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Report

The use of information and communication technology to support children and adolescents with ADHD and/or autism with everyday activities

The experience gained from four case studies.

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ABSTRACT

Mainstream ICT can assist children with ADHD and/or autism, but there are many potential challenges

In this report we explore how information and communication technology (ICT) can support children and adolescents with ADHD and/or autism and their families to organise and manage their everyday activities. Of particular interest is the use of mainstream ICT such as smartphones, tablet computers and smartwatches with accompanying apps and services. We present four case studies, detailing the practical provision of ICT, methodological considerations and user experiences with the technology. The findings indicate that mainstream ICT can be of assistance, but that its implementation can be challenging. The challenges and other pertinent findings are discussed. Key factors supporting positive outcomes when using ICT with the target groups are provided. The work will continue in the *Erre mulig* project.

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Table of contents

APPENDICES

1 Introduction

In this report we explore how information and communication technology (ICT) can support children and adolescents (henceforth referred to as *children*) with ADHD and/or autism and their families to organise and manage their everyday activities. Past projects have shown that ICT can play an important role to this end. In Norway these relatively large and heterogeneous groups have unmet needs for technological assistance. This pertains both to the suitability of the actual ICT solutions offered through the public provision of assistive technology (AT), as well as the provision process itself. The report details the practical provision of ICT, and subsequent experiences of four children and their families.

1.1 Background and context

This academic work is part of a larger ongoing R&D activity named *Erre mulig* (in English *Is it possible?*) which addresses the development, provision and use of ICT for children and adolescents with ADHD and/or autism and their families. This report is a joint deliverable in the *Erre mulig* and *Trygghetspakken* (in English *Safe@Home*) projects. Further, the work at hand is inspired by and draws upon findings and experiences from the projects:

- *The provision of welfare technology to families with reduced functional capacity (pre-study, 2013)*
- *Mapping of user needs in families with children with ADHD and/or autism (2014)*

These projects have helped shape both the focus, content and methodological approach used in the current study. The findings from these projects are documented in a joint project report[1].

1.2 Structure of the report

The structure of the report is as follows: A brief introduction which includes a review of the literature precedes a section detailing the purpose and specific aims of the study. This is followed by Methods and Participants covering the methodological and scientific approaches used in the data collection and subsequent analysis. Results are presented in section four, and provide the findings of which the most pertinent are elaborated upon and discussed in section five. Conclusions and Further work are presented in section six.

1.3 Terminology

We use the term ICT to describe the technological solutions utilised to support the children and their families. Our understanding of the term encompasses both mainstream ICT such as smartphones, tablets and smartwatches and digital services, as well as assistive technology (AT) specially developed to cater for special needs, e.g. cognitive impairments. Our focus is on the use of ICT in a way that supports human activity and participation in a multi-contextual manner

[1] SINTEF report A25853 (2014) "Formidling av velferdsteknologi til familier med barn med nedsatt funksjonsevne". The report is in Norwegian only, and can be downloaded from: http://www.sintef.no/Publikasjonssok/Publikasjon/Download/?pubId=SINTEF+A25853.

throughout society. This sentiment is echoed in concepts such as ambient assisted living[2] (AAL), pervasive computing and ubiquitous computing (Orwat, Graefe, & Faulwasser, 2008)

In Scandinavia the term *welfare technology* (*velferdsteknologi* in Norwegian) is widely used to describe the type of technological setups we are concerned with. The term is described as technologic assistance that:

> *"…support safety, social participation, mobility, and social, physical and cultural participation, and strengthens the individual's ability to manage on its own despite illness, and social, intellectual, and/or physical impairment."* [3]

We opted not to use the term *welfare technology* in the report given its geographically limited use and lack of international adoption. We do, however, subscribe to its sentiment of holism. Just before the publication of this report, the Norwegian Directorate of Health adopted the name *Norwegian National Programme for* ***Personal Connected Health & Care*** as their English name for their national effort in the field.

1.4 Review of the literature on ICT for children with ADHD and autism

In Norway about 3 to 5 % of children of primary school age are diagnosed with AD/HD (Surén et al., 2012). The prevalence is higher in boys. Different studies show a variation in prevalence in general and regarding gender related prevalence. The prevalence of autism spectre disorders has increased dramatically since the 1980s, in Norway as in other countries (Hertz-Picciotto & Delwiche, 2009; Isaksen, Diseth, Schjolberg, & Skjeldal, 2012). In Norway, one expects the prevalence to be about 51 per 10 000.

Despite large variations in functional level and need for assistance within and between the two diagnostic groups, they share a common need for assistance in structuring their everyday lives. Use of ICT to support children who need adapted assistance in order to concentrate on task performance, to structure their everyday activities, and to facilitate their social relations is a relatively new research area, and knowledge is scarce. A literature review shows that there are few publications in this area prior to 2004 (Lu, 2010b). We know very little about long term effects of use of ICT (Scassellati, 2007; Wainer & Ingersoll, 2011), and we know very little about how ICT is used as assistance on an everyday basis (Parsons & Kasari, 2013) both regarding the child and the rest of the family (Putnam & Chong, 2008).

The family unit is our society's main institution for children's socialisation. The family is shaped by the members and by its social structures of culture and class. We understand the family as a social system that strive for balance. For a family to function, the members have to balance between their resources and internal and external expectations and demands of what a "proper" family should be. The family members have to manage both own and external expectations on appropriate behaviour

[2] Ambient Assisted Living Joint Programme, www.aal-europe.eu.

[3] *NOU 2011:11, Innovation in the Care Services.* [NOU, Ministry of Health and Care Services, 16.06.2011]

and skills for parents and children. They also have to master expectations on various forms of behaviour in social participation. Children will face many different and age specific expectations regarding appropriate behaviour at the table, doing personal hygiene, dressing, and being polite and considerate towards others. When children need extra attention and support to cater for daily activities, it will affect the whole family. The parents as well as siblings may face particular challenges which they have to handle, and one risks that the balance of the family is tilted (Goudie, Havercamp, Jamieson, & Sahr, 2013).

Families with children with disabilities face challenges on an everyday basis (Eriksen, Askheim, & Andersen, 2003; Woodgate, Ateah, & Secco, 2008; Ytterhus & Tøssebro, 2006). Many families need individually adapted practical and financial support, and especially do they need support that takes into consideration the situation of the whole family group (Andersson, Ådnanes, & Hatling, 2004; Grut & Kvam, 2012). Research indicates that siblings of children who need extra attention and support may feel that their parents are busy, and they tend to take on more responsibility for the family's wellbeing than other children do (Tøssebro, Kermit, Wendelborg, & Kittelsaa, 2012). Research shows that technology can offer support and facilitate the children's and the families' social life (Solås, 2009; Tan & Cheung, 2008). However, research in this field is scarce, and we know very little about the situation in Norway.

Most studies have focused how technology can facilitate children's ability to learn and to manage in school (Lu, 2010b). Some studies have shown promising results with smartphones and similar tools for persons with ADHD as assistance with remembering appointments and structuring tasks (Winterberg, Hallberg, & Einan, 2010). Few studies focus on how technology can facilitate children's everyday life (Lu, 2010a). We also lack long term studies on the feasibility of technology, and studies that include the experience of the rest of the family – parents and siblings – and how the technology impact on the interaction in the family. We also lack knowledge about which aspects of everyday life that impact on successful design and use of technology.

Studies have shown that most children with learning disabilities, such as children with autism and related disorders, enjoy using ICT. Explanations offered are that with ICT the child is not distracted by the environment, the interaction between the child and the devise is predictable, the tasks are repeatable, and the child can work independently in its own pace without being disturbed by others or having to engage in communication with others (Ahlsen, Thunberg, & Sandberg, 2009; Ismail, Omar, & Zin, 2009; Putnam & Chong, 2008; Veeraraghavan & Srinivasan, 2006).

Other studies have pointed out that all facilitation for children with learning disabilities has to be adapted to the child and to the actual situation (Brown-Guttovz, 2008; McGuinness & Hardeman, 2007). The term *Kairos* is sometimes used to express the importance of having the appropriate action for the right person at right time. According to the literature, there are three elements that seem to be particularly important: source credibility, the child must have confidence in the other person; emotional attachment, the child must enjoy using the device; and not the least, all relevant actors must be included and they must cooperate (Mintz, 2013).

The attitudes of significant other persons in the child's life will impact on whether the child will use the device or not (Kidd & Kaczemarek, 2010). This directs the attention to the parents and also to the teachers. To maximise the child's use and the usability of the devices, both parties must involve themselves in the actual use and also the maintenance and upgrading of the device (Ahlsen, et al., 2009; Brown-Guttovz, 2008). Parsons and colleagues (Parsons et al., 2011) found that lack of interest from the parents will hamper the child's use of the device even when the child manages and enjoys the devices.

