	1.41	.24
Help	.72	.14	.11	.74

\* $P < 0.05$ , \*\*  $P < 0.01$

**Table 2** The mean scores on the social validity scale of the caregivers on the different themes

Theme	N	Start caregiver	End caregiver	End caregiver
		(daily care)	(daily care)	(work facility)
		Mean (SD)	Mean (SD)	Mean (SD)
1. Desirability of the intervention	2	3.50 (0.70)	3.50 (0.71)	4.50 (0.71)
2. The intervention itself	2	3.00 (0.00)	4.00 (0.00)	4.00 (0.00)
3. Practicability of the intervention	6	3.17 (0.41)	3.00 (0.00)	3.83 (0.41)
4. Effectiveness of the intervention	4	3.75 (0.50)	3.50 (0.58)	4.25 (0.96)
5. Subjective evaluation skills of the caregiver	9	3.00 (0.00)	3.33 (0.50)	3.89 (0.60)
6. Subjective evaluation skills of the client	4	3.00 (0.00)	3.25 (0.50)	4.50 (0.58)

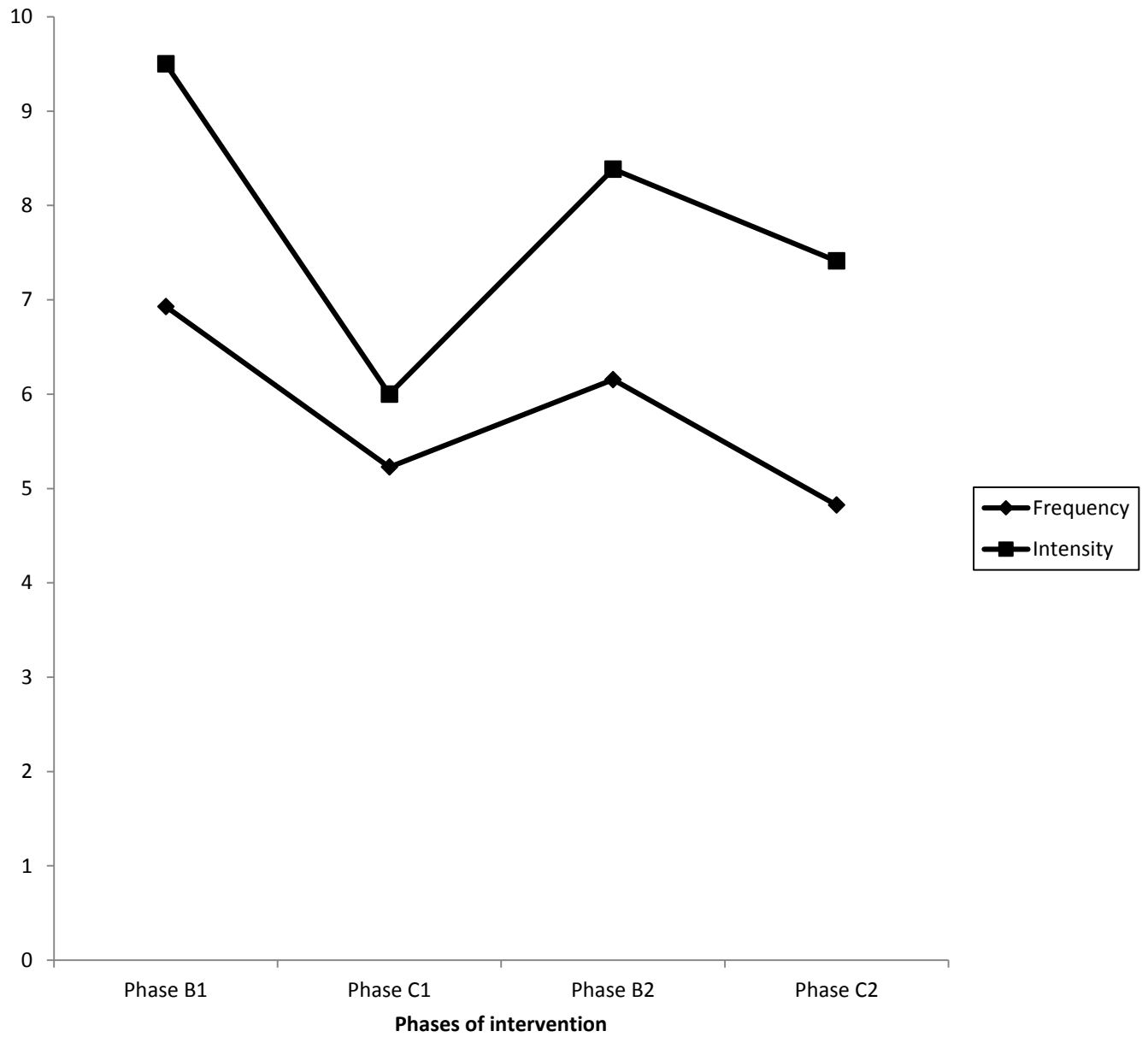
Figures



**Figure 1** Probability of the messages send by the client following the message ‘Anxious’ using a 2 second interval.

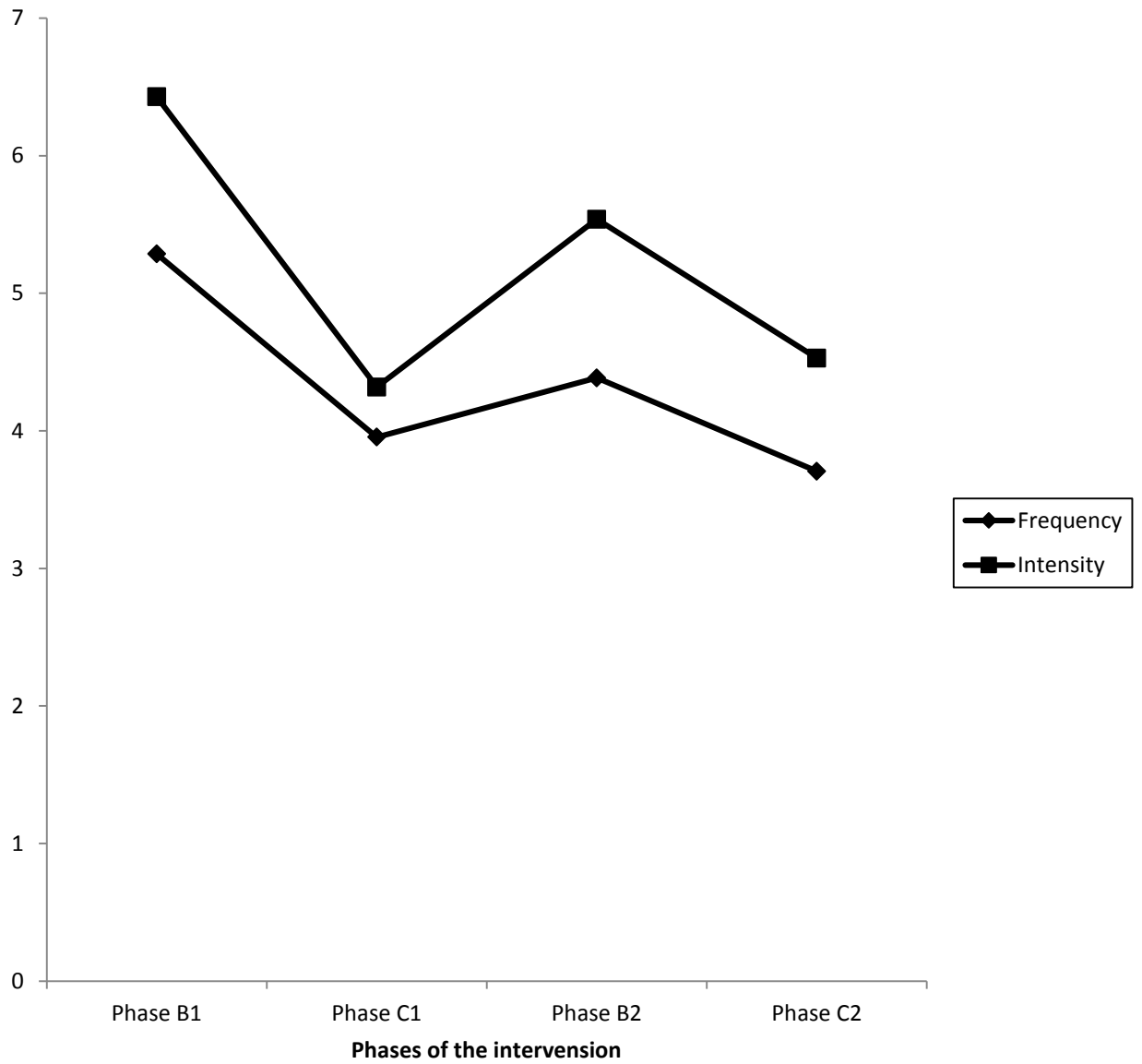


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**Figure 2** Mean frequency and intensity of all anxious behaviour scored on the residential observation lists

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**Figure 3** Mean frequency and intensity of all challenging behaviour scored on the residential observation lists

Appendix A

