Sharing Photos, sharing my life.

Improving social connectedness between mentally disabled children and their absent parents by introducing a distant photo exchange system.

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Abstract

In a case study at an institution for mentally disabled children a digital photo frame was introduced like in studies of Biemans and Van Dijk (2009) and Biemans, van Dijk, Dadlani and Van Halteren (2009). As suggested by Eisenhardt (1989) for case studies data triangulation was used. For all stakeholders, the mentally disabled children, their parents and their caregivers several measurements methods were used. All measurements methods together supported the findings of improved social connectedness between mentally disabled children and their parents through usage of a distant photo exchange system. The photos exchanged served as *food for talk* supporting the experiences of mentally disabled children when interacting with their environment.

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Introduction

Connectedness forms the basis for all human existence and it is the phenomenon of connectedness that brings quality of life (Register & Herman, 2010, p.53). Mentally disabled children living apart from their family experience a distance between themselves and their family. (Re) connecting with their family could improve their quality of life. Quality of life is said to be the affective evaluation by the child itself about different aspects of his/her life (Douma, Kersten, Koopman, Schuurman, and Hoekman, 2001).

According to Visser, Van Bel, Dadlani and Yarosh (2010) interpersonal awareness of each other's lives can stimulate social connectedness. Biemans, van Dijk, Dadlani and Van Halteren (2009) and Biemans and van Dijk (2009) studied the effect of social connectedness on individual's well-being and health improvement in care facilities (nursing home and rehabilitation center). As used in several awareness systems (e.g. Romero, Markopoulos, van Baren, de Ruyter, Ijsselsteijn and Farshchian (2007), Biemans et al., (2009) and Biemans and van Dijk (2009) used photos (sent to digital photo frames). They found improvement of awareness between themselves and the absent family.

The aim of this explorative case study is to improve *social connection* between mentally disabled children living apart from their parents in a home group at an institution, and the absent parents. To accomplish this an intervention was made. This intervention consists of introducing a photo sharing system. The research question is: *Does exchanging photos have a positive effect on the social connectedness between mentally disabled children living in a home group at an institution, and their family?* And therefore: *Increase the quality of life of the mentally disabled children?* This study focuses on concepts as social connectedness, quality of life, mental disability and photo sharing. In addition to these concepts, separate focus is put on the three main stakeholders in this case study: *Mentally disabled children*, their *Caregivers* and their *Parents*.

Background

Social connectedness definitions. A universal definition of social connectedness does not exist. The following definitions appoint to the predominant aspects of the concept social connectedness in this context. Visser et al., (2010) consider social connectedness to be the momentary experience of belongingness and relatedness with others. Lee and Robbins (1995; 1998) state that social connectedness is defined as an aspect of the self that reflects subjective awareness of interpersonal closeness with the world in toto. The definition of Lee and Robbins is therefore focused broader than just others. A sense of social connectedness develops early in life and extends throughout the life span (Lee, Draper & Lee, 2001). For a sense of social connectedness to develop early in life, the developmental period is the most important period.

Social connectedness and development. According to the Attachment Theory of Bowlby (1982) the developmental period is strongly related to social support. Attachment is defined as an interpersonal bond that has important developmental implications (Sarason & Sarason, 2009). The Attachment Theory acknowledges the role of social ties in personal development. Ainsworth, Blehar, Waters & Wall (1978) distinguish two dimensions of individual reactions to distress, anxiety (attachment-related anxiety) and avoidance (attachment-related avoidance). These two working models of self and others begin to develop early in life in response to experiences with attachment figures (Ainsworth et al., 1978).

It has been suggested that difficulties in social relationships for children with mental disabilities may be due to different or impoverished social interaction which in turn are due to a delay in the development of interactive skills in the developmental period (Sheridan, Hungelmann & Maughan, 1999). There is to be widespread consensus that mental disabilities originate during ontogenetic development (see for example Grossman, (1983) and various

definitions from sources such The American Association on Intellectual and Developmental Disabilities, The International Classification of Functioning, Disability and Health as well as that of The United Nations Convention on the Rights of Persons with Disabilities).

The ontogenetic developmental period is in two aspects crucial for mentally disabled children as their mental disability originates in that period. Consequently, their mental disability can cause a different or impoverished social interaction. The importance of social functioning for individuals with mental disabilities is recognized as relevant to an individual's quality of life (Nota, Ferrari, Soresi & Wehmeyer, 2007). Being socially connected to one's peers and relatives is of great importance to an individual's well being and contributes to one's happiness and contentment (e.g. Baumeister & Leary, 1995; Biemans, van Dijk, Dadlani & van Halteren, 2009).

Social connectedness and "others". Social connectedness can be threatened by interpersonal rejections (Williams, 1997). Deterioration or severance of valued social bonds that often accompany life transitions can make individuals feel adrift and lonely (Wildschut, Routledge, Sedikides, Arndt & Cordro, 2010). Recent work on connectedness invokes either explicitly or implicitly, attention to the origins of the *state* of being connected. More specifically, studies refer to the behaviors that *others* (e.g. parents, teachers etc.) engage in that are suspected to causally relate to the creation of connection (e.g. Barber & Schulterman, 2008). For mentally disabled children in home groups such behaviors come from mostly the parent(s) on their visit. Besides the parents, there are the caregivers and the other children at the home group. However, mentally disabled children are not always able to determine or change the behavior of *others*. Nor are all mentally disabled children cognitively able to interact with *others*.

The interactions and relationships we have with other people form an essential social network that supports us and adds meaning to our lives. This can be illustrated by the massive success of communication media such as e-mail, mobile telephony, text messaging, and the massive adoption of social networking applications such as Facebook and Twitter (e.g. IJsselsteijn, van Baren, Markopoulos, Romero & de Ruyter, 2009). The current development of Internet provides us with social networks and connectivity services to stay in touch with the whole world. Stay in touch with their family is a good start for mentally disabled children.

Social connectedness and awareness systems. There are several systems supporting social awareness between family and, or friends. Research prototypes include GeorgiaTech's Digital Family Portrait (Mynatt, Rowan, Jacobs & Craighill 2001), Intel's related CareNet display (Consolvo Roesler & Shelton 2004), SPARCS (Bernheim, Brush, Inkpen & Tee, 2008), Collage (Ashkanasy, Benda & Vetere, 2007) as well as the ASTRA prototype (Romero, et al., 2007). The aim of awareness systems is often simply to help people to stay in touch, i.e., to be reassured about the well-being of others, to let others share your experiences, or to let someone know you are thinking of him/her. Such systems fit into the category of connectedness-oriented communication (Kuwabara, Watanabe, Ohguro, Itoh & Maeda, 2002). Communication can create a sense of connectedness or feeling of being in touch. For awareness systems this may be more important than the content of communication (Rettie, 2006).

Using photos. Many of the awareness systems employ photos. The use of photos can be seen in the light of cognitive priming (Baldwin, 1994; Brewer & Gardner, 1996). In cognitive priming the memories of significant others are recalled, therefore increasing self-esteem and temporary feeling of belonging. This cognitive priming can be achieved by for example looking at a photo of a significant other (Visser et al., 2010). Cognitive priming is an individual process depending on the individual value of the content of the photo.

Previous research with digital photo frames. Biemans & van Dijk (2009) and Biemans et al., (2009) investigated the importance of social connectedness on individual's well-being and health improvement in institutions (nursing home and rehabilitation center) using digital photo frames. Distance between rehabilitant or elderly, and family increased permanent or temporally when the rehabilitant or elderly stayed in the care institution. In order to increase social connectedness Biemans et al., (2009) and Biemans & van Dijk (2009) used the Vodafone SIM card based digital photo frame. These photo frames enable delivery of photos taken on a camera phone through Mobile Message System (MMS). In addition it is possible to upload photos to the photo frame via the website.

The use of digital photo frames for displaying a slideshow of photos is becoming increasingly popular. Photo frames are considered to be a part of furniture or decorative objects that blend in the home environment (Biemans et al., 2009). Digital photo frames allow people to view digital photos away from desks where computers are. And watch the photos in a place in the home where photos are traditionally watched (Kim & Zimmerman, 2006). The family of the elderly or rehabilitant was provided with camera phones in order to make and send photos via MMS or the website.

In their study with elderly living in a nursing home Biemans & van Dijk (2009) found that the photo frames served as *food for talk* between the elderly and family members, and also between the elderly and caregivers. The frame was mainly used to send photos of special events that are meaningful to the elderly persons. In their study with the rehabilitants almost half of the photos had a focus on staying in touch by sharing everyday things of life. These photos were not necessarily followed by communication. Two different intentions of photos sent to stay in touch.

In this study the aim is to share photos by *exchanging* photos instead of sending from one side. Therefore, the intention of photos send and received can be different per user group. In the new communication via photo exchange, people can share information about their lives to give meaning and value to the social relationships. Such information can vary from rational to emotional information, and it can include positive and negative information (Visser et al., 2010). For connectedness-oriented communications the informational content of the message can be of secondary importance to the emotional, relational content that is being transmitted (Kuwabara et al., 2002).

That the informational content of the message can be of secondary importance to the emotional, relational content can be applied on photos exchanged. Biemans, Dadlani and van Dijk (2010) used a categorization based on the work of Kindberg Pasojevic, Fleck and Sellen (2005) to determine the *content* of the photos in their studies. The categories are based on the intention of the sender, to share the specific photo. These five categories are expected to fit the content of the photos exchanges in this study. Being cautious that the intention of the photos sent could differ per stakeholder.

Measuring social connectedness. To measure social connectedness, mostly questionnaires or scales are used (Lee & Robbins, 1995, 1998, 2000; Russel Peplau and Cutrona, 1980; Van Baren, Ijsselsteijn, Markopoulos and Romero, 2004; Romero et al., 2007). Douma and Kersten, (2001) mention the importance of involving mentally disabled peoples self. All regularly used measurement methods for social connectedness are too difficult for mentally disabled children. The measurement methods are written, or too long. Additionally they use concepts unfamiliar to mentally disabled children. For case studies (data) triangulation is strongly recommended (Eisenhardt, 1989). Decisions in order to find appropriate measurement methods for this case study are based on the stakeholders. In this case: Mentally disabled children, Caregivers and Parents. Several measurement methods are considered for usage per stakeholder.