ICT is in constant development and the market offers an enormous amount of choices and solutions. This is positive, as it strengthens the chance to find feasible solutions. However, the many opportunities and fast changes make it difficult for the parents who maybe do not have the required competence and special ICT skills to identify suitable solutions.

In Norway, the Labour and Welfare Administration (NAV) provides assistive technology through Assistive Technology Centres (HMS) located in each county. The HMSs manage a range of products made available to persons with disabilities and documented needs through a lending scheme. Devices that are considered everyday consumer technology such as mobile phones and tablet computers are normally not included in the lending scheme; nor are technologies that require a subscription fee. Cognition and use of ICT is a relatively new professional area.

In an earlier project we found that the parents of children with ADHD and/or autism did not know where to find information about suitable technologies (Dale & Grut, 2014). All families used technology on a daily basis, e.g. smartphones, tablets and PCs, but without training, assistance and support they were unable to reap the full benefits of the support that technology could offer in their daily lives. Also HMS staff stated that it was too demanding to stay up to date on all the potential technologies for these target groups. Further, they did not offer routine follow-ups after the devices had been provided, and the basic instructions for use had been given. Both parents and professionals who provided ICT to the client groups alike, called for improved cooperation and communication regarding use of technology between the families and the schools and educational staff. They also asked for better suited ICT to accommodate and facilitate this (Dale & Grut, 2014).

Given that knowledge on how ICT can facilitate children's and adolescents' planning and structuring of everyday activities is scarce, and there is little available documentation on possible implications for the child and the family, we wanted to conduct a study that explored how ICT can support children and adolescents with ADHD and/or autism and their families in their daily activities. To this end, we opted to gain practical experience with actual provision of ICT to the children and their families. We were particularly interested in exploring how mainstream technology could support daily activities. This would entail mapping, assessment and evaluation activities, as well as methodological exploration.

2 Purpose and aims

The overall purpose of the study was to explore how ICT can support children and adolescents with ADHD and/or autism and their families in their daily activities.

The specific aims of the study were to:

1. Map ICT that may be suitable to support children and adolescents.
2. Map user needs of children and their families.
3. Gain experience with the practical provision of ICT to children and adolescents.
4. Explore the suitability of mainstream technology to support daily activities.
5. Evaluate possible benefits of the introduction of ICT on the participant's daily activities.
6. Explore different ways of capturing, documenting, assessing and evaluating user experiences when using ICT to support daily activities over time.
7. Generate knowledge for subsequent field testing and studies.

3 Method and participants

The section below details the method utilised and describes the participants.

3.1 Method, data and analysis

To gain practical experience as close to a real life situation as possible, we used a case study approach. A case study approach is useful when doing exploratory, theory building, user centred studies (Stake, 1995). Case studies open up for a flexible approach where the researchers can adapt the research process according to the actual experiences that unveil in the process. The method allows for integration of unexpected incidents that one could not foresee when the study was planned. This case study was conducted as a descriptive in-depth study of the experiences of three families. Data was obtained through trials done by the families in their home and in an every-day setting.

The case study is built on various data. The two researchers paid between three to five visits to each family in addition to follow up contact over the phone and by e-mail. Video conferencing via Skype was used on one occasion. At each visit w e had informal interviews with the parents (predominantly only with the mother), and the child/children who participated in the trial. We did participant observation in the families' home. We recorded their experiences and reflections on the on using technology, as well as our own interpretations of the visits straight after every visit. We received feedback by e-mail from the mothers on their experiences. The practical trials lasted from Spring through Summer 2014.

In the analysis, we have looked for patterns that could give meaning to the case study as a whole rather than searching for isolated characteristic of the particular cases. To secure reliability and trustworthiness of the study, both researchers participated in the data collection and analysis. Further, we compared the case experiences with relevant literature.

Illustration 1 – Intra-family co-operation using ICT was a special focus in the study.

Source: www.istockphoto.com.

3.2 Participants

The case study includes three families with at least one child diagnosed with ADHD or autism. In two of the families more than one family member is diagnosed with ADHD, and a total of four children took part in the study. The families were recruited through a peer support network for people who have family members with disabilities. The families volunteered to participate in the case study after we had discussed possible implication of participation with them.

Several selection criteria were applied to decide upon the inclusion of the three families:

- Having a child diagnosed with ADHD and/or autism.
- The child had problems with self-management of daily activities in spite being of an age where self-management should be expected.
- The problems affected the whole family situation, and influenced the daily life of the child and other family members.
- The child was experienced with daily use of mainstream ICT, e.g. mobile phones, tablets etc.
- All family members accepted that the family participated in the study, which meant to participate in a home based trial that lasted approximately four to five months.

Information and consent forms where signed by both the parents and children. To safeguard the participants' anonymity the children are in the report given fictive names, their age is approximate, and the child's gender is not necessarily correct.

4 Results

The results are structured as follows: First, we provide a collective summary of the families' expressed needs, and a brief summary of their ICT skills. Next, we give an overall description of the type of technology used in the cases as well as an outline of how we conducted the technology trials. Then, each case is presented individually including the equipment they used and their experiences using it.

4.1 Collective summary of their expressed needs

Before we describe the cases in detail, we will outline some challenges connected to handling everyday routines that were common amongst the children and their families.

4.1.1 Daily activities

Examples of troublesome areas or activities were conducting activities of daily living (ADL) independently, remembering to take medication, having meals, doing chores, getting organised for school and extra-curricular activities. According to the parents, the children had general difficulties with keeping appointments, and to manage a time schedule without being constantly supervised by the parents. The most negative aspect, according to the children, was to be constantly nagged by the parents. The nagging created conflicts in the families. When the children engaged in activities during the day, it was often difficult for them to finish the activity within the allocated time agreed upon. They were easily distracted when something happened around them. The mothers told that the children all too often forgot about appointments they have made, and they were very often late. Some of the children found it difficult to conduct tasks in the correct sequence. They could for instance brush their teeth before a meal, instead of after.

4.1.2 The importance of smooth morning routines

The introductory interviews revealed that the morning was a challenging time of the day for all families. The children struggled to organise their morning routines independently. Many problems could occur before the child was ready to go to school. All participating youngsters had problems getting out of bed, and doing their morning routines in order to get to school in time. This easily disrupted the rest of the day, and could create problems for the whole family. It was the mothers who followed up the children closely in order to have the morning routines go smoothly. This often meant that she woke the child (sometimes several times), saw to that the child got out of bed, ensured that the child went to the bathroom, and to the kitchen for breakfast. For some children, the mothers also had to see to that they were properly dressed, for instance dressed appropriately for the time of year. The youngest children required assistance packing their school bags. All of the children suffered from poor appetite in the morning. They often did not eat if the mother did not pay particular attention to them. Some usually had their first meal at lunch time at school.

When the morning routines went smoothly, they could have a fair chance of having a good day. Therefore, the mothers and the children agreed that the morning was the most critical time of the

day and they all agreed that first and foremost they wanted assistance to create smooth morning routines.

4.2 ICT skills

The children and parents who participated in the trials were used to handle ICT on a daily basis. All had mobile phones, all families had access to laptop PCs and most also had tablet computers. In some families the children had their own tablet and/or PC. The children enjoyed using technology and were competent users of it. The children were eager to try out the devices suggested to them.

4.3 Technology used

Most solutions trialled were mainstream technology universally available, e.g. smartphones and tablet computers. Some of the solutions were so called assistive technology (AT), i.e. made to cater for special needs, such as learning disabilities and cognitive impairment. We intentionally tried to use mainstream technology, and opted for AT only when a mainstream solution was not suitable or there were other significant reasons for choosing AT. This was to test the suitability of mainstream technology to support daily activities.

Illustration 2 – Cloud based services with access for several users on multiple platforms.

Source: www.istockphoto.com.

The majority of solutions used were concerned with alerting and notifying the child of tasks, chores and duties that were to be performed during the day. This was achieved by creating shared Cloud based calendars (e.g. iCloud and Google Calendar) and shared to-do lists or task lists between the

parents and the child (see Illustration 2). Alerts and notifications where provided on smartphones, tablets and smartwatches. Other solutions supported time keeping, planning and conducting activities, organising school gear, and assistance with going to sleep/waking up in the morning. In addition the families were provided with information about a number of other products and solutions that could be beneficial for some of their expressed needs.

4.4 How the trials were conducted

The steps taken in this study in terms of providing the ICT was as follows (with minor variations between families):

1. A general needs analysis was conducted with each family through an in-depth interview, and an assessment visit was conducted. This included identification of concrete everyday activities that the families wanted assistance with, as well as a discussion of possible ICT solutions to support these.
2. Identification, selection, in-house testing and adaption of concrete ICT solution conducted by the researchers.
3. A new visit was conducted consisting of a demonstration of the technology, hand-over of solution, and basic training in how to use the equipment provided.
4. A written summary was e-mailed to the participants that also contained manuals for use, information on online support resources etc.
5. The families used the technology for a number of months. Phone support was made available.
6. Follow-up phone calls and visits. A summary e-mail was provided after each visit. Written feedback from parents was collected via e-mail.
7. Exit interview with each family at the end of the trial.