During the intervention a set attachment-based protocol, namely the Circle of Security (Figure 1) was followed by the caregivers (Marvin *et al.* 2002). The concept attachment refers to actively seeking and retaining immediacy to an attachment figure, enabling the individual to maintain behaviour, especially under stressful conditions (Shaffer & Kipp 2007; Haugaard 2008; Mash & Wolfe 2013). A child's attachment system will be challenged when discomfort, for example anxiety, is experienced. The attachment system aims to restore stability by means of consistent, reassuring feedback from the attachment figure (Bowlby 1969; Cassidy 1999).

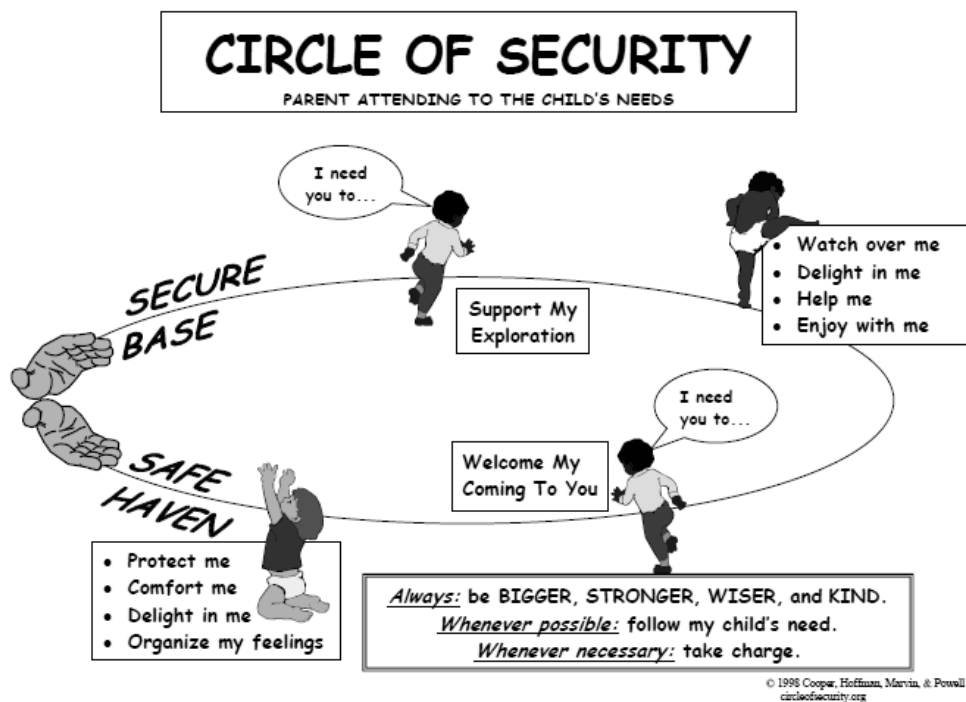


Figure 1 Circle of security by Marvin *et al.* (2002).