First the *Mentally disabled children*. Characteristics for mentally disabled children are a low cognitive level and difficulties in expressing themselves in communication. There are measurement instruments with a social component used with the children at the institution now e.g. the Communicatie Profiel – Z (CPZ) Dutch, Vragenlijst over Ontwikkeling en Gedrag (VOG) Dutch and, Sociaal Emotionele Ontwikkeling (SEON) Dutch. However all these tests have one or more obstacles to overcome in order to make them usable for mentally disabled children in relation to the social component. For example the level of the test is still too high.

Special attention is paid to the Family Relation Test (FRT) (Anthony and Bene, 1957). This projective test attempts to overcome the limitations of seeing the child as the identified problem, in isolation from their family (Griffin, 2005). The test uses postboxes representing family members to which the child can assign different statements. The original Dutch statements in the FRT do not fit the situations the children are in or would get in during the intervention. Some statements are rather inappropriate. For example the test stated; with whom would you like to play in your bed? This is a relatively sexually orientated statement. In order to

use the FRT statements, the statements had to be rewritten to fit the situation the mentally disabled children are in. Reliability issues had to be taken into account for a rewritten version.

The Landelijk Kennis Netwerk Gehandicapten (LKNG), a nationwide database on mental disability, published a guide on how to do research with mentally disabled people. This guide mentions several focus points. For one they note that there is still little known on which support materials are the best to use in research (Schuurman Speet and Kersten, 2004, p.69). Usability of the measurement methods has to be considered. Kraijer and Plas (2006) mention in their manual on psycho diagnostics three types of measurements; tests, scales and questionnaires. Scales, in observations by caregivers, are the most commonly used measure. Scales are followed by tests, which are relatively subjective measurements. Finally, questionnaires are scarcely used as measurement method at mentally disabled people. In an overview of research methods on mentally disabled people no tests as measurement method are mentioned. (Schuurman et al., 2004, p.111). This indicates that not all types of measurement methods are available for mentally disabled children.

The LKNG publishes so-called *Klappers*, which are folders with thematically ordered information, e.g. a *Klapper* on the quality of life. There is literature-based evidence for a relation between social connectedness and quality of life (Visser et al., 2010). In the *Klapper* on quality of life the Mental Disabilty Quality Of Life (IDQOL) (Douma et al., 2001) was found. This short questionnaire is based on the Dutch Children's AZL/TNO Quality of Life Questionnaire (DUCATQOL) (Koopman, Verrips, Fekkes, Theunissen, Wit and Verloove-Vanhorick, 1997). The IDQOL consists of three domains: Social, Living and Psychological. The domains can be extended with additional questions. There are also complete additional domains to the IDQOL. The IDQOL has the possibility to use the same measure as proxy (e.g. filled out by somebody close to the mentally disabled child) and measure for the mentally disabled child. Among other

measurements (see the method section) mentally disabled children will complete the IDQOL as an interview with aid of a psycho diagnostic assistant. An inclusion criterion is set in order to determine if the children would be able to express themselves in communication for the different measurement methods. The ComVoor (Verpoorten, Noens, van Berckelaer-Onnes, 2004) is a test designed for the mentally disabled population, to determine what kind of communication support is needed. In the test the participants sort different representations of objects. The result of the test is a degree between *presentation* to *representation* level. On the *presentation* level there is a match between the concept and a copy of the concept. At the *representation* level, a concept can be sort by a representation of a concept of the same category (e.g. a picture or drawing of the concept).

The second stakeholders, the *Caregivers*, are trained and experience observers of the children their behavior. Among other measurement methods, the proxy version of the IDQOL is used as a scale. The caregivers, based on their experience with the child, fill out the proxy version.

For the final stakeholder, the *Parents*, the Affective Benefits and Costs Questionnaire (ABC-Q) Dutch version (Van Baren et al., 2004) will be used. In a field test by Romero et al., (2007), the ABC-Q proved to be sensitive for change, in their case introduction of an awareness system. Because introducing a system for photo exchange is a change is situation, the used measurement method must be sensitive for this. The ABC-Q makes a distinction between the Benefits and Costs of an introduced system. It is expected that parents will have to make some effort to make the system work. The ABC-Q is able to show what the balance between the Costs (e.g. effort) and Benefits (e.g. staying in touch) is. Besides the ABC-Q parents are involved in the evaluative interviews, predominantly to evaluate the photo exchange system.

Introducing a photo exchange system. Similar to other studies in this field, a user requirement inventory is conducted to develop a system addressing the communication needs (Visser et al., 2010). The requirement inventory involves the stakeholders *Parents* and *Caregivers. Mentally disabled children* are not able to contribute to the requirement inventory, due to their disability. Therefore *Specialists* (e.g. behavioral experts at the institution), warrant the needs of the children. Several open question interviews with all these stakeholders will be conducted, to determine the requirements for a photo exchange system.

Explorative case study. In this explorative case study a photo exchange system is introduced in order to improve social connectedness mentally disabled children and their parents. Based on the results from the user requirement inventory, a photo exchange system is set up. In a trial period of about 14 weeks photos can be exchanged between parents and children. For this trial period the dependent variables, social connectedness and quality of life will be measured with pre- and post measures.

The objective data coming from the photos exchanged will be analyzed. Using the exchangemoments of the photos, the amount of photos exchanged and the content of the photos. The requirements from the requirement inventory will be used to design a photo exchange system. This photo exchange system will be evaluated for its usability. All in order to answer the research question: Does exchanging photos have a positive effect on the social connectedness between mentally disabled children living in a home group at an institution, and their family? And therefore: Increase the quality of life of the mentally disabled children?

Method

This study is an explorative case study at an institution for mentally disabled people at Almelo, The Netherlands. The study takes place at two home groups; *Home-A* and *Home-B*. These home groups provide care for mentally disabled children. In this section the participants and measurements are described. An overview of the analyses of data of these measurement methods is given. Additionally, in this section the photo exchange system is described based on the findings in the requirement inventory.

Participants

As mentioned earlier three stakeholders are distinguished; *Mentally disabled children*, their *Caregivers* and their *Parents*. There are differences for the stakeholders on different aspects of introducing an intervention to improve social connectedness.

Mentally disabled children. The *Mentally disabled children* live in a home group at the institution for mentally disabled people. Dependent on the disabilities of the child, care is focused on specific care domains e.g. personal care. Several caregivers work at one home group. Children live together and share some communal areas like the living room, kitchen and all sanitary. All children have their own room, arranged to their own preferences.

During the day children are at school, a day care, or perform 'social work'. During the week these children are at the group in the afternoon. For the weekend there is a strong difference between the children. As some go home to their parent(s), and some do not go at all. In addition when children go home to their parent(s), there is difference in duration of the stay. This is also a predominant difference between *Home-A* and *Home-B*.

For *Home-A*, 4 boys and 1 girl participated, aged between 14 and 26 years old. The girl moved to the home group during our study. A sixth inhabitant of the home group moved to the group as well though she and her parents did not participate in the study.

All children of *Home-A* are allowed and do go home for the weekend, though with differences in frequency and duration of the stay. Two children go to school during the day. The other three children work during the day. Three children are unable to communicate through words. These children use some form of sign language. The children who are able to communicate are allowed to call their parents once during the week, and for special occasions once more. The call during the week is most times used, but is not required. *Home-A* exchanged photos for 13 to 15 weeks. Except for the last girl, she exchanged photos for 4 weeks.

For *Home-B*, 5 boys and 1 girl participate, two of the boys are brothers. These children are younger, aged 6 to 11 years old. All children stay at the home group for the weekend, except for special events. Parents, with strong differences in frequency, come visit their child at the home group. Most visits are during the weekend and sometimes during the week. For some parents a visit is under supervision, in the interest of the child. Some children can visit one of the parents for a day or two. All children go to school during the day, though not all at the same school. All children of this group are able to communicate through words, sometimes with aid of signs. All children are allowed to call their parents during the week, though this is not always done. *Home-B* exchanged photos for a shorter period of 7 to 8 weeks.

Clearly the participants do not form a homogeneous group. There is the age difference, though due to mental disabilities this is somewhat nuanced. There are strong differences in disability, physically and mentally. For this study the mental disability is the most present in the ability to communicate through words or signs. For the differences in communication skills the scores on the inclusion criteria are used. Representation level on the ComVoor indicates that

there is understanding that a photo on the digital photo frame is a representation of the moment the photo was taken. It does not guarantee there is understanding of the content of the photo. All children of the two home groups, Home-A and Home-B, reach the representation level.

The differences in contact with the parents were the second big difference between the children. The differences in visits to their family and from family could not be influenced; therefore it is documented and this difference is acceptable.

Caregivers. The second stakeholder is the caregiver. Caregivers are trained and used to observe the behavior of the mentally disabled children. Since observations are really subjective difference per caregiver are expected. For this study the caregivers are determined by the choice of the two home groups. As in most healthcares most caregivers are women. For *Home-A* most of the time between one and two caregivers are present at the home group. For *Home-B* this is sometimes three at the same time present at the home group. For *Home-B* caregivers have to work nightshifts, therefore they sleep over.

Parents. The third stakeholders are the *parents*. For *Home-A* all parents but one live together, in case of the separated parents the father of the child participates. While for *Home-B* all parents but one are separated. The parents still together are the parents of the brothers. In some cases separated parents no longer communicate together. For this study it is not essential for the parents to work together or communicate.