If a solution or set up malfunctioned or did not work as expected it was either fixed, replaced, or a new, hopefully, more appropriate solution was provided. All new equipment was paid for by the project. In some instances the families utilised their own equipment and the project financed additional equipment such as apps, additional hardware and accessories. The families could keep the equipment tested after project completion if they so desired.

4.5 Experiences with ICT as support in daily activities

Each case is presented individually including the equipment used and experiences using the following structure:

- Issues revealed in the specific needs analysis and assessment.
- A description of the technology used.
- A summary of the specific experiences using technology during the trial.

The experiences are subsequently elaborated upon and discussed in the Discussion chapter.

4.5.1 John

John is 10 years old, and is diagnosed with ADHD. He lives with his parents and siblings.

Challenges and ICT solutions

John had problems waking up in the morning and getting out of bed. He found it challenging to complete his morning routine within a reasonable time schedule. His mother monitored him in order to get ready for school in time. He forgot about appointments, and on occasions the parents had to call neighbours and friends to search for him because he had not come home at the time they have agreed upon. John had poor appetite, and his parents followed up meals closely to ensure that he ate and took his medication.

John wanted assistance with the morning routine so that he could get ready for school in time, and remember to take his medication. After discussing this with him and his mother, we agreed that they would share a virtual calendar. The mother would make entries in the calendar either on a computer or her Android based Samsung smartphone, and John would receive the calendar entries as notifications on a smartwatch. The latter would give a discreet reminder of important tasks he was required to do. By opting for a watch we circumvented the ban on using mobile phones during class.

Unfortunately, there was no smartwatch commercially available at the time which provided this feature satisfactorily as a stand-alone product as they had to be tethered to a mobile phone or similar via Bluetooth. John already had a mobile phone, but this was not suitable for this purpose. We discussed other options with the family, but it was agreed that all calendar notifications would go via a Sony Xperia V mobile phone to a Pebble smartwatch.

A shared Google Calendar was used to create calendar entries. In addition to calendar notifications, John was also able to receive other notifications regarding calls and text messages on the Pebble smartwatch. We further created a Pebble account to be able to use the smartwatch. The mother administered the accounts, and followed up the daily use of the equipment. As the standard Pebble notification smartphone app did not forward notifications from the phone to the watch consistently, we opted to use a third party app to convey the notifications from the smartphone to the watch. The complete set up is shown in Picture 1.

Picture 1 – Shared Google Calendar with notifications pushed to a smartphone and a smartwatch

Source: SINTEF/Google//Pebble.

This was not an ideal setup as he would always have to carry the phone with him to be able to receive notifications on the watch. For reasons detailed below we had to replace both the phone and the watch with another phone from Sony and a Sony Smart Watch 2. The complete setup with components and services is detailed in Appendix 10.1.

Experiences

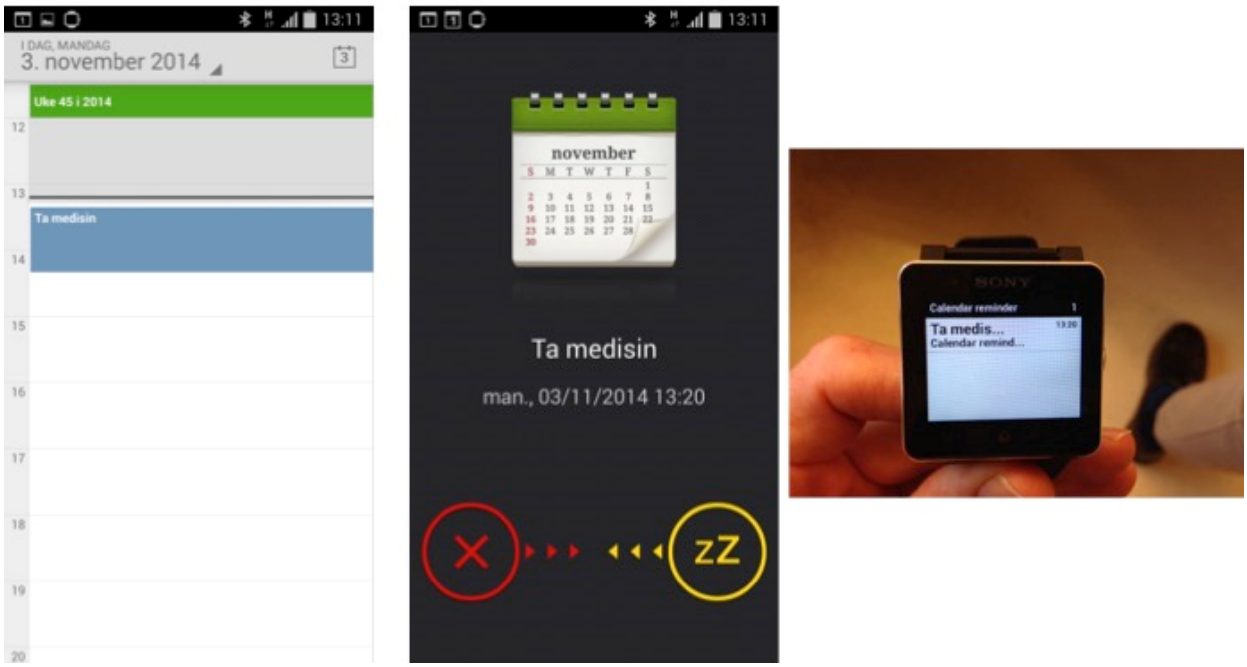
After having taken receipt of the equipment and received help with downloading apps, setting up all the accounts and apply the appropriate settings, basic training was provided. The family then started using the solution to provide support with John's everyday activities. For some inexplicable reason it was difficult to consistently get John's phone to display the calendar notifications when sharing a calendar. We therefore opted to add all new calendar items straight into the Google Calendar account on John's phone by way of a PC connected to the Internet. This seemed to work, and calendar notifications were displayed on both the smartphone and the Pebble watch.

Unfortunately, the smartwatch stopped displaying notifications after a few days. Despite making sure that everything was set up correctly, the notifications did not show up on the watch in a reliable manner. In addition the watch needed recharging every five to seven days, and the family had difficulties determining the battery level on the display. As a consequence it ran out of power, and it

was difficult to re-establish a connection with the phone after a flat battery. Because of this, they discontinued the use of the watch.

To remedy this, we introduced a new smartwatch manufactured by Sony, the same company who manufactured John's phone. This to simplify the setup, as it was easier to connect the two devices via NFC. An example of a notification on the Sony smartwatch can be seen in Picture 2. After one week of usage, however, the phone and watch lost connection and the family were unable to re-establish a connection between the devices. To make matters worse, the phone was rendered useless when the touchscreen broke due to physical trauma. A new phone was provided, and notifications were yet again pushed to the watch. Alas, after some time the new phone stopped working altogether.

Picture 2 – Screenshots of a calendar entry in Google Calendar on a smartphone which shows up as a notification on Sony smartphone and smartwatch



Source: SINTEF/Google/Sony.

John was very enthusiastic about using technology, and displayed great interest in exploring the devices. Games and playing with the phone and watch could potentially divert attention away from the notifications intended to support his daily activities.

Despite the problems that John and his family encountered, they found the set up to be helpful when it worked. John became somewhat more independent, and they reported that communication between John and his mum had improved as he responded more often to text messages and telephone calls.

We also discussed the use of other solutions with John, but decided it would complicate matters if we tried out different solutions concurrently. To be specific we looked at apps that could help him to plan his day and to conduct activities independently. We identified the apps Mobilize Me (http://www.mobilize-me.com) and First Then Visual Schedule

(https://play.google.com/store/apps/details?id=com.apps.gk.firstthen) for this purpose.

Unfortunately, we ran out of time and the trial period ended so we were unable to pursue this further.

4.5.2 Susann

Susann is 13 years of age, and lives with her parents and siblings. She is diagnosed with ADHD.