The upper half of the circle symbolises the investigative needs of the child. The child is able to explore his/her surroundings to the level that his/her motor maturity allows it. The child will feel more confident to explore if he/she is safeguarded by his/her attachment figure's

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accessibility. The bottom part of the circle symbolises the attachment system of the child. The attachment figure serves as a stable base of safety, comfort and contentment to which the child can return under stressful conditions. During moments of distress, the attachment figure qualifies the child's feelings and behaviour, defining how the child will regulate his/her emotional responses. The attachment figure thus provides a safe base from which the child can venture to discover and grow and presents a safe haven to return to when needed.

**Table 1** *Example applying the set attachment-based protocol when using TTSA*

Condition	Example	Reaction of caregiver	Example
You get a message from the client	"I am sad"	Recognise the emotion by responding	"You are sad"
When you are reunited with the client, you talk about and reflect on the sent messages	"I have received the message that you are sad"	Mirroring the emotion of the client. Acknowledge that the client is sad, consider only the emotion of the client and give reassurance and lots of opportunity to express his emotion. Round off the interaction by helping the client to focus on the next activity.	"Why are you sad, why did you send the message?"  Avoid saying: "Oh, don't be sad, it happens to everyone."

### **SECTION 3: CRITICAL REFLECTION**

There were three underlying aims in this study. The first was to evaluate the use of an operative aid for acquiring the abstract concept of person permanence, in particular technology alone versus the inclusion of caregivers in TTSA. The findings indicated that this intervention serves as a functional tool for an adult with intellectual and visual impairments to develop the abstract concept of person permanence.

The second aim was to determine whether TTSA decreased anxiety and challenging behaviour levels in an adult with intellectual and visual impairment. The findings suggested that the inclusion of caregivers in TTSA serves as a valuable aid for reducing anxiety and challenging behaviour in an adult with ID and a comorbid visual impairment.

The findings of this study suggest that TTSA, when supported by the inclusion of caregivers, can also be a useful tool to lessen the burden of care of caregivers. Challenging behaviour can also be an exhausting burden on the health system (Felce et al., 2000; Matson & Shoemaker, 2009). Quality of life can be improved for both the individual with ID as well as the caregivers by reducing levels of challenging and anxiety behaviours.

The last aim of the study was to investigate how the participants in the study experienced TTSA. Overall, the participants were positive about the social validity of the intervention. From the study it is evident that a person with ID and visual impairment can benefit from the use of modern technology, particularly when equipped with characteristics to ensure cognitive access. It confirms the findings of a study done by Stock and colleagues (2008), namely that individuals with ID are more competent operating a specially adapted mobile phone than when using a traditional mobile phone. When modern technology is adapted to accommodate the special needs of a disabled person, a much larger percentage of people with ID are empowered to use technology to their advantage. This study focused only on an individual with intellectual and visual impairment experiencing separation anxiety, but

research has confirmed that other cognitively disabled persons could gain the same rewards (Stock et al., 2008).

The findings also confirmed the positive impact of building an attachment relationship with the intellectually and visually impaired individual, supporting the study done by De Shipper and Schuengel (2010), which indicated that behaviour would improve by securing attachment behaviour in multiple relationships with caregivers. Especially in residential settings, it would be worthwhile to train the professionals to build a secure attachment relationship with individuals using TTSA and to incorporate it in daily caregiving.

A limitation of the data gathering was the absence of data displaying the onset scores obtained from the caregivers for using the device at the participant's work facility. Only the onset and end scores measuring the use of the device in daily care could be evaluated. Further research is needed to investigate if the caregivers would be positive about the device when the participant is at the work facility and not only at day care.