As mentioned for the children the contact between child and parent(s) is different for every parent-child-couple. Mediated communication is mostly through telephone with prearranged calls. There could be mail contact from parents, but this is more directed towards the caregivers than the child, asking how their child is doing. There were prior attempts to email

photos but since the mail server at the home group could not handle attached photos this was no longer done. One parent couple has already provided their child with a digital photo frame on which they occasionally put new photos from a memory card.

Photo exchange system

The set up of the requirements inventory contributed to the results of the requirements inventory. The photo exchange system designed was based on the requirements for the requirements inventory. Therefore the results will already discussed.

Set up of the requirement inventory. The requirements inventory is conducted by interviewing several stakeholders. Open interviews were used, so stakeholders are open to mention all sorts of requirements. Consequently the results cannot be statistically analyzed. The main results from the requirements inventory are requirements for a system supporting distant photo exchange.

Results from the requirements inventory. From the requirement inventory three main issues have to be covered by the system: *Costs*, *Simplicity* and *Control*.

Costs can be seen as financial contribution and also as effort needed to make the system work. For this case study financial contribution is covered by subsidies. So only the *Costs* coming from effort to make the system work have to be covered. Effort can be seen as ease of performing tasks on the system. Three main tasks can be distinguished from a photo exchange system; *making photos*, *uploading photos* and *manage photos* (viewing).

Making photos is strongly dependent on personal experience with photo making. Van House (2010) underlines the relative lack of ethnographically informed research on people's actual daily practices of photography. The difference in photo making is accepted. *Uploading the*

photos from the camera to the personal computer is supported mostly by software of the camera. More effort is needed to choose photos that you want to share. *Managing the photos* (e.g. on the personal computer) in order to retrieve the photos is strongly dependent on personal preferences (e.g. folder structure, back up, and printing options). Further *management* comes with the photos received and sent on the actual display.

Simplicity is related to the effort part of Costs. Effort is minimized with a simple system. In this study the parents demand Simplicity, since they described themselves as inexperienced with new technologies, and expressing fear for new technologies. Simplicity can be achieved by using pre-existing structures. In making photos, Simplicity can come from using their own camera they are familiar with. Uploading from their familiar camera and software is therefore simple. Managing the photos should resemble familiar structures. Familiarity in the system can reduce the fear of new technologies.

Mostly the *Caregivers* and *Specialists* demand *Control*. The moment and time the photos are watched by the children had to be controlled. Moreover they also wanted *Control* on the content of the photos exchanged in the system. The caregivers, turning on the photo frame at appropriate times for photo watching, will control the moment photos are watched. Additional to the control of the moment was the security of the photo frame. Some children are careless with objects and apparatus. For these children a protection around the photo frame is recommended to prevent damage of the photo frame. This protection will be locked by key, so that caregivers have to unlock in order to turn on the photo frame.

An intervening reviewer can control the content of the photos exchanged. A reviewer is able to determine if the content is appropriate, and whether the photos are of good quality. Based on these requirements and recommendations a system for distant photo exchange is designed.

Decisions in designing a photo exchange system. For making photos the own cameras of the parents are used, or alternatively a Kodak Easyshare M580 is provided. The Kodak Easyshare M580 camera is able to choose automatically the appropriate setting for a photo moment. These cameras are used at the home groups. Because there is the possibility the children can also make photos a highly automatic camera is preferred. This camera would also be lent to those parents that have no camera. Since these parents probably did not previously use a digital camera it is desirable that the camera is easy to use.

Uploading photos dependents upon the software of the camera in use. The users determine which photos are shared. In order to *Control* the content of these photos direct sharing is intervened with a reviewer. The reviewer makes sure the photos are appropriate to be seen by the children. Photos can contain inappropriate content or quality of the photos is low (e.g. blurry). In order to have a reviewer before forwarding photos, photos are uploaded to a shared Dropbox folder with the reviewer. In the current study the reviewer is the researcher.

Dropbox is free online available software for sharing and storage of documents, for more see www.dropbox.com. Dropbox enables you to access folders with documents on different apparatus and the Dropbox folders are accessible online. Folders in Dropbox can be shared by inviting other Dropbox user to share this folder. Additionally the structure and design of Dropbox is intuitive to use to manage the photos. Dropbox resembles folders used on all types of personal computers. A known structure and design like Dropbox invokes Simplicity. In order to send photos, the user drags and drops or copies and pastes the photos in the Dropbox folder. Since the folder is shared, all invites are able to see and use the photos in this folder. Enabling Dropbox to insert a Control system, all involved share a folder with the researcher. Just as the researcher reviewed the photos they are send through to the receiver.

After reviewing the photos are forwarded to a digital photo frame. The Kodakpulse 10" (see Figure 1) frame supports distance photo exchange through a wireless network connection. Biemans et al. (2009) and Biemans and van Dijk (2009) used the digital Vodafone SIM based photo frames, but those are no longer available. The only distant photo exchange options available are trough wireless connections with the digital photo frame. The Kodakpulse and Samsung SPF 105V support wireless network connection. The Samsung frame is less intuitive to use when interacting with the photo frame. Especially connecting the frame to the wireless network is difficult. *Simplicity and Costs* is better covered with the Kodakpulse 10" digital photo frame.

For the Kodakpulse 10" digital photo frames it is their specific online support page www.kodakpulse.com you have to enter to upload the photos to the frame. One online kodakpulse-account can be connected to more than one photo frame.

Figure 1. The Kodakpulse 10" photo frame, front view, side view and back view.

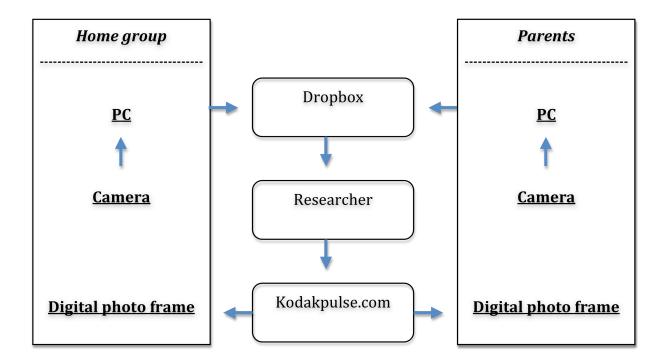






Photo exchange system. In its entirety the system is as follows (see Figure 2). (1) Make photos with a digital camera (Kodak Easyshare M50, or own camera). (2) Upload to the photos to a personal computer (or laptop). (3) Place photos to be shared in the shared Dropbox folder. (4) The researcher reviews the photos from this shared folder than forwarding to the corresponding kodakpulse.com online account. (5) This kodakpulse.com account is connected to the digital photo frame of the child and parent(s), making photos appear on both frames at the same time.

Figure 2. Distant photo exchange system.



Because of a limited amount of available digital photo frames by Kodak during our study, not all involved could be provided with a digital photo frame Kodakpulse 10". In order for *Home-B* and the parents to exchange photos whiteout the photo frames a second system is set up.

The second system is based on sending and watching from Dropbox folders on the personal computer. Parents and the home group *Home-B* share two folders with the researcher, a folder for *sending* photos and one for receiving photos for *watching* photos. The researcher reviews the photos in the folder *sending* before placing them in the corresponding *watching* folder of the parent or child. In order to watch the photos, parents can, at any time, open the folder *watching* and watch the photos. In the same manner children, accompanied by a caregiver, watched their received photos.

Measurements

Different measurement methods are used. De dependent variables social connectedness and quality of life are measured with the ABC-Q (Dutch version) and IDQOL (Dutch version). The *Parents* complete the ABC-Q. The ABC-Q is completed as pre- and posttest. The *mentally disabled children* complete the IDQOL (client version). *Caregivers* complete the IDQOL (proxy version), one or two caregivers together complete an IDQOL per child. The IDQOL is completed as pre- and posttest.

Qualitative measurement methods are used for data triangulation. Observations made by the *caregivers* are filled out during the complete trial period. All users of the system, caregivers and parents fill out evaluative interviews on the user experiences. The evaluative interviews are completed after the trial period.

Finally the objective data from the photos is used. Using the exchange-moments of the photos, the amount of photos exchanged and the content of the photos. Additionally the photos are used in an explorative new measurement using the LEMTool. The LEMTool is used to subjectively determine an evaluative score from the *mentally disabled children* on the photos.

ABC-Q. The ABC-Questionnaire (ABC-Q) (Van Baren et al., 2004) is a test to address the affective characteristics of communication means. The ABC-Q is sensitive for change, therefore the parents fill out the ABC-Q Dutch short version as a pre- and posttest.

Compared to the original ABC-Q, questions on the *others perceptions* are left out. The *other* meant by the questionnaire are in this case mentally disabled children. Interpreting what mentally disabled children think of the affective characteristics of communication is difficult. Therefore the ABC-Q consists of twenty-seven questions on a 7 points licker scale from strongly agree to strongly disagree (see Appendix A). It covers nine domains with three questions per domain. The domains are; (1) *personal effort*, (2) *thinking of each other*, (3) *sharing experiences*, (4) *staying in touch*, (5) *recognition*, (6) *obligations*, (7) *expectations*, (8) *invasion of privacy* and (9) *process effort*. The first five domains together measure the Benefits, the last four cover the Costs (Ijsselsteijn et al., 2009).

According to IJsselsteijn et al., (2009) the ABC-Q (original version) has good internal consistency, with a Cronbach alpha coefficient reported of .96. In the current study for the ABC-Q pretest (Dutch short version), the Cronbach alpha coefficient is .53. For the ABC-Q posttest (Dutch short version) the Cronbach alpha coefficient is .81. ABC-Q scores from the pre and posttest will be compared using paired-samples t-test

IDQOL. The IDQOL (Douma et al., 2001) is a test to determine the level of quality of life of mentally disabled people. The IDQOL is a Dutch written questionnaire with open questions, supported by pictograms. The questions can be scored with five smiley's from very content tot very discontent. The IDQOL consists of sixteen questions on three domains: (1) Psychological, (2) Social and (3) Living. From the additional questions for the Social domain three questions are added. These three extra questions are; (1) What do you generally think of other persons. (2)

How do you think about visiting others and (3) What do you think of being alone. The complete IDQOL consists of 19 questions (see Appendix B). Children complete the IDQOL with support of a psycho diagnostic assistant. The psycho diagnostic assistant asks the questions, and can explain the question when needed. The same psycho diagnostic assistant supports at the pre- and posttest. In total 10 children complete the IDQOL as pretest.