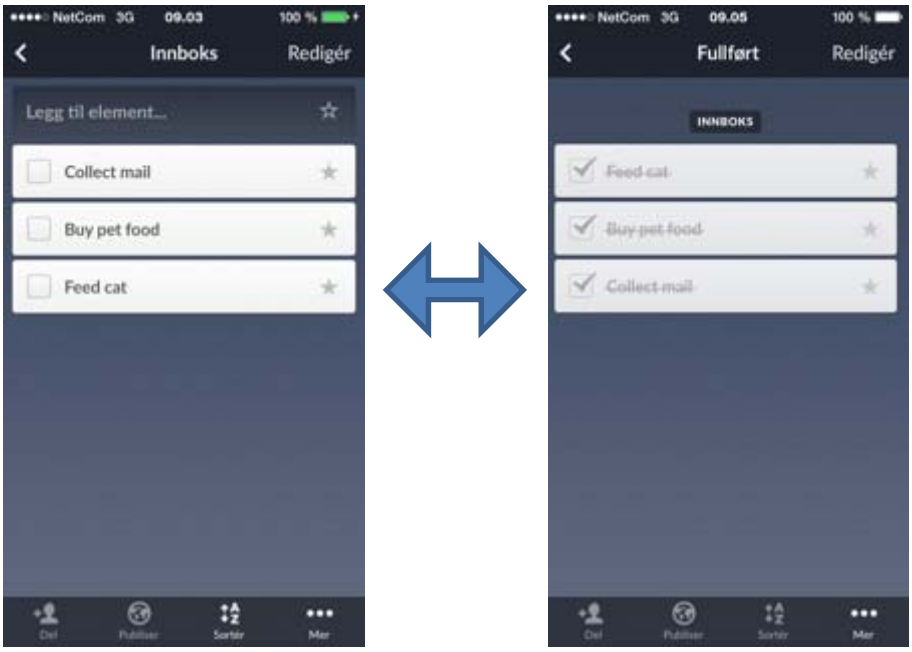
Challenges and use of ICT

Sue needed help from her mother to see to that she brought the school material that she needed for school, i.e. text books, clothing for P.E. etc. On her way to school she often saw something that caught her interest, and thus she forgot the time and could be late for class. Susann had poor appetite, and meals and nutrition was closely followed up by her mother. Susann wanted to receive notifications about tasks, chores, meal time reminders and ADLs. As she already was an experienced smartphone user, it was decided with the family that she would receive the notifications on a smartphone provided by the project. A shared Google Calendar was established, and the mother administered the calendar and created calendars entries that would consist of the tasks, chores etc. For reasons detailed below, this set up was deemed inadequate for her needs so it was discontinued after some weeks. In its place they shared the To-Do List & Tasks on the app Wunderlist (see Picture 3). The complete set up is detailed in Appendix 10.2.

Experiences

First, Susann tried a shared Google Calendar with her other. The mother and Susann had agreed upon which calendar entries or tasks that should be listed. Examples of tasks were to take her medication, tidy her room, and to feed the pets. It was important for them not to put too many tasks on the list in the beginning, and they had agreed that three tasks should be manageable. Self-determination regarding type and number of tasks was important for both of them. The mother administered the list and tasks from her computer or smartphone. Each task came up as notification on Susann's smartphone. Susann found the Google Calendar easy to understand and operate. She said that it was nice to do homework and chores without constantly being reminded by the mother in person.

Picture 3 – Screenshots of shared use of Wunderlist app. Users can share task lists. As items are checked, the other user's list is updated.



Source: SINTEF/ Wunderlist app (https://www.wunderlist.com).

However, although the shared Google Calendar with notifications worked technically, she only found it somewhat useful. What she really wanted was a shared list of items or a checklist, so that she could tick off each item on completion. This function in Google Calendar was not deemed suitable. As a consequence we researched possible alternatives, and decided to try an app called Wunderlist. This allows for management of to-do and tasks lists on a smartphone, tablet or PC. Susann and her mother shared a Wunderlist account. This enabled the mother to add different tasks on the app on her phone, which showed up with a notification on Susann's phone. When Susann checked a task as being completed, for instance having taken her daily medication, her mother would be able to see this on her own phone. They found this very useful when it was working, but after about a week of usage the synchronisation between the phones stopped working for no apparent reason. The reinstallation of the app on Susann's phone remedied the problem, but only for about a week. We were unable to identify the reasons for this instability. Susann used social media services. All new messages and postings from these showed up as notifications on her phone. These notifications potentially diverted the attention from the notifications from Wunderlist.

4.5.3 Lisa

Lisa (14) has been diagnosed with ADHD, and she lives with her parents and siblings.

Challenges and use of ICT

Lisa had difficulties with organising her daily activities. It was difficult for her to initiate an activity, and then finish it in order to start up another. The mother supervised and monitored her every day, and this could cause conflicts between them. She found it especially difficult getting up in the morning. Lisa said that it was painful to be woken up abruptly. Her mother followed up closely to ensure that she gets up, eats breakfast and conducts her morning routines.

To assist with remembering and being prompted to do tasks, chores, meal time reminders and ADLs, Lisa wanted to try a shared calendar with her mother with notifications on her iPhone and a Pebble smartwatch (Picture 4). The setup was similar to John's as shown in Picture 1.This set up was for reasons explained below replaced with a shared iOS Calendar and Reminders using Apple iCloud on two iPhones. Further, to aid getting to sleep and getting up, a wake up light with an accompanying smartphone app was selected for testing. The complete setup is detailed in Appendix 10.3.

Picture 4 – The Pebble smartwatch

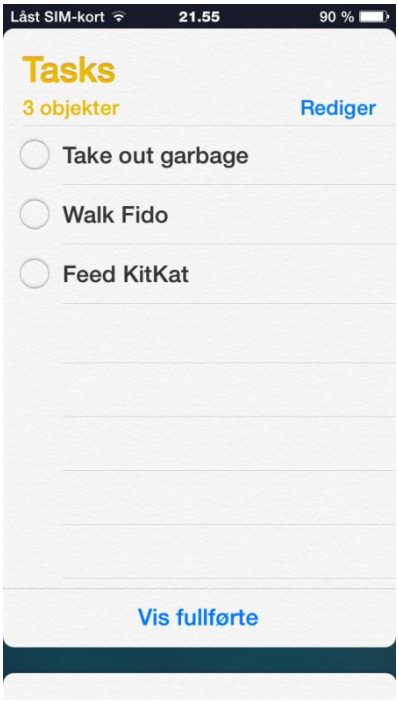
Source: SINTEF.

Experiences

Lisa experienced problems with receiving notifications on the Pebble watch from her iPhone. Similarly, the notification service on her iPhone using Google Calendar was not stable. In addition, she found that the smartwatch was too big and not aesthetically to her liking. As a consequence she stopped using the smartwatch. Further, the Google Calendar set up was replaced by Apple's iCloud equivalent to see if it would provide a more stable notification service. This was made possible because her mother obtained an iPhone during the trial. We had a notion that by using a setup in which only one company (Apple) provided the hardware, software and service, better stability could be expected. Lisa and her mother decided that the Apple's inbuilt Reminders to do list would suit

their needs best, and we created a shared to do list (Picture 5). The mother added to-do items, and these were checked by Lisa on the app when completed.

Picture 5 – Screenshot of the to-do list on iOS (iPhone)



Source: SINTEF/Apple.

Lisa tried a wakeup light/alarm clock with music (Philips Wake Up Light – Picture 6). It was used in conjunction with an iPhone app used to control the watch and as access music on the phone for waking up. The brightness of the light increased slowly in the morning to mimic a sunrise, and at bedtime the light was slowly dimmed to mimic the sun setting. Sounds from nature or music could accompany the process. The clock gave a gentle and somehow slow waking up process. Lisa tried the set up for a short while just before the Summer vacation. She reported that the clock was a comfortable way to start a new day. The mother confirmed that with the wakeup clock Lisa got up and to the bathroom by herself without being monitored and nagged by her mother. She also reported that it assisted falling asleep at night. She discontinued use during the Summer vacation, but would resume using it when going back to school.

Picture 6 – Philips Wake Up Light with iPhone app

Source: Philips: http://images.philips.com/is/image/PhilipsConsumer/HF3550_60-RTP-global-001?wid=2688&hei=1400&fit=constrain&$jpgsmall$.

4.5.4 Mikal

Mikal (12) lives with his parents. Mikal had multiple impairments. He had learning disability, visual and hearing impairments, and autism. Mikal was dependent on spectacles and hearing aid in one ear in order to read and write and to follow a conversation. He was eager to participate in conversations with the researchers, and showed a good understanding of the trial and seemed to comprehend its purpose. When we ask questions that he found difficult to answer, he directed the attention to the parents and asked them to answer. He used a smartphone and an iPad Mini on a daily basis for communication and entertainment purposes, as well as for support in daily activities.

Challenges and use of ICT

Mikal and his mother decided that they wanted a set up that could assists Mikal in becoming more independent in the mornings, as well as improving his time management skills. We chose a watch named Time timer Watch PLUS Youth to assist with reaching these goals (Picture 7). This is a stand-alone digital watch that in addition to the normal watch functions includes a visual countdown timer. The user is alerted visually, auditory and with vibration when the desired time period has elapsed. This device was later replaced with a visual countdown timer app on a smartphone as the watch was inappropriate for him for reasons explained below.

Picture 7 - Time timer Watch PLUS Youth

Source: SINTEF.