Sequential analyses were used to record the changes in the probability of a pattern occurring. Specifically, the probability of an angry, sad or happy message following an anxious message with a two-second interval was analysed in the study. The two-second interval was chosen randomly by the researcher as a time slot to disregard inadvertent messages. A different time slot could have had a different effect on the study.

In summary, the findings indicated that the inclusion of caregivers in TTSA is an effective method to reduce anxiety and challenging behaviour in an adult with ID and visual impairment. The findings also suggest that both the caregivers and the participant were generally positive about the social validity of the intervention. However, as seen by other single case design studies that followed a quantitative approach (Damen, Janssen, Huisman, Ruijsenaars, & Schuengel, 2014; Sterkenburg et al., 2008), due to the nature of a single experimental design and purposeful sampling, the results cannot be generalised to the greater

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population (Bless, Higson-Smith, & Kagee, 2007; Coolican, 2014). Further research is needed to study the use and benefit of modern technology when applied to a larger population.

Although it is evident from previous research that a close association between challenging behaviour and anxiety in this population exists (Hagopian & Jennett, 2008; Pruijssers et al., 2014), the nature of this relationship is still unknown. This study demonstrated that TTSA in tandem with the participation of caregivers is an effective tool to reduce anxiety and challenging behaviour in the participant. Furthermore, the intensity and frequency of the participant's anxiety and challenging behaviour levels significantly decreased in the caregiver response phase when measured against the automated response phase. The aim of this study was only to reduce anxiety and challenging behaviour through the use of the inclusion of caregivers in technology-assisted therapy. It is recommended that further research be done to examine the specific relationship between these two behaviours in order to obtain valuable insights regarding the nature of this relationship.

During the study the caregivers received training in an attachment-based protocol. The advantages of a secure caregiver-participant relationship, specifically in individuals with ID, are outlined in numerous studies (De Schipper et al., 2006; De Schipper & Schuengel, 2010; Sterkenburg et al., 2008). The results of this study indicated that the use of TTSA is more effective when an attachment relationship is built with a caregiver. In this study the caregivers followed a similar attachment-based protocol; however an individual's attachment behaviour can vary, depending on the unique quality of the connection with the caregiver (De Schipper & Schuengel, 2010). Further research must include the different variables and contributing factors of caregivers and examine how the individual caregiver-client relationship can effect or enhance the results.

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This study was done on secondary data that was collected in the Netherlands. Overall, the intervention showed valuable outcomes and indicated that the inclusion of caregivers in technology-assisted therapy can serve as an effective treatment method in an adult with ID and visual impairment. Further research is needed to investigate whether an application similar to the one conducted in the Netherlands can be applied in a third world country such as South Africa.



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**ADDENDUM – ETHICAL CLEARANCE**

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Medisch Ethische Toetsingscommissie  
VU medisch centrum  
voorzitter: Prof. dr. J.A. Rauwerda  
intern postadres: BS7, kamer H-565

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## VU medisch centrum



onderwerp  
Positief oordeel  
NL33646.029.11

ons kenmerk  
2011/37

datum  
12 april 2011

doorkiesnummer  
(020) 44 43488  
e-mail [subcom-ethiek.org@vumc.nl](mailto:subcom-ethiek.org@vumc.nl)

Geachte mevrouw Sterkenburg,

De Medisch Ethische Toetsingscommissie Vrije Universiteit medisch centrum (bevoegd tot oordelen op grond van WMO art. 2.2.a) oordeelt thans in positieve zin omtrent de uitvoering van het onderzoek met titel:

### **Mobiele technologie ter ondersteuning van relatieontwikkeling, welbevinden en sociale participatie van mensen met een visuele en verstandelijke beperking**

Aanvrager van het onderzoek: dr. P.S. Sterkenburg  
Verrichter: VU te Amsterdam  
METc VUmc registratienummer: 2011/37

### **Vergadering en documenten**

De goedkeuring, waartoe in principe besloten is in de vergadering van 10-3-2011, is gebaseerd op de volgende documenten:

- Informatiebrief t.b.v. volwassenen versie 2, d.d. 1-4-2011
- Informatiebrief t.b.v. ouders versie 2, d.d. 1-4-2011
- Informatiebrief t.b.v. kinderen versie 2, d.d. 1-4-2011
- ABR-formulier definitief versie 4, d.d. 6-4-2011
- Correspondentie tussen METc VUmc en onderzoeker, d.d. 6-4-2011 en 22-3-2011
- Verzoek tot ontheffing van verzekeringsplicht (in begeleidende brief)
- Faktuuradres (in begeleidende brief)
- Begeleidende brief, d.d. 18-2-2011
- Begrotingsverklaring
- Goedkeuring CWO EMGO, d.d. 26-5-2010 (inclusief correspondentie)
- Privacyreglement ten behoeve van onderzoek in het VUmc, d.d. 2-2-2011
- Protocol versie 1, d.d. 5-1-2011
- Toestemmingsformulier voor de verzorgende ouders/vertegenwoordigers, december 2010
- Toestemmingsformulier kinderen, december 2010
- Informatie voor de proefpersonen; informatie bij brief ouders (kopie artikel InZicht, oktober 2010)
- Informatie voor de proefpersonen; informatie bij brief ouders (handleiding aangepast mobieltje, d.d. 29-9-2010)
- Vragenlijst voor begeleider 1: Psychopathology inventory for mentally retarded adults

- Vragenlijst voor begeleider 2: Sociale redzaamheidschalen verstandelijk gehandicapten
- Vragenlijst voor begeleider 3: The health of the nation outcome scales learning disabilities
- Vragenlijst voor begeleider 4: The adult behavior checklist
- Gedragsvragenlijst voor kinderen van 6-18 jaar
- Vragenlijst voor begeleider 5: The secure base safe haven observations adult version
- Vragenlijst voor begeleider 6: Social validity scale
- Vragenlijst voor begeleider 7: Evaluatie cliënt
- Vragenlijst voor cliënt 1: Intellectual disability quality of life
- Vragenlijst voor cliënt 2: Brief symptom inventory
- Vragenlijst voor cliënt 3: Evaluatie mobieltje door cliënt
- CV onafhankelijk arts, drs. C. van Alfen
- CV coördinerend onderzoeker, dr. P. Sterkenburg
- CV hoofdonderzoeker, prof. dr. C. Schuengel
- CV uitvoerend onderzoeker, Ir. W.L.J.E. den Brok MSc

### Motivering

De commissie is van oordeel dat het onderzoek voldoet aan het bepaalde in de van toepassing zijnde wet- en regelgeving, met name de WMO en, voorzover relevant, het ICH/GCP richtsnoer.

### Verzekering

De commissie verleent aan de verrichter van het onderzoek ontheffing van verzekeringsplicht, gelet op het bepaalde in het Besluit verplichte verzekering bij medisch-wetenschappelijk onderzoek met mensen. Naar het oordeel van de commissie gaat het onderzoek gepaard met geen enkel of verwaarloosbaar risico.

### Deelnemende centra

De goedkeuring betreft de uitvoering in het VUmc.

Het betreft een multicenteronderzoek, dat wellicht ook in een of meer andere instellingen in Nederland zal worden uitgevoerd. De coördinator van het onderzoek dient de raad van bestuur/directie van deze instelling(en) om een advies over de lokale uitvoerbaarheid te vragen. Naar aanleiding van dit advies zal de METc VUmc een nader oordeel uitspreken over de participatie van die instelling(en).