Caregivers fill out the proxy version of the IDQOL (Douma et al., 2001). This Proxy version consists of exact the same questions. Additional information, specifically from the open questions, is used as background. This background information helps interpreting the IDQOL scores of the children. For all children the IDQOL is filled out as pre- and posttest. When possible the same caregiver(s) fill out the IDQOL as pre- and as posttest.

According to Douma et al., (2001) the IDQOL has good internal consistency, with a Cronbach alpha coefficient reported of .85. In the current study there were four different reported Cronbach alpha varying from good to very bad internal consistency. Pretest of the (childrens version) of the IDQOL has low internal consistency, with a Conrbach alpha coefficient of .41. Posttest of the (childrens version) of the IDQOL has good internal consistency, with a Conrbach alpha coefficient of .79. Pretest of the proxy version has good internal consistency, with a Conrbach alpha coefficient of .74. Posttest of the proxy version has good internal consistency, with a Conrbach alpha coefficient of .76. For both the IDQOL from the children as for the caregivers, the pre and posttest scores will be compared using non-parametric tests, the Wilcoxon Signed Rank Test.

Observations. During the photo exchange period the caregivers report observations of the children's behavior on a checklist. The checklist of possible behavior of the children is filled out daily (see Appendix C). By using a checklist for the observations the observations are structured over the various caregivers of the children. Inserting additional space for comments and observations not listed, at the end of the checklist. Occurrence of behaviors will be scored and compared to the exchange-moments documented in a log over time.

Evaluative interviews. Parents answer questions presented in a structured oral interview (see Appendix D). The interviewer asks about their opinion on the value of the system. How they experience the system. And what they think of the type of photos sent and received.

Caregivers answer questions presented in a structured written interview (see Appendix E). There are questions on their opinion of the value of the system for the children. But since the caregivers also have to operate the system there are also questions about their user experiences. The results for both interviews will be described in a qualitative manner

Photos exchanged.

The exchange-moments of the photos are documented in a log. The amount of photos per exchange-moment and total amount are documented aside. The log distinguishes between users.

The content of the photos is determined by content analysis. The content analysis is based on the 5 categories of Van Dijk, Dadlani, Van Halteren, and Biemans, (2010). The categories are (1) Message: *I tell you something with this photo or I will show you something new.* (2) Greetings: *I want to say hi to you.* (3) Everyday life: *I want to keep you involved in the regular events in my environment.* (4) Special events: *I want to inform you about a special event.* And (5) Something funny or aesthetic: *I want to show you something and cheer you up.*

In the current study the photos are exchanged instead of sending from one way as for Van Dijk et al., (2010). In this study the photos on the photo frames can come from different senders, with different intentions. With the researcher in the photo exchange system the log of photos will keep track of the sender of the photos.

LEMTool. For a subjective value of the photos the children used the LEMTool (Huisman and van Hout, 2010). The LEMTool displays graphical emotions on small round stickers. According to Huisman and van Hout (2010) the stickers can be assigned to anything you want to assign an emotion too. In a playful setting the children will assign stickers to photos. All children stickered 12 photos out of the photos they receive.

Four out of the eight emotions of the LEMTool, (1) joy, (2) desire, (3) sadness and (4) disgust (see Appendix D) are selected. Joy and sadness are the extremes of the likability spectrum. Desire and disgust are the extremes of the aesthetics spectrum. Choice is limited in order to make it easier for mentally disabled children. The LEMTool is used in an explorative manner, therefore the results are uncertain. So no analysis is foreseen.

Results

Several measurements were used for (data) triangulation, therefore both tests and other measures are described. As described in the method section the ABC-Q and IDQOL are analyzed statistically. For the ABC-Q, an alpha of .05 was accepted for all statistical tests. For the IDQOL an alpha of .10 was accepted for all statistical tests, due to the small sample size.

The qualitative measurement methods describe the qualitative information supported with descriptive data.

For the photos the exchange-moment, amount of photos and content, are presented as descriptive results. Results are presented for the parents separated per home group and for the caregivers per home group. Because the LEMTool was used explorative the results are the descriptive data and qualitative information.

ABC-Q

The reliability of the pretest was low Cronbach alpha was .53. Comparison of the pretest scores with the posttest scores was not relevant. Independent-samples t-tests on differences scores on the pre- and posttest (see table 1) were not significant.

Table 1

Difference in scores from the pretests and posttests of the ABC-Q.

Dimension of the ABC-Q	Mean score pretest	Mean score posttest	p
Costs	3.49	3.37	p = .61
Benefits	5.88	5.74	p = .09

Posttest showed good reliability, Cronbach alpha was .81. A paired-samples t-test was conducted to evaluate the difference in scores on Benefits and Costs. There was a statistically difference in scores of Benefits (M = 5.74, SD = .57) and Costs (M = 3.37, SD = .87), t (9) = 11.59, p < .001 (two-tailed). The magnitude of the difference in the means (mean difference = 2.37, 90% CI: 2.00 to 2.75) was a large effect (eta squared = .83).

IDQOL

Ten children completed the IDQOL as pretest. Due to difficulty with completing the pretest only 8 children completed the IDQOL as posttest. Two Wilcoxon Signed Rank Test revealed a statistical significant difference in IDQOL scores on the proxy version and the scores on the IDQOL completed by the children, z = 1.96, p = .05 (pretest) z = 1.96, p = .05 (posttest).

There was no significant difference on IDQOL scores for the pretest and posttest on the proxy version. A Wilcoxon Signed Rank Test revealed a statistical significant difference in IDQOL scores on the pretest and posttest scores on the IDQOL version completed by the children, z = 1.89, p = .06. For all but one child the posttest scores were higher.

Difference was found on the domain Psychological, z = 2.39, p = .02. For all but one child the scores on the domain Psychological was higher at the posttest. Further analysis was not relevant due to low reliability of the pretest.

Observations

Caregivers did not keep up the observations. During the first 2 weeks half of the checklists were filled out. Note that children are not always at the home group. This was already less for the third week. Children were about the same time at the home group than the first two weeks. Some checklists were not completely filled out.

Caregivers indicated to forgot or have to little time to fill out the checklist. Besides that the caregivers stated that the behavior did not change that much it would change the way the lists per day were filled out. The relative low change in behaviors could not be confirmed since the short time frame and low quantity of filled out observations. The second home group never filled out any behavior observation checklist. They started at the time the first home group long stopped filling out the observations.

Additional questions in the interview are introduced to cope with the lack of behavioral observation data. These additional questions were also applicable to both home groups.

Evaluative interviews

At the end of the exchange period interviews with the parents and caregivers were conducted. The interviews asked about their experience with the photo exchange system. The interviews were different for the parents and caregivers, based on the specific user experiences. The results are descriptive data and qualitative data.

Evaluative interview by the parents. There was an structured interview schema used (see Appendix D). Not all parents completed the interview. Due to personal problems the interviews could not be conducted. These were all parents using Dropbox. Besides that, the user experiences were somewhat different for using the photos frame or Dropbox, so results will be presented separately for the two parent groups. Five parents using photo frames, and 6 parents using Dropbox completed the interviews.

The first question in the interview was to rate the project in its totality with a grade from 1 tot 10 (see Table 6).

Table 6

Grades given per parent group for the complete project.

Parents							Average
Photo frame	10	8	8	8	7		8.2
Dropbox	10	10	8	8	8	8	8.7

The photo frame using parents found the project to be *fun*, users *like watching photos* and *it worked!* Parents would liked that the photo frames could be used with Picasa (an online photo sharing service), want their child to turn it on himself, or would want to ad text to the photos. One parent commented they were less content about their own participation, based on the quantity of photos they sent. The Dropbox parents found the project to be *fun*, users *like getting photos of their child*, it was *easy to use* and they experienced *more contact*. Parents were less content about their own participation, based on the quantity of photos they sent. They would also like that vague or blurry photos would not be sent.

Photos were watched with strong difference in frequency. The photo frames were almost always turned on daily, and especially when the child was there. Dropbox users had to turn on their PC in order to watch. There were parents who watched the photos from Dropbox daily, others when new photos were added. All parents sent photos the child would recognize, and could 'talk' about at the home group. Recognition was mentioned again when asked if they had an underlying idea of the photos sent. Parents were especially glad to receive photos of everyday life at the home group, or things they 'forgot' would happen at the home group. Trips of and special events at the home group showed how much the children did. A few photos were deleted, mostly vague photos or the oldest photos on the frame.

Parents were asked to give a score of the involvement/ connectedness they experienced with this system. -5 to 0 was a *decrease*, 0 to +5 was an *increase* (see Table 7).

Table 7

Increase in involvement/connectedness experienced with their child, by the parents.

Parents							Average
Photo frame	+2	+3	+3	+3	+4		+3
Dropbox	+1	+3	+4	+4	+5	+5	+4

Suggestions, problems, and solutions were noted in order to determine future implications. Some parents mentioned to lack the option to add text to the photos. Parents would also like to use the wireless connection to use other communication supports like Skype (e.g. video talk) *Home-B* already used the digital photo camera to make short home videos. The videos were a success to all parents. In the future they would like to keep this option of video exchange.

Evaluative interview by the caregivers. Caregivers completed a written structured interview about their experience, especially about the use of the system and their opinion on what value it would have for the children (see Appendix E). We will separate the results for photo frame users and Dropbox users for the same reason as we separated the results of the parents their evaluations. Both groups filled out the same interview. Three caregivers from both home groups completed the interview. The first question in the interview was to rate the project in its totality with a grade from 1 tot 10 (see table 8).