Further, to assist with his morning routine, the family tried a product called Mobilize Me (http://www.mobilize-me.com). The purpose of Mobilize Me is to provide visual support to structure and conduct everyday activities for persons with cognitive impairments. It is calendar based and runs on a tablet computer. Mikal's mother would add activities physically on the iPad in the planner's view, and Mikal would view and interact with the calendar on his iPad Mini. It is also possible to edit activities in a web browser for the person who conducts the planning. The setup is illustrated in Picture 8, and is detailed in Appendix 10.4.

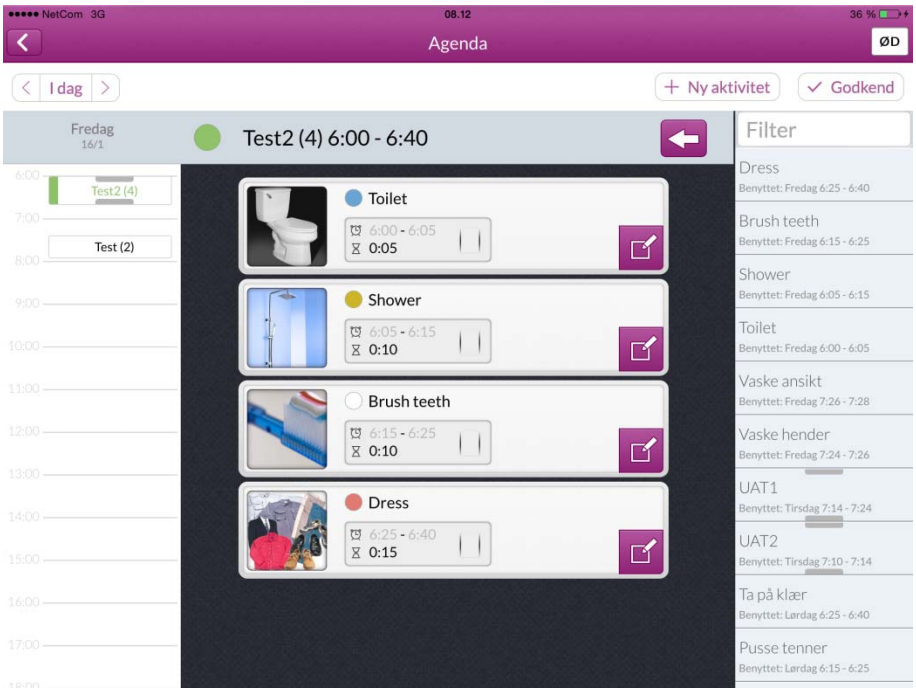
Experiences

Mikal used an iPad app to wake up in the morning. The app gives off a sound just like Donald Duck's laughter. It starts with his laughter, and after a couple of seconds it turns into an angry Donald Duck commanding the child to get out of bed. Mikal enjoyed to be woken up this way.

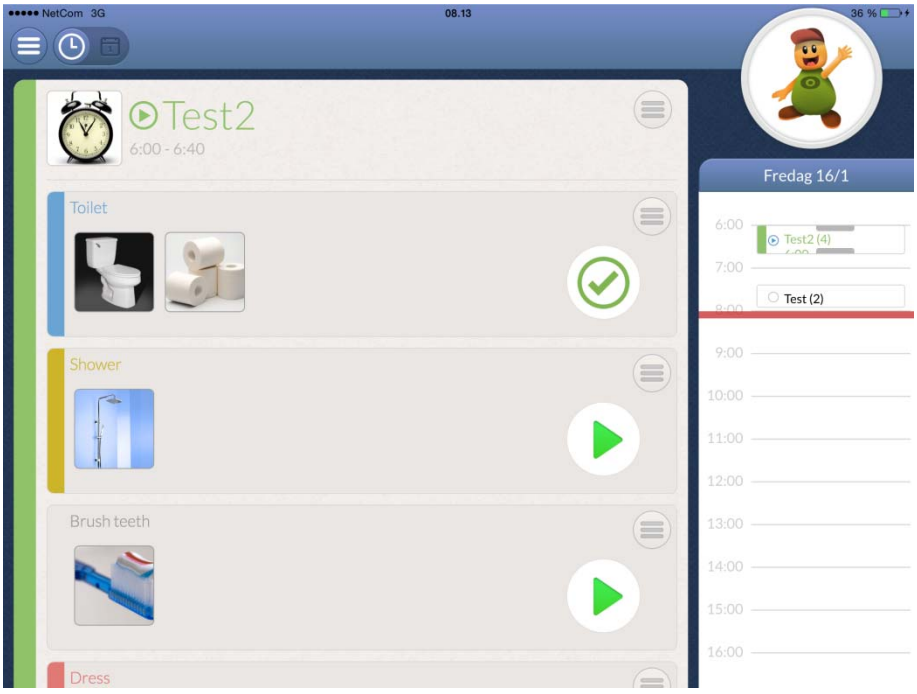
Unfortunately, the Time timer Watch PLUS Youth proved to be unsuitable for Mikal partly due to his visual and hearing impairment. The visual countdown timer had poor contrast, and the auditory signal was very faint, and he was unable to effectively use the watch as intended. In addition it was somewhat large for his wrists. The watch was replaced with an app that provided similar features on an iPhone. He used the app to keep track of how much time that was left before an event, and to assist him in doing activities within certain time limits. This worked well.

Picture 8 – Screenshots of a) MobilizeMe– the planner's view, b) the user's view.

a) Planner's view



b) User's view



Source: SINTEF/MobilizeMe.

The Mobilize Me interactive calendar and activity structuring app proved to be a great success in Mikal's case. Mikal’s mother made the calendar entries. These consisted of both events and tasks. Some of the tasks had sub-tasks, and included pictures, pictograms, and visual timers to assist Mikal. Activities were checked by Mikal as they were completed. The app was used for both planning and executing activities such as washing, dressing, and brushing teeth, as well as keeping track of time. The app is synchronised and backed up through a Cloud service.

Mobilize Me made a big difference in improving Mikal’s independence in the mornings. According to the mother, the app led Mikal through the morning routines without having to be nagged by her. She did not have to stay in the bathroom and supervise Mikal, but could prepare breakfast while he was in the bathroom. This had never happened before, according to the mother. We were able to use the app for free during the trial, and in exchange we shared our experiences with the developers to further improve the product. This was in accordance with the family.

5 Discussion

Before we discuss the findings related to the specific aims of the study, we will point out that there are large variations in functional level and need for assistance within and between the diagnostic groups ADHD and autism. The type of technical solutions described in this report is suitable for individuals who have a reasonably high level of functioning. As such the findings are most relevant to these groups, and the solutions described may not be appropriate to all. This is important to take into account when considering using ICT to support children and adolescents with AD/HD and/or autism. This does not mean that ICT may not play an important role in supporting individuals with less functional capacity, but that other solutions may be more relevant and suitable.

5.1 Mapping of ICT

The user needs analysis showed that assistance with structuring, organizing and performing activities in the mornings was important, i.e. ADLs, getting ready for school, time management of tasks and chores. It was a mutual wish from the children and the parents that the children would develop greater independence in these activities. We therefor sought out and mapped possible ICT solutions that could support morning activities and help development independence.

Our mapping unearthed a vast number of possible ICT solutions. These consisted chiefly of everyday or mainstream ICT, but also a number of assistive technology solutions were identified. In accordance with recent technological trends, our focus was predominantly on solutions made up of smartphones, tablets and smartwatches with accompanying applications (apps) and services. The apps were either available on Google's Android platform, or on the iOS platform from Apple.

The decision to focus on mainstream products was not coincidental. Firstly, we wanted to try technology that was readily available. Secondly, we wanted to avoid solutions that could stigmatize the children. The use of AT may have the potential to do so. Thirdly, mainstream products are usually far less expensive than AT, and lastly, we wanted to see if mainstream ICT-products could be a viable replacement of AT for these groups.

The quality and suitability of the solutions, and particularly the apps, varied greatly. Some apps were frequently updated and provided ample information about their target group(s), the development process, clinical testing if appropriate, who the developers were and whether support was available. Other apps were infrequently updated, lacked or offered limited user support, and important and pertinent information about their origins was lacking such as full name and affiliation of the developer.

Some solutions were part of comprehensive services relying on Internet access, e.g. Apple iCloud, whereas others were stand-alone solutions with no connectivity, e.g. the Time timer Watch PLUS. Some solutions relied upon collaboration and interaction between parents and child, and consisted of a number of devices, platforms, apps and services. An example of this was the use of a shared

calendar between parents and child, with notifications pushed to the child's smartphone and Pebble smartwatch via a third party app.