### Verplichtingen

De commissie verwacht dat

- de startdatum van het onderzoek de commissie ter kennis zal worden gebracht (de startdatum is de datum van het eerste bezoek van de eerste deelnemer)
- elke onverwachte bijwerking die zich tijdens het onderzoek voordoet bij de proefpersonen onverwijld aan de commissie gemeld wordt, voorzien van een toelichting betreffende de consequenties voor het onderzoek
- veranderingen in het onderzoeksprotocol aan de commissie worden voorgelegd, voorzien van een toelichting betreffende de consequenties voor de proefpersonen
- jaarlijks een rapport over de voortgang van het onderzoek aan de commissie zal worden toegestuurd
- de beëindiging van het onderzoek, hetzij omdat het onderzoek voltooid is hetzij om andere redenen, de commissie ter kennis zal worden gebracht (de einddatum is de datum van het laatste bezoek van de laatste deelnemer)
- de resultaten van het onderzoek aan de commissie zullen worden gemeld

#### Samenstelling commissie

prof. dr. J.A. Rauwerda	voorzitter, chirurg		
dr. K. Hoekman	plv. voorzitter, internist-oncoloog		
mw. M. Baak	verpleegkundige	dr. M. Klein	neuropsycholoog
mw. dr. B. van Baarsen,		dr. B.W. van Oosten en	neurologen
dr. M.J.P.A. Janssens en	medisch ethici	dr. J. Killestein	
mw. dr. L.A.M. van der Scheer			
mw. dr. C. Boer	biomedicus	mw. P. Roodenberg	lekenlid
mw. dr. M.A. Bremmer	psychiater	prof. dr. F.J.H. Tilders	farmacoloog
mw. prof. dr. A.M. Van Furth	kinderarts-infectioloog	mw. dr. A.I. Veldkamp en	ziekenhuisapothekers-
dr. E.G. Haarman	kinderlongarts	drs. A.J. Wilhelm	klinisch farmacologen
mw. mr. A.J.G.M. Janssen en	juristen	dr. ir. P. van de Ven en	methodologen
mr. F.J. Faber		mw. dr. C.B. Terwee	
dr. D. de Jong	chirurg	prof. dr. ir. R. Verdaasdonk	klinisch fysicus

De commissie heeft de bevoegdheid haar positieve oordeel in te trekken als vaststaat dat de uitvoering van het onderzoek ernstig tekort schiet.  
Het voorliggend oordeel verliest zijn geldigheid indien de start van het onderzoek niet binnen 1 jaar plaatsvindt.

### Brok

De commissie wijst de onderzoekers erop dat, conform landelijke afspraken, klinisch onderzoekers verplicht zijn de "Basiscursus regelgeving en organisatie van klinisch onderzoek" (BROK) te doorlopen en het bijbehorende certificaat te behalen. De commissie gaat ervan uit dat indien dit nu nog niet het geval is, de klinisch onderzoekers van deze studie maximaal zes maanden na aanvang van de studie aan deze verplichting voldaan hebben. Voor informatie over de inhoud van de BROK-cursus: drs. Jennifer Benit, tel. 020 4443345. Voor praktische informatie (zoals data waarop de cursus plaatsvindt en inschrijving): PAOG cursusorganisatie, tel. 020 4449372.

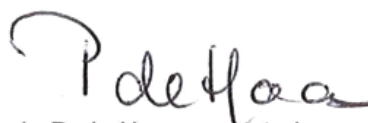
### Administratief beroep

Tegen dit besluit kan een belanghebbende op grond van artikel 23 WMO binnen zes weken na de dag waarop het besluit is bekend gemaakt, administratief beroep instellen bij de Centrale Commissie Mensgebonden Onderzoek (CCMO). Het beroepschrift dient u te adresseren aan: CCMO, Postbus 16302, 2500 BH Den Haag.

Met vriendelijke groet,  
namens de Medisch Ethische Toetsingscommissie,



prof. dr. J.A. Rauwerda, voorzitter



dr. P. de Haan, secretaris

c.c.: Centrale Commissie Mensgebonden Onderzoek te Den Haag (CCMO) - *digitaal uploaden*

c.c.: Prof. dr. C. Schuengel, VU FPP Afdeling Orthopedagogiek, [c.schuengel@psy.vu.nl](mailto:c.schuengel@psy.vu.nl)

c.c.: Ir. W.L.J.E. den Brok MSc, VU FPP Afdeling Orthopedagogiek, [wlje.den.brok@psy.vu.nl](mailto:wlje.den.brok@psy.vu.nl)

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