Table 8

Grades given per home group for the complete project.

Home group				Average
Home-A	8	9	9	8.7
Ноте-В	8	8	8	8.0

The best aspect was the ability to use the system for the child to watch photos and talk about the photos, and related events. And the other way around was the ability for the parents to see photos from the children. This was promoting contact between children and parents.

The technical support from ICT was less. There occurred problems with the wireless network and therefore related problems with uploading photos. The Dropbox users had hoped to use the photo frames as well. The time needed to operate the system was for some a downside of the project. The trial period lasting 3 months was good. Evaluating then was seen as the right moment. For the Dropbox users it lasted to short, almost two months, they felt to have just started. They believe the evaluation would therefore not be complete.

On a scale from -3, *deterioration* to +3 *huge added value* caregivers scored the added value of the photo exchange system (see Table 9).

Table 9
Scores from the caregivers on the added value of the photo exchange system

Home group	Average			
Home-A	+2	+2	+2	+2
Home-B	+3	+2	+3	+3

The added value accounted for all children but not the same for all children. This was related to the background of the child. The added value came from the ability to watch the photos (together) and use them as a basis for conversation. A child was now able to share what it had done at the parents, away from the home group.

All children were enthusiastic to watch the photos. The reactions of the children on the photos varied from neutral to happy/ content. Here was once again mentioned that children used the photos as support for sharing their experiences. Photos were sometimes watched more than once. At *Home-B* children asked to watch the photos if they knew there were photos made by the home group. When they watched those photos the photos from the parents were watched too.

The children did not show a difference in connectedness towards the parents. *Home-A* said they believed the children did not experience any form of connectedness at all. This was different for *Home-B*, they believed that through the photo exchange connectedness of the parents was changed. Parents now see what happens at the home group and see their child doing all kinds of activities. Caregivers mentioned to experience acknowledgement of their work from the parents. Children who see their parents just once in a month can see photos of them in the

meanwhile. The success of the photos was especially seen when the children went fishing and by change the father of one child sent photos of himself fishing that same day. The child was said to grow with confidence.

The second part of the interview was about the user experience when interacting with the photo exchange system. The first question was to give a grade from 1 to 10 on the system (see Table 10).

Table 10

Grades from the caregivers on the photo exchange system

Home group	Average			
Home-A	7	8	8	7.7
Home-B	7	7	8	7.3

The system was relative easy to use. The manual and instructions were enough to operate the system. Problems with the system were due to problems with the wireless network.

Sending photos took 15 to maximal 30 minutes. Half of the caregivers did not want to have to do more effort or operations in order to keep exchanging photos. The other half of the caregivers was open to have to do more effort or operations in order to keep exchanging photos. These operations have to be introduced with good instructions and a good manual. To continue with exchanging photos more support form ICT was needed. Parents, caregivers and external involvement from are needed. The option to use Skype as complement to the photos could be a good direction to go. All caregivers mentioned they would like the keep exchanging photos in the future.

Photos exchanged.

Because of strong difference in time period photos were exchanged the results of the photos exchanged are described separately for both digital photo frame users (*Home-A*) and Dropbox users (*Home-B*). And results are separated for *Caregivers* and the *Parents* of the corresponding home groups.

Amount of photos exchanged by parents. Digital photo frame users (*Home-A*) exchanged photos for 13 to 15. The Dropbox users (*Home-B*) exchanged for 6-8 weeks. The descriptive data from the log on the amount of photos sent by the parents is displayed in table 2 for digital photo frame users (*Home-A*) and in table 3 for Dropbox users (*Home-B*). For the parents using digital photo frame, the data is represented over time in Figure 3. Figure 4 shows the data represented over time for the parents using Dropbox.

Table2

Descriptive data of photos sent for parents using digital photo frames

	1	2	3	4	5	Total
Total amount of photos sent	166	205	124	35	35	565
Amount of exchange-moments	6	9	2	6	3	26
Minimal amount of photos sent per exchange-	4	3	14	2	4	-
moment						
Maximal amount of photos sent per exchange-	89	124	110	11	23	-
moment						

Figure 3. Amount of photos sent per parent(s) for digital photo frames users (Home-A).

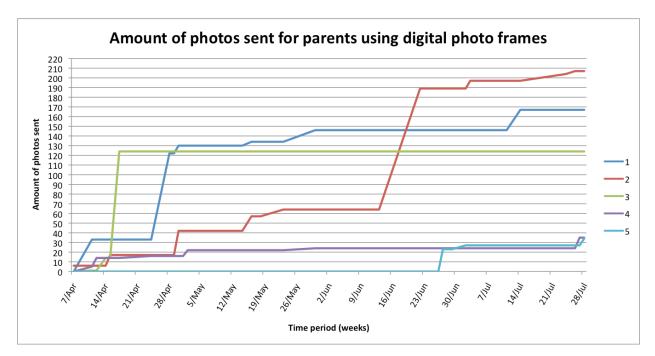
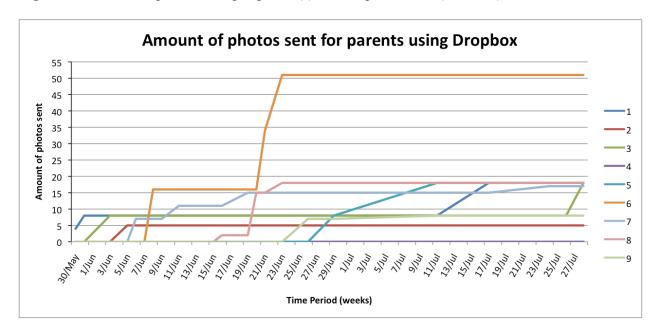


Table3

Descriptive data of photos sent for parents using Dropbox.

	1	2	3	4	5	6	7	8	9	Total
Total amount of photos sent	18	5	18	-	18	51	17	18	8	153
Amount of exchange-moments	3	1	2	-	2	3	4	3	2	20
Minimal amount of photos sent per	4	5	8	-	8	16	2	2	1	-
exchange-moment										
Maximal amount of photos sent per	10	5	10	-	10	18	7	13	7	-
exchange-moment										

Figure 4. Amount of photos sent per parent(s) for Dropbox users (Home-B).



Amount of photos exchanged by the home groups. All caregivers were instructed on how to exchange photos. For this analysis no difference between individual caregivers was made. The descriptive data from the log on the amount of photos sent by both home groups is displayed in table 4.

Table 4

Descriptive data of photos sent for Home-A and Home-B

	Home-A	Home-B	Total
Total amount of photos sent	456	496	952
Amount of exchange-moments	13	11	24
Minimal amount of photos sent per exchange-moment	1	7	-
Maximal amount of photos sent per exchange-moment	180	216	-
Minimal amount of photos sent for one child	34	91	-
Maximal amount of photos sent for one child	133	114	-

Both home groups sent 54% *unique* photos, photos sent to one child only. The other photos were sent to two or more children. For *Home-A* a child had minimal 4 and maximal 12 exchange-moments. For *Home-B* a child had minimal 5 and maximal 7 exchange-moments. The time children were at the home group differed.

The two brothers at *Home-B* had more than the maximal amount of photos sent for one child, for the brothers together 151 photos were sent.

Figure 5 show the data represented over time for *Home-A*, Data For *Home-B* is presented in Figure 6.

Figure 5. Amount of photos sent for children of Home-A.

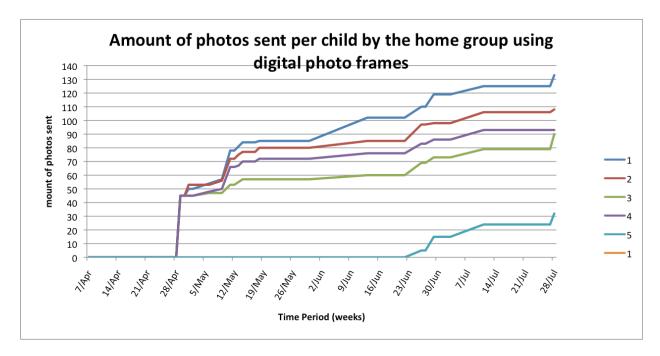
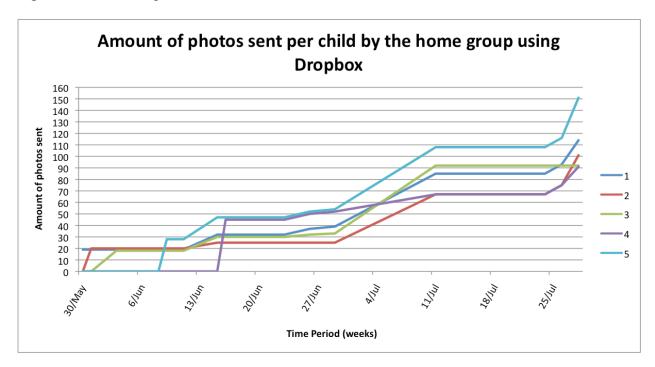


Figure 6. Amount of photos sent for children of Home-B.



Content analysis of the photos exchanged. The content of the photos was determined by categorizations of the photos exchanged. The categorization was based on photos from both the parents and the home groups. A categorization was done by the researchers, based on the work of Van Dijk et al., (2010). The children themselves did the second categorization. The use of the LEMTool was explored in order to let the children categorize photos with stickers.

Categorization of the photos by the researcher. We started with the categorization of Van Dijk et al., (2010). The categories are (1) Message: I tell you something with this photo or I will show you something new. (2) Greetings: I want to say hi to you. (3) Everyday life: I want to keep you involved in the regular events in my environment. (4) Special events: I want to inform you about a special event. And (5) Something funny or aesthetic: I want to show you something and cheer you up. In order to see if the content of the photos fitted the categories three additional people categorized a small random set of 110 photos as a pretest of the categorization

The raters completed an unstructured open interview about the usability of the categorization. They commented to have to little background information on the photos to fully use the categories. These categories were based on the intention of the sender. A suggestion was to categorize on the objective components of the content. That would deal with all objections of the raters.