Some of the solutions identified were according to their promotional material especially developed for specific target groups, i.e. youngsters with ADHD and/or autism. Some of these, such as the calendar tool Mobilize Me, were clearly the result of an elaborate, documented, and domain sensitive development processes leading to appropriate and good quality products. Others had seemingly only added the terms "ADHD" or "autism" to their names or app descriptions to appear to be specialised niche products suitable for these groups. It seem to be no regulations or criteria that needs to be met to be able to claim that a given product is suitable for one diagnostic group or another, or whether it has been through some form of quality assurance process ensuring its appropriateness to meet the needs of certain groups. Searching with the term "ADHD" results for instance in a number of hits in the Google Play app store. The majority of these hits did at first glance not cater to the specific needs of this particular group of users. One may also ask oneself whether adding a diagnostic term to the actual name of a product potentially be stigmatizing for the users of the product, i.e. ADHD Alarm Clock.

5.2 Experiences with providing and trialling ICT

One of the key activities of this study was to gain practical experience with the actual provision of ICT to the user groups. In the following we share and discuss a number of issues pertaining to the process of providing technology to the families.

5.2.1 Home visits and timing

The field testing showed the importance of paying attention to practical considerations to maximise the potential for positive outcomes. The visits to the families were all carried out in their private homes. Each visit usually lasted for two to three hours, and sometimes up to four hours. Due to school and working schedules for the participants, the visits were chiefly done in the afternoons and evenings. Our experience is that the sessions tended to be too long, too late in the day, and that their length and timing were taxing on the families and the researchers alike. The children did impress us with their patience, but it was evident during several of the visits that it was difficult for the children to stay focused for the whole time.

Overly cumbersome technological set ups and technical difficulties encountered were partly to blame for the longer than planned sessions. That being said, choices made by the researchers proved also to be overly ambitious and may have prolonged the visits needlessly. We did for instance try to implement more than one solution per child during some of the visits. Because we had underestimated the time required to set up and familiarise the families with each solution, the time schedule suffered as a consequence. More frequent and shorter visits earlier in the day would have been preferable. In addition more of the technical preparatory work could have been done prior to the actual visits. The timing and length of the home visits may have impacted adversely on the families' ability to take in all the information dispensed, and on the effectiveness of the training provided.

Conducting the visits at home seemed to have a number of advantages; e.g. being able to perform assessments and see ICT used in the users' natural environment, having access to the participants' additional ICT equipment, and no travel time for participants. It also proved to have its drawbacks; some of them being the potential for distractions from other family members (including pets), friends calling in, not having a controlled environment in terms of access to supportive technologies like WIFI and others. Perhaps a combination of home visits and visits to a more controlled environment would work better.

5.2.2 Challenges encountered

The field trials uncovered a number of challenges which can adversely affect the process and subsequent outcomes. Some of the more elaborate technological setups were very cumbersome to implement requiring a multitude of downloads, establishing user accounts with accompanying user names and passwords, as well as making sure that a whole number of settings were correctly set up. This requires a great deal of competence, discipline and diligence. The above mentioned example involving sharing a Google Calendar and pushing notifications to a smartphone and smartwatch required a long and elaborate process setting up. It also proved to be very fragile when up and running, as an alteration in one minor setting would lead to malfunction and the system no longer working. The more elaborate the setup, the more vulnerable to malfunction is an important lesson learnt. This potential vulnerability may have a significant impact on the usability and feasibility of a solution in a particular context. One has to consider whether less elaborate or alternative setups may be preferable. This may be at the expense of functionality, but a working solution with less functionality is of course of more use than an unstable or non-working elaborating one.

We experienced a number of technical difficulties. Sometimes the cause was evident, e.g. something was physically broken, and other times it was impossible to determine the cause. The latter was especially the case in complex set ups involving many devices, services and apps. Sometimes it was impossible to determine whether the problem arose from something being broken, an unintended alteration to a setting, or whether it was caused by the user not following correct procedure (usually known as *user error).* In some cases both technical and user errors were ruled out, and it was concluded that the solution had just stopped working for no apparent reason. This was usually the case when a set-up consisted of components from a number of different manufacturers. The solution in the above mentioned example using shared Google calendars comprised hardware, software and services from more than six separate providers. Although, everything was set up as instructed, it was impossible to get a stable solution over time sharing calendars with notifications being pushed to the child's smartphone and smartwatch consistently. It was also difficult to conduct effective debugging and issue tracking because of the high number of possible sources of error.

To remedy this we tried with one of the families to use a shared to-do and task list solution in which the hardware, software, and service were provided solely by one provider, namely Apple. Unfortunately, we were not able to assess the long term stability of this as the project came to an

end. Testing and early experiences indicated that this set was more stable than the ones with multiple manufacturers involved.

Support was difficult to address, as it was sometimes impossible to pinpoint where in the service chain the problem arose, e.g. was there a problem with the phone, the app, the service, the Internet provider etc. As a result it was difficult to know which manufacturer or technology provider to contact. This will always be the case when the ICT solution is made up of a number of components and services from different vendors. We also discovered that documentation like manuals, instructions, and support materials from the different manufacturers often were lacking, not very comprehensive and/or only available in English and not the users' native language.

The researchers provided first-line support for setups tried out in the project. Due to a substantial geographical distance between us and participants we were unable to provide the participants with a service level that matched their needs adequately. It is our experience that access to local support is essential to ensure successful outcomes when using this type of ICT with these client groups. Within the constraints of an R&D project we were not able to provide this, and this may have played an important part in the mediocre outcomes. As will be discussed in a later section, besides access to the technology, matters such as appropriate guidance, facilitation and support are equally important for successful outcomes.

Smartphones, tablets and smartwatches are under constant development, and new versions are being released constantly. In addition updates to operating systems and software are being released on a regular basis. Sometimes such updates may render set ups such as the shared calendar solution useless because of a temporary incompatibility between the different components caused by an update to one of the components, e.g. an update to a phone's operating system may cause an app to stop working. This may have caused some of the problems we encountered.

Some of the technologies used, like smartwatches, can be considered to be rather immature technology. It may be that so called "teething problems" with immature technology may have contributed to some of the challenges encountered during the trials. Such problems are usually ironed out with subsequent releases of the technology. One major drawback with the smartwatches commercially available at the time of the study was that they needed to be tethered to a smartphone to receive and display notifications. The two children, who received notifications on their smartwatches, had to have their mobile nearby for this to work. As a consequence they had to carry two devices at all times, and both of these had to be charged and maintained. This could be a nuisance. A number of next generation smartwatches are in the process of being released which can act as a standalone device without being tethered to a smartphone via Bluetooth.

Illustration 3 – Most smartwatches needs to be tethered to a smartphone to function properly.

Source: www.istockphoto.com.

We also experienced on two occasions that the equipment, in this case smartphones, stopped working due to physical damage. This is a hazard when providing children and adolescents with hi-tech devices, and seems to be unavoidable. Physical durability is very important in terms of the feasibility of a solution, and frequent disruptions to usage due to physical damage may rule out certain solutions. It is possible to buy ruggedized versions of smartphones and tablets which can withstand rough treatment or the devices can be equipped with protective covers to the same end. Three of the phones used in the project were water and dust resistant. Two of these failed.

5.3 Evaluation of possible effects

The ultimate goal of introducing ICT to the families was that it would have a positive impact on their lives. A number of factors impacted on whether the solution led to positive outcomes or not. We will discuss and elaborate on some of these factors below.

5.3.1 ICT as support to ADL

Several of the solutions tried out proved to support the participants with their daily activities. An example of this is Mobilize Me which helped Mikal becoming much more independent with conducting his morning activities. The mother reported that for the first time she did not have to constantly supervise her son. Mikal also benefitted from the visual timer app. Several of the other participants found the shared calendars and to do lists with notifications on either a smartphone or smartwatch beneficial. The wake up light was also reported as being useful, although it was only tested for a short while. Also Mikal and John and their mothers reported increased independence as a result of the use of technology, and improved electronic communication between parents and child.

Unfortunately, technical issues impacted negatively on some of the user experience and outcomes. The main reason for non or discontinued use were technical malfunction or instability, cumbersome routines for usage or the solution did not met the need or expectation of the child and family. Other reasons given for non-use were aesthetic reasons or equipment was physically too big for the child. In one instance the equipment was not accessible due to reduced vision and hearing. Practical issues such as short battery life with frequent need for charging did also impact on non-use.

5.3.2 Mainstream vs. AT

As mentioned previously we opted to give preference to mainstream technology rather than AT. We suspect that mainstream solutions – especially the more complex and elaborate ones – may be more prone to malfunction and technical difficulties when used in this specific context than AT equivalents. The latter having been developed and tailor made to suit specific needs and use of specific groups. This higher degree of technical problems may inadvertently have had an impact on the outcomes and the usefulness as experienced by some of the families. Specialised AT may provide core functionality and features that better address the needs of the users. One example being the Cloud based Mobilize Me solution. It provides much more appropriate functionality and features than possible mainstream alternatives such as the multitude of calendar, to do and timer apps one could consider. This is not to say that mainstream solutions may not be more appropriate for some users in certain instances. The challenge is to balance complex needs with technology which works and is simple to use. Sometimes this may only be achieved by using specialised AT.

