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POSEIDON – Personalized Smart Environments to Increase Inclusion of People with Down's Syndrome – Results of the First and the Extended Pilot Study

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Abstract. The POSEIDON project aims to increase the independence and autonomy of people with Down's syndrome with the help of technical assistants. Therefore, several personalized and smart technology solutions were developed (e.g. a Navigation app, a Home Navigation System, a Money Handling Game, a Calendar app) to help people with Down's syndrome to become more independent and more included in society. A first pilot study (and in an extended pilot in form of a one-day-event) was conducted in three countries, wherein the prototypes of these technical devises were tested by people with Down's syndrome and their parents/care givers. Quantitative and qualitative methods were used to collect comprehensive feedback, which is used to develop new technical requirements for revision and further development.

Keywords. Down's syndrome, smart environment, ICT, inclusion, integration into society, autonomy

1. Introduction

Down's syndrome, also known as trisomy 21, is caused by extra genetic material in chromosome 21. Infants with Down's syndrome often have a decreased muscle tone, a flat face, eyes slanting up, irregular shaped ears, the ability to extend joints beyond the usual, large space between the big toe and its neighbouring toe, large tongue relative to the mouth, etc. (WHO) According to the WHO, 1 in 1,000 to 1 in 1,100 live births worldwide is affected by Down's syndrome. People with Down's syndrome usually are more likely to have health problems e.g. heart diseases [1]. Down's syndrome also affects mental areas being responsible for cognitive, linguistic and sensomotoric skills [2]. There is a general perception that people with Down's syndrome are poorly integrated into the society they live in. One reason might be, that they have problems in expressing theirselves [3]. Moreover, problems in expressive language can cause an underestimation of intelligence and other competencies. [4]. Meanwhile it is established that the abilities of people with Down's syndrome differ widely [5]. With appropriate support, they often

exceed the expectations of their environment [for example, 6]. In some cases, they successfully complete university [6] and become independent professionals in their own right. Up to now it has not been widely explored what form of support could be helpful. The idea of POSEIODN is to support people with Down's syndrome with the help of modern information technology.

2. Objectives

POSEIDON is a three-year project which is sponsored by the European Commission. Nine partners¹ from the United Kingdom, Norway and Germany are involved in this project. POSEIDON aims at developing a technological infrastructure which supports people with Down's syndrome to achieve greater independence and inclusion in their everyday lives with the help of technical assistants. POSEIDON was developed to support people with Down's syndrome and their caregivers, parents and other relatives and helpers.

Based on the results of a requirement study (which we conducted at the beginning of the project), it was clear persons with Down's syndrome have a tight schedule with lot of activities. They need support to handle time, place, distance, money and support for mobility in order to be more independent outside their living environment.

The developmental process follows a user centered approach and involves primary (people with Down's syndrome), secondary (e.g. caregivers, parents) and tertiary users (e.g. teachers). This means that from the beginning of the project users were involved to test the apps on several stages of the developmental process. Their feedback was fundamental for design and functions and led to a greater personalization of all apps.

Based on the requirements, the project has developed apps for navigation, calendar and for money handling and a web, primarily for the caregivers, for personalizing the POSEIDON-system for the person with Down's syndrome.

To support problems of orientation a Home Navigation System (HNS) was developed. With this system routes can be trained at home on the computer. The routes can be individually configured and customized through the photos, advices, voices and symbols to the needs of the primary users. These routes can be transferred to a smartphone app and used for navigation outside. To facilitate the organization of everyday life appointments (e.g. sport activities) can be entered into the calendar app – with pictures and instructions (e.g. "Think of your umbrella if it is raining") and linked with the appropriate routes (Route to the gym). Parents or carers can add appointments via POSEIDON web and track the primary user about a tracking function (with the agreement of the person with Down's syndrome).

¹ Karde AS, Middlesex University, Fraunhofer IGD, BIS – Berlin Institute for Social Research, Funka Nu, Tellu AS, Norwegian Network for Down Syndrome (NNDS), Down's Syndrome Association – UK (DSA), Association Down-Syndrome – Germany. The project is funded by European Commission.



In order to practice handling money and to be prepared to go shopping, a Money Handling Game (MHG) was developed, which is played on an interactive table or on a smartphone and simulates paying various products.