Based on work of Kindberg et al., (2005), the photos are categorized on the subject depicted on the photo. The difficulty with this type of categories was that photos fitted in more than one category when more than one subject was depicted. Therefore it was still not clear how to handle series of photos of one event.

The taxonomy of Kindberg et al., (2005) has a social and affective dimension. The social use can be broadly broken down into sharing with people co present at the time of photo capture

versus sharing with people who were not physically co-present. The two categories fitted the underlying ideas of photo exchange in this study. First *mutual experience*; images used to enrich a shared, co-present experience. Secondly *absent friends or family* (images used to communicate with absent friends or family).

There were no problems to objectively determine if the child was on the photo or not (see Table 5). Therefore the sender could also objectively be determined. For the home groups the *unique* photos were used.

Table 5

Number of photos for parents and home groups depicting the child on the photo or child not on the photo

	Parents		Home gr	Home groups			
Child on the photo	504	70%	474	92%			
Total child NOT on photo	214	30%	41	8%			
Total	718		515				

These 2 objective data together fit with the categories of Kindberg et al., (2005). On the photos of the home groups in 92% of the photos the child or children were depicted, sent from the home group to the parents therefore fitting the second category *absent family or friends*. For the parents we saw that on 70% of the photos the child was on the photo, sent to the children, therefore fitting in the first category, *mutual experience*.

LEMTool. In an explorative new way the LEMTool (Huisman and van Hout, 2010) was used. All children got 12 photos out of all photos received (the brothers had 17 photos since it was not known to whom the specific photo was sent). In total 118 photos were stickered. Children were asked to rate the photos with the LEMTool stickers.

Five of the 11 children were able to use the LEMTool. Two Children did not want to use the stickers at all. In other cases the child always chose the closest type of sticker at hand, independent of which this was. When asking the child why he/she chose for a specific emotion all answers involved the people on the photo. Some children wanted to put more than 1 sticker on the photo, mostly to make a distinction of the emotional expression per person on the photo.

For the photos frame condition it was striking that the emotion Joy was used the most (33), followed by Desire (12), Disgust the least (1), and Sadness also scarcely (2). For the Dropbox users Desire (34) and Joy (32) were used the most, than Disgust (9) and finally Sadness (4). Note that 3 pictures got two stickers, always Disgust en Desire combined.

General discussion

The photos served as *food for talk*, between the children, between children and their parents, and between children and the caregivers. Between the caregivers and parents it served for understanding of the work of the caregivers. However the photos in this study depicted both special events as everyday life as compared to the findings of Van Dijk, et al., (2010).

This discussion starts with focus upon various reasons for use of both photos depicting special events as photos depicting everyday life. The results contributing to social connectedness between parents and children will be discussed. And this discussion focuses on research limitations and suggestions for future research. Finally recommendations and implications will be discussed.

Content of the photos exchanged

Categorization of the content of the photos based on Van Dijk et al., (2010) appeared from a pretest to be difficult to use for photos exchanged in this study. The major problem was lack of background information in order to determine the intention of the photo sent.

The fact that digital photo cameras were used instead of camera phones generated more photos of one event. It is clear that with the ease and convenience of digital technologies (e.g. digital cameras), the number and also variety of images made has increased substantially (Van House, 2010). A so-called funnel effect (Van House, Davis, Takhteyev, Good, Wilhelm and Finn, 2004) where many photos are taken but only few get added was not found. The current categorization did not show how to treat multiple photos of the same event.

While people still make traditional kinds of images, what is considered photo-worthy has expanded to include the everyday (Van House, 2010). The rater of the pretest said in the interviews that it was difficult to say if what was depicted on the photos was an everyday life

event, since there was a photo of it. This explains why for one rater an event is special just because there is a photo of it.

Photos appear to be objects with no stable meanings. Photos have always had the ability to convey a meaning other than the owner intended (Van House, 2010). Their meaning may change over time, for different viewers, in different context, in different associations with text and other images.

Categorizations. The difficulties with using the categorization from Van Dijk (2010) gave reason to use the objective properties of the photos exchanged. As Kindberg et al., (2005), the photos were categorized on the subject depicted on the photo. This way of categorizing has other complications. Photos fitted in more than one category when more than one subject was depicted. For series of photos it was still unclear how to handle them.

Kindberg et al., (2005) used their categories based on the subjective properties of the photos to come up with taxonomy. Since the photos were used to improve social connectedness the main focus was on the social-affective dimension. The social-affective use can be broadly broken down into sharing with people co present at the time of photo capture versus sharing with people who were not physically co-present. First *mutual experience*; images used to enrich a shared, co-present experience. Secondly *absent friends or family* (images used to communicate with absent friends or family).

Based on wheter the photos came from the parents or home group and secondly wheter the child was on the photo or not photos fitted in one of the two categories. On the photos of the home groups in 92% of the photos the child or children were depicted, sent to the parents therefore fitting the second category *absent family or friends*. For the parents we saw that on 70% of the photos the child was on the photo, sent to the children, therefore fitting in the first

category, *mutual experience*. Drawing someone into an experience happening at the same time despite being separated by distance represent a compelling way to stay close Kindberg et al., (2005). Supported by Kindberg et al., (2005) the sender and the social use of the system contributed to sending photos of all kinds of events. The sender could be both the child as the parent, since photos were exchanged instead of sent from one part.

LEMTool. That people depicted on a photo were the main trigger for the children when watching the photos became clear with the use of the LEMTool. When presenting a photo to the child, the child always started with pointing out him or herself on the photo. Than (all) the others on the photos were mentioned. Consistent with Kim and Zimmerman (2006) when families shared stories bout the photos; they always started by who was in the photo, the social connection between themselves or the person they are engaging with. Most reactions of the children when stickering the photos where on the people depicted on the photo. This was strengthen when children asked to use two stickers to make a distinction on their judgments for the different people on the photo. The two positive emotions *joy* and *desire* were stickered the most. This is reason to believe that children were positive towards the photos they received. These results must be seen in the light that not all children seemed to understand and be able to use the stickers.

In the interview filled out at the evaluation the reactions of the children were described to be neutral to positive/content. Combined with reactions from the children when they stickered the photos, the photos themselves generated an overall positive effect.

Amount of photos exchanged

Contribution to this effect was not found for the amount of photos exchanged. As with the content of the photos it was not clear how to treat multiple photos of one event, series of photos. The time the photo exchange system used was not the same for all parents. And when children were not at the home group when photos were taken, no photos were sent for this child.

Attaching to much importance to the amount of photos does not add value to the results. More photos do not have to be better. According to Kuwabara et al., (2002) the emotional and relational information transmitted in the communication (photos), are more important. This can be done with sending simply one photo 'saying it all'. Communication with small amount of information (e.g., one photo or a trivial message) may be enough to create a sense of connection between people (Bernheim Brush et al., 2008)

In line with the studies of Biemans et al., (2009) and Biemans and van Dijk (2009) it is not that clear if a baseline in exchange moments has been reached, nor for the home groups, nor for the parents. There is too much difference in exchange moments per person and also in minimal amount of photos per exchange moment. In order to determine the baseline the photo exchange system needs to be used longer.

ABCO

The ABC-Q scores given reason to believe that the baseline for photos exchanged will not be zero. The experienced Benefits of the photo exchange system were significantly higher than the Costs. Benefits of exchanging photos weigh heavier than the Costs, making it plausible that users accept the Costs in order to be able to exchange photos.

When designing the system the costs were kept as low as possible, since that was a design requirement from the user requirement inventory. The costs should have been low enough

to have out weighted the Benefits. Simplicity of the system can contribute to low perceive Costs. This believes were strengthen by results from the evaluation interview of the parents. In the interview the photo exchange system was said to be easy to use.

Whether the Costs were higher than the Benefits before using the photo system could not be determined. The pretest of the ABC-Q was not found reliable. When completing the ABC-Q some parents had difficulty understanding the questions. An explanation for reliability at the posttest as opposed to the pretest is that parents just at the posttest understood the test. This is supported with the fact that at the pretest parents had to score on what they expected from the system, while at the posttest they could rely on their actual experiences of the system.

Evaluative interviews

In the evaluative interviews of the parents the experiences of exchanging photos with their child were asked. We found that all parents were positive about using a photo exchange system. Several parents said to sent photos to their child he or she could talk about at the home group. And they experienced that their child told more about his or her experiences when there was support from photos. What was found promising is that the photos served as *food for talk* not only towards the parents. The caregivers too reported the photos supported stories from the children on their experiences.

Social connectedness.

Storytelling by the children based on the photos, despite the content of the photos supports social connectedness. One of the most common and enjoyable uses for photos is to share stories about experiences (Balabanovic, Chu and Wolff, 2000) Storytelling and reminiscing using photos are one way of keeping and sharing memories (Kim and Zimmerman, 2006) Photos are not only

one's own memories but other' (Van House et al., 2004). When remembering the people on the photo, one is using nostalgic reverie. In nostalgic reverie "the mind is 'peopled'" (Hertz, 1990, p. 195). Important figures from one's past are brought to life and become part of one's present (Davis, 1979). Wildschut et al., (2010) propose that nostalgia can holster social connectedness.

Photo exchange system

The designed photo exchange system to support distant photo sharing was based on the requirements form the requirement inventory. The usability of the photo exchange system was acknowledged by the both the parents and caregivers using the system. The usability of the system came from the *Simplicity*, low *Costs* and right execution of *Control*.