5.3.3 Provision of ICT vs. AT – training, service, and support

In Norway the publicly funded AT scheme provides it users, for all intents and purposes, with specialised AT solutions rather than mainstream solution. This is irrespective of the circumstances, even though mainstream technology in certain instances could have been better suited. This is because the legislation which applies to the provision of AT in Norway states that mainstream technology with some exceptions is not to be financed by the governmental scheme.

With AT provided by the government AT scheme the family receives training and follow up. This is the responsibility of and is organised by the local municipality. With mainstream ICT obtained privately there is no training provided, and the level of support available is variable but most often low or lacking. In most cases the support one can expect is limited to online materials and phone support. For a number of the apps we looked in this project, the only support available was an e-mail address. As indicated elsewhere, if the set up one uses to support the child is made up of several products from different vendors, there is no clear actor with the overall responsibility of ensuring that the solution works or who can be consulted if something malfunctions. This necessitates that the families and possible informal helpers they may access to, possess a high degree of technological expertise and competence. Without access to such expertise, we suspect that the likelihood of positive outcomes for many families decreases dramatically – especially when elaborate set ups are in use. We noticed in the practical testing that a family which appeared to have very good ICT skills reportedly experienced few technical problems.

5.3.4 Access to local support – a key factor for successful implementation

Our experience from these technological trials is that successful implementation of ICT for these client groups using mainstream technology is dependent on a number of factors; a key factor being access to local support. We suggest that the type of support required is the right amount of guidance and facilitation during the assessment and implementation phase, and practical close follow up once the solution has been implemented and is operational.

5.3.5 The importance of user behaviour

These cases have shown that user behaviour can impact negatively on the feasibility of solutions. Some examples of the behaviours noted were:

- Not being able to use the device or service correctly, e.g. not remembering a certain procedure when entering new appointments or how to connect different devices.
- Filling up device with games, photos and other content.
- Inadvertently tinkering with settings which causes malfunction.
- Playing games, using social media etc. at the expense of using technology for intended purpose.
- Becoming preoccupied with certain features or functions of the technology.
- Physical damage due to accidents like dropping devices.

As a consequence of these user related factors the intended outcome could be impeded, and its full potential not achieved. To combat this it is of vital importance that the child has an adequate understanding of why they use the ICT. This is linked to maturity, and may be difficult for the younger children to understand. Regarding the youngest children in the study in particular, it was critical that they understood and accepted that they could not play around with the devices. In Mikal's case the mother solved this by giving Mikal two iPads; one for games, movies and entertainment, and another for organizing and structuring activities. John was eager to experiment with the functionality of the smartphone, tinker with its settings and installing games. This may have impacted on the stability of the set up. We also noted with the older kids that seemingly constant notifications from a variety of social media can also impact negatively on keeping track of the more pertinent notifications and reminders from their parents.

5.3.6 Factors that may support control of use

To minimize certain types of user error, it is possible to place restrictions on what a user can and cannot do with a particular device. There are different settings and mechanisms available which one can utilize to control both the content and change of settings on smartphones, tablets and other devices. Requiring passwords before changing important settings or undertaking certain activities such as downloading apps is one action that limits use. Another example of such measure is the Parental control settings on Apples iOS devices. This allows for a number of limitations to be placed on what the end user can and cannot do with the device. This is an example of a control mechanism which is built in on the operating system (OS) level. This provides a powerful tool

which provides universal control over the device. Other solutions provide control mechanisms through third party apps, or inside individual settings and apps. These provide less control than on an OS level. The need for a parental control feature may vary from child to child and the need will probably diminish with increased age and maturity. It is important, however, to have some form of mechanism in place which can be utilized to control and restrict the use of the devices. This is especially the case for the youngest users, or for children who have a tendency to tinker with their devices. Irrespective of control mechanisms, it is important with close follow up from the parents.

One will also have to determine and decide whether or not certain types of technologies are inappropriate for the youngest users, e.g. smartphones. It is difficult with certainty to deem what technology is age appropriate or not for an individual, and this need to be decided on a case by case basis. Age appropriateness and individual maturity should be taken into account when selecting a solution. Individual suitability in terms of being able to take care of and look after the equipment is also important when selecting a solution. We discussed this with the families when selecting solutions.

To limit costs on apps and services it is possible to control and place limitations on both the purchase of apps and so-called in-app purchases on most modern mobile devices. It is also possible to place limitations on content services and overall spending by contacting the mobile phone carriers.

5.3.7 Security and privacy issues

It is always of the greatest importance to ensure that all technical solutions deployed adequately retain and provide a desired level of security and privacy (S&P). When dealing with minors and potentially vulnerable individuals, it is even more important to pay particular consideration to such matters. It goes beyond the scope of this study to elaborate further on S&P issues, but suffice to say that these matters needs to be addressed adequately and appropriately when using technology with these groups. The importance of S&P may limit some of the possibilities that new technology offers. It is important to strike a balance between functionality and possibilities on the one hand, and S&P on the other. Sometimes they will pull in opposite directions. This is an area that will becoming increasingly important and challenging as our lives and activities become more and more digitalised, and become entwined with and dependent on the Internet-of-things, wearables, social media and Cloud based services.

5.3.8 Motivation and commitment

In order for the solutions to be usable the children had to commit to and be motivated to use the solutions. Some of the children said that even if they noticed a notification on their smartphone screen, they did not always comply with them. This shows that ICT is only useful if the child really wishes to use it as an assistive device. It is not enough that the parents want the child to use it. There are ways of facilitating this. Susann wanted the mother to be alerted on her mobile phone every time she had completed a task as this could motivate her and make it easier for her to comply. Given this, we chose a solution that allowed for this. When completed, Susann checked the task as

completed, and this was shown on her mum's phone immediately. Susann did point out, however, that even if she had checked a certain task as completed, this did not necessarily mean that she actually had done the task in real life, e.g. eaten lunch.

It is in this context important to identify behaviours and activities that are to be supported with technology which both the child and the parents alike agree upon as being of importance. It may be difficult to obtain positive results if the child is not motivated to change, and it is only the parents' agenda which is being pursued.

5.3.9 Impact on siblings

When the technology worked as expected and supported the child in self-management activities, it was reported that the relationship between the child and the mother, in particular, improved because conflicts related to monitoring everyday tasks were eased. In families with more than one child, the siblings expressed a feeling of sometimes being neglected because the parents spent much time on follow-up and supervision of the child with ADHD. In one of the families one sister expressed the feeling of sometimes being *invisible* (her own words). When the ICT functioned, the technology supported the child to act more independent in ADLs, and the parents could spend less time with monitoring the child. This could give the parents more time for the other children, and in this way ICT could benefit other family members than the actual child.

That being said, we also noticed that the extra attention given to the child who participated in the trial could be difficult to handle for some siblings. We took time to chat with the siblings, as with any other person that was present when we arrived, but our main focus was directed to the child and the parents who should use the devise. The technical setups demanded much attention, and we spent most of the time with this, adapting it to the child's needs and ensuring that we gave the proper training. Our attention was first and foremost directed at collecting first hand experiences with the functionality and the usefulness of the devices.

An important lesson learned is that one needs a detailed plan for how to include sibling in the trials even when they are not expected to use the chosen devises. This could provide knowledge about how siblings experience own and the family situation. The siblings' perspectives will contribute to findings and analysis, and it will enrich ethical issues on use of ICT for children who need extra support as well for research on these issues.

5.4 Capturing, documenting and assessing user experiences

As a part of the study we wanted to gain experience with and try different ways of capturing, documenting and assessing user experiences in the technology trials. We intended to use the Canadian Occupational Performance Measure (COPM) (Law et al., 1990) as an assessment and outcome assessment measure, but dismissed this after the first set of interviews. We made this decision because there had been a prior thorough assessment process, and the focus of the intervention and the type of interventions were already determined. Despite that COPM is a potentially useful tool in a project like this, we decided that given the context and timing of its

introduction we decided not to use it. However, we intend to use COPM in future studies, but then at an earlier stage in the research process.

The scheduled visits proved to provide the majority of data. Their purpose was twofold: firstly, they were the meeting point for making assessments, as well as discussing, providing and following up the ICT solutions; secondly, the participants were able to provide their feedback and sharing their practical experiences. The parents (usually the mother) were the main recipient of information and instructions, and provided the majority of feedback. We provided follow ups per phone and once using Skype (video).

The active data collection taking notes and audio recordings during the sessions worked well. The use of audio recordings was an unobtrusive way of ensuring that we did not miss any of what was being verbally expressed, and it enabled us to pay more attention to listening to what was being communicated rather than being preoccupied with writing it down. In addition, we received written feedbacks from the families per e-mail. This was structured feedback with responses to concrete questions from us. This provided us with very useful input.