Picture 2: Money Handling app



3. Methods

In a first step we tried to find out what people with Down's syndrome need, what they want and what they are able to handle. Therefore, we developed a standardized onlinequestionnaire addressing caregivers, made face to face interviews with both caregivers and their protégées, and conducted workshops to get a first impression on how people with Down's syndrome use modern information technology.

Center of these analysis was the online questionnaire on the everyday life of people with Down's syndrome, their interests, and the extent to which they are familiar with modern information or assistive technologies. The questionnaire has been send out through Down's syndrome associations in 2013. It was provided in English, German and Norwegian, Slovenian, Portuguese and Italian. 553 questionnaires were answered. The respondents were mostly parents having a child with Down's syndrome.

In Summer 2015 a pilot study was conducted with three families in three countries (United Kingdom, Norway and Germany). The families who took part in the pilot were recruited by the national Down's syndrome associations. The criteria were the person with Down's syndrome had to life with their parents, 15 years and older, (no survey on cognitive skills).

The pilot lasted in each family at least four weeks. Members of the POSEIDON project regularly visited the families to rehearse tasks and consider about learning successes. For data collecting different qualitative and quantitative methods were used. The secondary users had to fill in questionnaires for every device and app at the beginning and at the end of the pilot, we conducted interviews three times with the primary and the secondary users and we observed them during the visits while they used the POSEIDON apps (with standardized observation sheets). The main questions were addressed to the usability, usefulness, safety, the impact on independency and integration into society and if they like it.

On this visit days, the primary users played the Money Handling Game, trained a route using the Home Navigation System, walked this route outside using the navigation app, added appointments in the calendar, edited or deleted them. After that, interviews were conducted with the primary users and secondary user had to fill in the questionnaires. Between the visit dates, the primary users were asked to use POSEIDON independently supported by their parents/carers and to fill in a diary sheet to document their experiences.

Moreover, an extended pilot, in the form of a one-day event, was conducted in all three participating countries. There, all together 28 primary and 22 secondary users took part.

4. Results

The general impression of the first pilot is that all participants seem to like the idea behind the POSEIDON applications and the POSEIDON vision itself. Although they were well aware of the limitations of the system. They first of all mentioned a lot of advantages. They liked to learn how to handle money on a new device (interactive table) with the help of a gamification approach. They also considered the calendar app as helpful. Most of them can imagine that the Home Navigation System can help to learn new routes at home safely, and they liked very much the idea of having a navigation app using routes which can be adapted to their needs.

However, there is still place for improvements. Especially usability and user experience, safety and personalization aspects have to be considered for further developmental activities. The second pilot, starting in May 2016 is based on the experiences of the first pilot and has a lot of new and better functions.

During the first pilot phase, many technical and organisational problems had to be overcome. Overall, we got data from interviews, questionnaires, diaries and observation sheets.

The Home Navigation System seems to be fun for the primary users. They enjoyed to walk through the routes at home, especially unknown routes. Nevertheless, an intense training to handle the systems is required. Handling the mouse adequately is difficult for some primary users.

Most important would be to make the system more reliable. However, it is also important to make the setting up of routes easier as well as writing information texts. These texts should always be visible and not delete themselves. The users should be informed when text has been saved.

The navigation seems to be fun for the primary users as well. Secondary users liked the idea behind. The tracking function was considered as a fantastic feature both for parents and carers. It gives confidence to the primary users that they can always be found if they get lost and gives secondary users the assurance that they are well informed about the whereabouts of their protégées. Most people interviewed could imagine using the tracking function in their daily lives. Nevertheless, there is an option for the primary users to switch this function on and off.

However, disadvantages were also mentioned: time consuming to create routes on the POSEIDON web, a lack of route options, inability to add steps to the route and problems to synchronize with the phone. Further problems were that the system sometimes was too slow. Sometimes it was inaccurate, arrows give wrong direction so that the primary users can't always rely on the system.

Improvements for the navigation application would be the ability to add steps in between main decision points on navigation, the possibility to video the journey instead of using Google maps (unusual views), considering additional routes and having the tracking function on smartphones. Moreover, a larger font-size would be fine, as well as to have more possibilities to customize and to make smaller steps in a longer journey.

The Money Handling Game is fun for primary users, e.g. the tapping. Many see it as a possibility to improve their knowledge. But it was mentioned that the sizes of the coins and bills should have relative sizes as in reality and not just one size. A shopping basket should be installed. The variety of competencies within the group of the primary users is big. Some are easily demotivated by using the system, for others it seems to be too easy. Improvements would be to have different tasks for different competence levels.