Simplicity was met with preexisting structures from Dropbox. And as mentioned in the interviews, the system was found easy to use. The researcher executed the *Control* over photos exchanged. No photos with inappropriate content were exchanged. The only photos not sent through were some photos with low quality, vague photos. The *Costs* is different for the two introduced photo exchange systems. This difference in systems was not prearranged but came from delivery problems by Kodak. The main difference was whether photos had to be watched actively on the personal computer or appeared automatically on the photo frame. The active watching demanded more effort, *Costs*. There was no information on whether there were new photos in Dropbox to be watched. This was changed half way during the exchange period when the researcher started sending e-mail when new photos were placed in Dropbox. Parents appreciated this e-mail. The *Costs*, effort the researcher had to make to upload the photos the support page to get them on the photo frames was the same as the effort made to place photos in the corresponding Dropbox folder and send e-mail. Though the support page is limited e.g. in options on order of photo display.

Dropbox over the photo frame has the advantage to be relative cheap. For the users in the current study the process to sent photos was exactly the same. The main difference came with watching the photos received. For future implications the differences in watching photos with the systems can be used to determine future directions.

Research limitation

The current study was an explorative case study. As suggested by Eisenhardt (1989) data triangulation was executed. Due to participation of different stakeholders and difficulties with the measurements methods not all findings proved their value. For the analysis of the results in this case study problems occurred with small sample sizes. Some problems with the used measurements methods came from difficulty with including mentally disabled children with different mental disabilities. Mainly their difficulty in expressing themselves through speech influenced the results. Though children all reached the *presentation* level on the ComVoor this was no guarantee their expression in the different measurements methods was usable.

The parents filled out the ABC-Q. It was found that the ABC-Q was too difficult to fill out based on expectations instead of actual experiences. The reliability was higher when parents could rely on their experiences. The *others* perception was already left out, but it could be that parents still used the others perception to base their answers on. In this study, the others perception is difficult to determine and can be different for several facets of communication. The test was sensitive for social desirable answers. Questions concerned the relation between parents and their mentally disabled child. This relation is not always easy and there are reasons parents can no longer provide care for their child.

For the IDQOL child version difficulty in expression from the children was compensated by separately printing the Smiley's so they could easy be reached and used to support answers.

More important was that these smiley's differ from pictograms used at the institution. Smiley's predominantly differed in eyebrow position, which children are not accustomed to.

The IDQOL was found to be difficult to complete by all children and was therefore not completed by two children as posttest. The low reliability scores on the pretest compared to the posttest of the IDQOL completed by the children could have been a learning effect of the psycho diagnostic assistant. Several comments from the psycho diagnostic were made on difficulties interpreting answers from the children. For the only child with posttest scores lower than the pretest scores, comments are documented noting that the child experience being bullied by other children. This is a strong contributor to a lower quality of life.

Video recordings could have done the observations of behavior of the children. This has privacy concerns and costs. To keep observations simpler, color codes could be assigned to the behavior. Documentation of color codes is faster.

The findings and categories of the content of the photos exchanged could have been presented back to the sender. This takes away lack of background information on the photos. Especially for the photos sent by the parents this could be useful. As seen with the LEMTool this could be too difficult for the children. The LEMTool used other new pictograms not in use by the institution to represent emotions. The emotions used in LEMTool where not all clear to the children. With determining the content of photos exchanged the difficulty remains on how to treat multiple photos of one event.

Some research limitations could not have been overcome since this was a case study. Participants and methods available had to be used. By using data triangulation and combining objective and subjective data this case study was a good start in research on social connectedness and mentally disabled children.

Future implications

The findings from this study are positive, suggesting continuing exchanging photos between mentally disabled children and their parents. In a future system a photo frame is recommended. Photos appear automatically and a photo frame can be placed in the living room becoming part of the furniture (Biemans et al., 2009). The current photo frames are limited in file types they display. For parents to be able to exchange other type of files e.g. digital home video recordings an upgrade of the current system is necessary. This upgrade may involve the use of another device able to show photos and videos e.g. an iPad like device. This makes it also possible to use other online support to upload photos, since one is no longer depending on KokakPulse for the display of photos and videos.

In the future day care or school could be incorporated in exchanging photos. Children could use the photos to share their experiences at these locations. And experiences at day care or school can be shared at the home group towards their parents. If more parties get involved in exchanging photos it is recommended to design an own system. This system should have additional functions and different rights for different stakeholders. For a new system it is recommended to use a requirements inventory to get requirements from future stakeholders. It is also recommended to test the new system in a case study with a small sample of all stakeholders, included mentally disabled children.

For future research new measurements methods could be used or current measurements methods could be improved. Important is to test the usability of several research support aids for completing tests by mentally disabled children. For one the type of icons and emoticons usable for mentally disabled children.

Future research can determine the effects of a photo exchange system by other mentally disabled people, e.g. adults. The influence of other social relations and life style can be investigated.

Further research on the content of digital photos exchanged could focus on solutions to handle multiple photos of one event. And what can be said about the selection of digital photos chosen to share. The other measurement methods not used with the mentally disabled children could also be further investigated. The usability of the ABC-Q in order to determine the relation between family of and mentally disabled people. The ABC-Q or other social connectedness measurement methods need to be evaluated for usage in case studies.

The current study has come up with several focus point for future implications and research on photo exchange between mentally disabled children and their parents. For examples, future photo exchange systems, measurements instrument for the mentally disabled population and future research on social connectedness measurement methods.

Conclusions

Exchanging photos between mentally disabled children and their parents improved social connectedness between mentally disabled children and their parents. As found by Biemans and Van Dijk (2009) the photos exchanged served as support for exchanging experiences. As (Register and Herman, 2010) suggest improvement of quality of life could come with improvement of social connectedness. Improved was not conclusive from scores of the IDQOL. The main improvement of quality of life was on the Psychological domain and is difficult to relate to social connectedness.

Parents felt to be more involved in the lives of their children due to the photos they received and additional *conversations* with their child. Parents saw the Benefits of exchanging photos to weigh heavier than the Costs. Caregivers found the photos to support the experience of the children when talking about past events. The caregivers felt therefore to be more involved in the other aspects of the mentally disabled children.

The photo exchange system met the requirement set by the requirement inventory. The photo exchange system supported, with low costs, simplicity and enough control, distant photo exchange. The aim of awareness systems fitted the aim of photo exchange in our study. Photo exchange helped people to stay in touch, i.e., to be reassured about the well being of others, to let others share your experiences, or to let someone know you are thinking of him/her (Kuwabara et al., 2002). The photos were used socially and affective with a distinction between sharing a copresent experience or as communication with an absent friend or family (Kindberg et al., 2005). It appeared that parents shared more co-present experiences, while the home groups communicated to absent family

Methods are scarce and lack good support. Mentally disabled children have different relationships with their environment, therefore the parents and caregivers have to be incorporated to get an complete view. This data triangulation and involving all stakeholders is important in case studies with mentally disable children.

The research in practice with a case study makes standardization of results and measurement methods difficult. The researcher must be adaptive and open to all requirements. This was necessary when the photo frames were no longer available and a new system had to be designed. Eventually both systems worked well and were easy to use. Adaptation for measurements methods needed to be made when observation were not filled out. This could be compensated with an evaluative interview.

This study is a good start in research to improve social connectedness and eventually quality of life for mentally disabled children by introducing a distant photo exchange system.

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Leeftijd:

Geslacht.

Appendix A: ABC-Questionnaire

ABC Vragenlijst

`	Soldon.
	Op de volgende pagina's worden u vragen gesteld over uw ervaringen m.b.t.
	communicatie met gebruikmakend van de digitale fotolijstjes.

Er zijn geen goede of foute antwoorden, we zijn geïnteresseerd in uw persoonlijke mening en ervaringen. Denk niet te lang na over de vragen, maar probeer te vertrouwen op uw eerste reactie.

De vragenlijst bestaat uit in totaal 27 vragen. Alle vragen kunt u beantwoorden met een score op de 7-puntsschaal van sterk mee oneens, tot sterk mee eens.

lk ben het er											
1 = sterk mee oneens 2 = mee oneens 3 = enigzins mee oneens 4 = mee eens noch mee oneens 5 = enigzins mee eens 6 = mee eens											
6 = mee eens 7 = sterk mee eens											
1 lk voel me verplicht om conta	act t	e ma	aken	met	de a	nde	r	Ι			
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
2 lk vind het moeilijk om aan de hand van een contact te bepalen hoe het met de andere persoon gaat											
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
3 lk heb het gevoel dat het communiceren via de digitale fotolijstjes met de ander veel tijd inneemt											
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
4 lk probeer een contact speciaal te maken voor de ander											
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
5 Als ik contact maak met de a	ande	r, da	n ve	rwac	cht ik	dat	hij/z	ij antwoordt			
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
6 Door middel van contact blijf ander zijn/haar leven	ik o	p de	hoo	gte v	van d	de be	elanç	grijke gebeurtenissen van de			
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
7 Het is gemakkelijk om dinge	n vo	or m	ijzell	f te h	oud	en d	ie ik	niet wil delen			
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
8 lk verwacht dat de andere pe	erso	on re	egelr	natig	g cor	ıtact	met	mij opneemt			
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
9 Gedurende de dag denk ik re	egel	mati	g ter	ug a	an e	en c	onta	ct met de andere persoon			
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			

10 De digitale fotolijstjes helpe	en m	ie co	ntac	t te h	noud	en n	net d	e andere persoon				
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
11 lk vind het moeilijk om erva	ring	en te	e del	en m	net d	e an	der v	via de digitale fotolijstjes				
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
12 Door onze contacten leert	12 Door onze contacten leert de andere persoon meer over mij dan ik zou willen											
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
13 De contacten geven mij het gevoel betrokken te zijn bij de andere persoon zijn/haar leven												
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
14 Als de andere persoon contact maakt met mij heb ik het gevoel dat ik moet antwoorden												
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
15 lk doe moeite om een contact leuk te maken voor de andere persoon												
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
16 Behalve op het moment dat we contact hebben, denk ik amper aan de andere persoon												
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
17 lk weet wat de andere pers	oon	voe	lt tijd	ens	een	cont	act					
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
18 lk doe niet veel moeite voo	r de	con	tacte	n								
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
19 lk ben teleurgesteld als de	and	ere p	oerso	oon g	geen	con	tact	met me maakt				
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
20 Na een contact blijf ik nog	ang	e tijd	l aan	de a	ande	re p	erso	on denken				
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
21 lk vind het moeilijk om in co fotolijstjes	onta	ct te	blijv	en m	net d	e an	dere	persoon via de digitale				
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens				
								i				

22 lk kan mij met de andere persoon identificeren vanwege de contacten											
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
23 lk ervaar de contacten als een inbreuk op mijn privacy											
sterk mee oneens 1 2 3 4 5 6 7 sterk me											
24 lk vindt het belangrijk dat de ander het contact als waardevol ervaart											
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
25 lk zou meer moeite kunnen doen om contact te maken met de andere persoon											
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
26 lk kan gemakkelijk het cont	act v	verm	ijder	n als	ik d	at wi	l				
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
27 lk weet hoe het met de and	lere	pers	oon	gaat	t van	weg	e de	contacten			
sterk mee oneens	1	2	3	4	5	6	7	sterk mee eens			
	•							•			
						enlijs		1			
1	Bedankt voor uw medewerking!										