Actual use of the technology was only observed by the researchers during the information, training and follow up sessions. We have no first hand observations of use in real life situations, e.g. at school. This is a major drawback as invaluable and important information and data is not available for analysis. Access to such data would have provided us with a much deeper appreciation and understanding of the participants' experience. Further, first hand observation would have enabled us to provide better support and follow up of usage, as we would possible have been able pick up user error or other factors that impacted on the feasibility of the solutions. Being able to observe the children use their solutions in a school setting would have been of particular interest. This will be pursued further in the *Erre mulig* project, as this project has a much greater emphasis on the child's ability to function and manage their lives and activities in a school setting.

5.5 To generate knowledge for subsequent studies

The study has provided us with a wealth of practical experience pertaining to both the types of possible ICT solutions in existence, their provision, and methodological approaches to capturing the user experiences. The knowledge will prove invaluable in the further work in the *Erre mulig* project.

6 Conclusion and Further work

6.1 Conclusion

Despite mixed outcomes, all families that took part reported that participation had been a worthwhile experience, and that it had been beneficial to take part. For some it had opened their eyes to a number of new possibilities on how they could manage a number of the daily challenges using ICT. There is an abundance of mainstream ICT available, and many set ups may support children and adolescents with ADHD and/or autism in their daily activities. This is only likely to increase as we move into the age of wearables and the Internet-of-things. ICT may assist with providing structure, help maintaining focus, assist in remembering things, aid communication, and support the ability to persevere when conducting everyday activities.

That being said, the more elaborate the setup, the more vulnerable and prone the solution appears to be to suffering technical difficulties, instability and malfunction. This is especially the case with setups that consists of hardware, software and services from a number of different vendors, and/or contains immature technology such as smartwatches. Such set ups displayed surprisingly poor usability. The quality of the products we mapped as possible solutions for the purpose at hand varied greatly, as do the level of support one can expect to receive if something does not work. For some users, and in certain contexts, solutions consisting partly or fully of especially developed AT is more appropriate than mainstream ICT.

We identified a number of key factors that are important and support potential positive outcomes when using ICT with these user groups:

- Ample time set aside for assessment, the introduction of ICT solutions, training and follow-up.
- Attention to practical details such as appropriate venue for assessment, timing and length of sessions, minimizing disturbances etc.
- Active user involvement, and a motivated family who are in agreement on the goals they would like to achieve.
- A technical competence in the family.
- Limit number of components and number of vendors in a given solution, and limit use of immature technology.
- Use specialised AT when needed.
- The right amount of guidance and facilitation, and local practical close follow up.
- Solution and all support material s should be in the user's native language.
- Separate devices for fun and games.
- Use of administration and parental control settings to limit use of secondary functionality like games etc. and reduce likelihood of important settings being tinkered with.
- Opt for physically robust equipment when given a choice, or consider obtaining additional accessories which adds robustness (protection covers, screen protectors etc.).

Paying attention to these factors will of course not guarantee positive outcomes, but should assist in avoiding or remedying some of the issues we experienced in these trials.

The trials confirmed what others have found, namely that one should not underestimate the amount of time required and level of support needed to implement mainstream ICT solutions successfully with these user groups. Access to local support when required is vital. We were not able to provide this adequately within the constraints of a R&D project, and this did have an adverse impact on the outcomes. The need for guidance and facilitation throughout the process can be great depending on the complexity of the solution and the technical skills of the family. The need and demand for a publicly funded service that adequately addresses the need for guidance, facilitation and support is likely to increase as it is recognised that mainstream ICT increasingly can be used to support user groups such as children and adolescents with ADHD and/or autism. The current Norwegian public system dispenses primarily specialised AT solutions to support these groups. Although, this study has shown that the use of mainstream ICT is not without its challenges, we believe it may replace many of the presently used AT solutions in the future for these target groups. This will necessitate a change in how NAV and the municipalities go about distributing and following up technology.

6.2 Further work

This study has revealed a number of interesting lines of enquiry which we will pursue further in the *Erre mulig* project. The ultimate goal of *Erre mulig* is to facilitate increased activity and societal participation and improved quality of life for children and adolescents with ADHD and/or autism and their families. To achieve this we will develop and try out innovative ICT set ups suited to the particular needs of the user groups, and conduct service innovation in the public sector through the development of a comprehensive and user centred provision of ICT and AT.

We will focus on technology that can assist the children to better organise and manage their lives at home and in school. The project partners and advisory board comprise of key actors locally and nationally in Norway from professional and end user organisations. SINTEF is the project leader, and Nøtterøy municipality the project owner. Other partners are the municipalities of Tønsberg and Fredrikstad, Buskerud and Vestfold University College, NAV Center for vocational rehabilitation av assistive technology, and NAV Østfold and Vestfold Assistive Technology Centres. (see http://www.sintef.no/erre-mulig for further information). Industry partners will be invited to join as the project progresses. We will seek to share information and knowledge with other national and international R&D endeavours.

A key activity in the project is practical testing and evaluation of ICT with end users. This is organised through pilots in the participating municipalities. We will work closely with the children, their families and the local public support systems (education, health etc.) in the development and trialling of ICT and different methodologies of its provision.

We believe that practical testing of the ICT solutions in a realistic manner with real life users in their own environments is a must to ascertain its suitability or not. The proof of the pudding is, and always will be, in the eating. The project at hand has showed that although the use of mainstream

ICT can be of benefit in the daily lives of children and adolescents with ADHD and/or autism and their families, its use is not without challenges. The lessons learned will be of great benefit to the further work in the *Erre mulig* project, which hopefully will lead to better suited ICT solutions and accompanying methodology on how to provide them in an appropriate manner.

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9 Appendices

9.1 Overview over technological setup John

- **Hardware**
  - Initially:
    - Sony Xperia V smartphone: http://www.sonymobile.com/global-en/products/phones/xperia-v/specifications
    - Pebble Smartwatch: https://getpebble.com/discover
  - Replaced by:
    - Sony Xperia Z smartphone: http://www.sonymobile.com/global-en/products/phones/xperia-z/specifications.
    - Sony Smart Watch 2: http://www.sonymobile.com/global-en/products/accessories/smartwatch-2-sw2
- **Software/services**
  - Google Calendar: https://support.google.com/calendar/answer/2465776?hl=en
  - Pebble (Pebble app): https://play.google.com/store/apps/details?id=com.getpebble.android
  - Notification Center for Pebble (Pebble app): https://play.google.com/store/apps/details?id=com.matejdro.pebblenotificationcenter
  - Sony Smart Watch 2 SW2: https://play.google.com/store/apps/details?id=com.sonymobile.smartconnect.smartwatch2
  - Sony Smartconnect: http://www.sonymobile.com/no/software/smart-connect
  - Various notification apps on smartwatch (calendar, SMS etc.) from Google Play.
  - Misc. Google account, Pebble account.

9.2 Overview over technological setup Sue

- **Hardware**
  - Sony Xperia V smartphone: http://www.sonymobile.com/global-en/products/phones/xperia-v/specifications
- **Software/services**
  - Wunderlist: To-Do List & Tasks (Android app): https://play.google.com/store/apps/details?id=com.wunderkinder.wunderlistandroid.
  - Google Calendar: https://support.google.com/calendar/answer/2465776?hl=en
  - Misc. Google account, Wunderlist account.

9.3 Overview over technological setup Lisa

- **Hardware**
  - iPhone 5C: https://www.apple.com/no/iphone-5c
  - Pebble Smartwatch: https://getpebble.com/discover
  - Philips wake-up light: http://www.usa.philips.com/c-p/HF3550_60/wake-up-light
- **Software/services**
  - Google Calendar: https://support.google.com/calendar/answer/2465776?hl=en

- Pebble (Pebble app): https://play.google.com/store/apps/details?id=com.getpebble.android
- Notification Center for Pebble (Pebble app): https://play.google.com/store/apps/details?id=com.matejdro.pebblenotificationcenter
- Wake up light Philips (iOS app): https://itunes.apple.com/us/app/wake-up-light-philips/id544145415?mt=8
- iOS Calendar and Reminders
- Misc. Google account, Pebble account, Apple iCloud with an Apple account.

9.4 Overview over technological setup Mikal

- **Hardware**
  - Timer: Time timer Watch PLUS Youth: http://www.timetimer.com/store/product/29/watch-plus-youth---light-grey
  - Phone: iPhone 5 (iOS 7): http://www.apple.com/no/iphone/compare
  - Tablet: iPad mini with Retina display (iOS 7): http://www.apple.com/no/ipad-mini
- **Software/services**
  - App iPad (iOS): Mobilize Me: http://www.mobilize-me.com
  - App iPhone (iOS): TimeTimer: https://itunes.apple.com/us/app/time-timer/id332520417?mt=8
  - App iPhone (iOS): Visual timer: https://itunes.apple.com/us/app/visual-timer-time-countdown/id665881297?mt=8
- **Other set ups used by the family:**
  - Wake up with Disney app (alarm clock): https://itunes.apple.com/us/app/wake-up-with-disney/id625533670?mt=8

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