Appendix B: IDQOL

Uitleg over het invullen van de IDQOL-16



Eerst vertellen we kort waar de vraag over gaat. Dan stellen wij de vraag. Je kunt zelf kiezen welk antwoord het beste bij jou past. Dit antwoord kun je dan aankruisen of omcirkelen op jouw vragenlijst.



Je vertelt in je antwoord wat je mening is of wat je gevoelens zijn. We geven eerst een voorbeeld. Je hoeft deze vraag niet in te vullen.

Veel mensen kijken wel eens televisie. Kijk jij ook wel eens televisie? Hoe vind je dit?





Televisie kijken vind ik ...



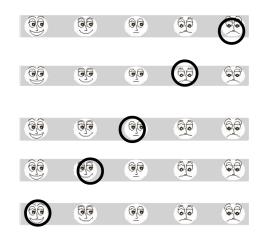
Als je televisie kijken heel erg vervelend vindt ...

Als je televisie kijken een beetje vervelend vindt ...

Als je televisie kijken niet echt leuk, maar ook niet vervelend vindt ...

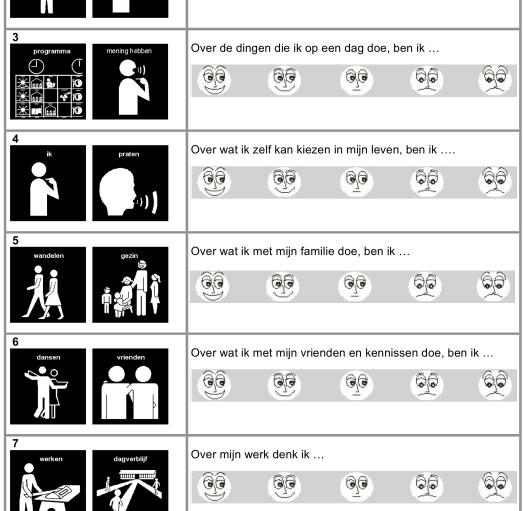
Als je televisie kijken wel leuk vindt ...

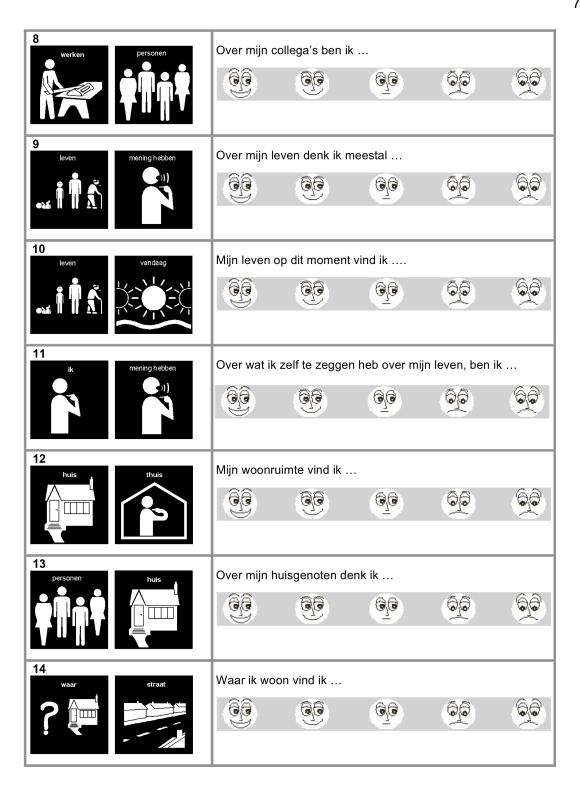
Als je televisie kijken heel erg leuk vindt ...



Zo geldt het ook bij de volgende vragen. Probeer op zoveel mogelijk vragen een antwoord te geven.









Appendix C: Checklist for observations of the behavior of the children

Datum: /2011	
Zijn er vanuit de Burcht foto's verstuurd? (meerdere a nee ja van de groep ja specifiek van dit kind alleen ja van iets wat het kind graag wilde sturen	antwoorden mogelijk)
Stond het fotolijstje aan? ☐ ja ☐ nee	
Hoe lang stond het fotolijstje aan? O tot 1/2 uur 1/2 tot 1 uur 1 tot 2 uur 2 tot 3 uur meer dan 3 uur, namelijk	
Welk dagdeel stond het fotolijstje aan? ☐ ochtend ☐ middag ☐ avond	
Waren er nieuwe foto's op het fotolijstje? ☐ Nee ☐ Ja(aantal) van de groep ☐ Ja(aantal) van de familie, namelijk van	
Werd er gevraagd naar het fotolijstje of foto's op het f Stond het fotolijstje op dat moment aan of uit? ☐ Er is niet naar gevraagd	
☐ Er werd gevraagd naar het fotolijstje ☐ Er werd gevraagd naar foto's op het fotolijstje	aan/ uit* aan/ uit*
Werd er verteld door het kind over het fotolijstje of foto's genoemd?) Niets verteld over het lijstje Verteld over het lijstje Niets verteld over foto's op het lijstje Verteld over foto's op het lijstje oude/nieuwe foto's	

^{*}doorhalen wat niet van toepassing is.

	noties gepast of one	toond bij het zien van de foto's op het fotolijstje? gepast gezien de inhoud van de foto's?
☐ Er werd niet ☐ Er werd gefa	nn de foto's aanleidi gefantaseerd of geïn intaseerd aan de han niteerd aan de hand v	nd van de foto's
☐ Geen (extra) ☐ Wilde graag ☐ Wilde graag	behoefte aan contac bellen	de familie? (met wie?) ct met
☐ Er was vraag ☐ Er was de vr	geven alleen te will g even alleen te zijn aag alleen te zijn me aag alleen te zijn zor	
Andere opvalle	ende dingen, op en	aanmerkingen

^{*}doorhalen wat niet van toepassing is.

Appendix D: Evaluative interview *Parents*

•	Geef ee	n cijfe	r voor h	et proj	ect van	1 tot 1	0				
	1	2	3	4	5	6	7	8	9	10	
 •	Wat wa	ıs er go	oed aan l	het pro	oject						
 •	Wat wa	ns er m	ninder/s	lecht ii	n het pi	roject					
 •			wanneer								
 •	Welke	foto's ((type) w	ilde je	graag v	/ersture	en				
 •	Zijn er	foto's	die je be	wust n	niet heb	ot verstı	ıurd				
 •	Zijn er	foto's	die je he	bt verv	wijdert						
 •	Welke	foto's v	vond je l	euk (h	et leuk	st) te or	ntvange	en			

	• Zat er een idee achter de foto's die je hebt verstuurd											
			g in be									
	-5	-4	-3	-2	-1	0	1	2	3	4	5	
•	Ontv	angen:					aantal 1					
•	Wat			Ü					et proje			

Appendix E: Evaluative interview *Caregivers*

•	Geef een cijfer voor het project in zijn geheel										
1	2	3	4	5	6	7	8	9	10		
•	Wat was l	het ster	kste pu	ınt van	het pro	oject					
Wat was het minst goed/slechter aan het project											
•	Wat vond	d je van	de duu								
•	Hoeveel t	ijd was	je gemi	iddeld	kwijt p	er dag	aan het	project			
 Wat was de meerwaarde van het project Verslechtering -3 -2 -1 0 1 2 3 grote meerwaarde 											
Had het project voor alle kinderen dezelfde meerwaarde											
									·		

Wat droeg volgens jou met name bij, aan de meerwaarde
Waren er opvallende reacties van de kinderen
Hoeveel leefde het project onder de kinderen volgens jou
Wat veranderde er met betrekking tot de betrokkenheid van/met de ouders
 Geef een cijfer voor het systeem (alles om foto's te kunnen uitwisselen) 1 2 3 4 5 6 7 8 9 10
Vond je het systeem makkelijk te gebruiken
Werkte het systeem altijd?

Uit welke onderdelen bestond volgens jou het hele systeem
Wat zou het systeem volgens jou nog meer moeten kunnen
 Zou je bereid zijn extra handelingen te verrichten om foto's te blijven versturen en ontvangen?
Wat zou er volgens jou met het systeem moeten gebeuren na de pilot
 Wat is er volgens jou nodig om door te kunnen blijven gaan met foto's uitwisselen?
Wie zijn er volgens jou belangrijk in het project
Wat vond je van het onderzoek om het project heen (een afstudeerder op het project)

	_ _
Heb je nog opmerkingen, aanmerkingen, tips of een leuke anekdote	
Had je het gevoel dat er inbreuk op je privacy was door het onderzoek	

Bedankt voor het invullen!

Appendix F: LEMTool