The calendar app is regarded as helpful to organize daily activities. The possibility to add instructions, images and voice messages via the POSEIDON web to calendar appointments makes the POSEIDON calendar special. The primary users seemed to be able to add/delete appointments. They appreciate the simple design. Problematic seemed to be that the "Save" button disappears under what is initially seen on the screen on the smartphone and that it is difficult to turn off the alarm.

	Not agree at all/ Not agree	Not sure	Agree/ Totally agree
The font size is suitable	1		10
The colours are suitable			10
The Money Handling Game is easy to understand	1	2	8
The Money Handling Game is time consuming to use	3	2	
The Money Handling Game is fun to use			5
The Money Handling Game is better than other kind of money handling training	1	5	2
The interactive board is good to use for money handling training	2	1	8

Table 1: Money Handling Questionnaire Norway and UK

Improvements would be to add arrows on the previous and next function. Primary users should be able to set an alarm before an event on the app. An intermittent sound would be better than a continuous one (eventually a flashing light would be helpful). The calendar on the web and app should look more alike to avoid confusion if the primary user uses both. A weather notification should be installed. For those who are not able to write or to read, the use of symbols and signs would be an improvement.

5. Prospects

The overworked prototype will be evaluated in a second pilot with nine other families. The fieldwork started in May 2016. For the second pilot the POSEIDON apps and the web were updated and revised and new technical functionalities were developed. A shopping support and personal instruction videos are included in the POSEIDON app. Moreover, a route creation app was developed to create routes more easily than using the Home Navigation System on the PC. Furthermore, there is a social network on the POSEIDON website for communicating with groups and individuals who are also using POSEIDON apps. Based on the results of the second pilot the systems will be revised again. The results of both pilots will show what kind of personalization is needed and what kind of applications are useful.

	Not agree at all/Not agree	Not sure	Agree/ Totally agree
The font is appropriate.	1		10
The font size is appropriate.	1		10
The colour and contrast ensure good readability.	1		10
The calendar is intuitive.	2	1	8
The calendar gives the user joy.	1	1	9
The calendar overstrains the user.	8	2	1
The calendar stresses the user.	8	1	2
The calendar bores the user.	9	1	1
The calendar stimulates the user.	3		8
The calendar confuses the user.	6	3	2
The calendar frightens the user.	10		1
The calendar helps the user to organize easily daily life.	1	2	8
The calendar helps the user to be more independent	2	1	8
The calendar is just a gimmick.	10		1
The font size of the calendar app is suitable.			5
The colours on the app are suitable.		2	3
The calendar app is easy to use.			5
The calendar app is time consuming to use.	3	2	
The calendar app is fun to use.	1	2	3
The calendar app combined with input from the POSEIDON web is better to use for the person DS than other calendar apps		1	3
The calendar app with entries from the smart phone is better to use for the person DS than other calendar apps.	2	1	1
In the calendar app the use of pictures is suitable for persons with DS		1	3
In the calendar app the use of lists is suitable for persons with DS	2	1	1
In the calendar app the use of voice recordings is suitable for persons with DS		1	3
In the calendar app the use of navigation routes connected to a calendar appointment is suitable for persons with DS	1	1	
In the calendar app the use of advices about what to wear according to weather forecasts is suitable for persons with DS	1	1	

Table 2: Calendar Questionnaire: Norway and Germany

References

- F. Hickey, E. Hickey, K.L. Summar, "Medical update for children with Down syndrome for the pediatrician and family practitioner.". Advances in pediatrics 59 (1): pp.137–57, 2012.
- [2] L. Abbeduto, M. Pavetto, E. Kesin, M.D. Weissman, S. Karadottir, A. O'Brien, S. Cawthon, "The linguistic and cognitive profile of Down syndrome: Evidence from a comparison with fragile X syndrome. Down Syndrome Research and Practice." 7(1), pp. 9-15, 2001.

- [3] S. Buckley, and G. Bird, "Speech and language development in individuals with Down syndrome (5-11 years): An overview Tech. rep.: Down Syndrome Educational Trust" Portsmouth, UK, 2001.
- [4] L. Kumin, "Early Communication Skills in Children with Down Syndrome: A Guide for Parents and Professionals." Bethesda, Maryland: Woodbine House, 2003.
- [5] J. Lazar, L. Kumin, L. and J.H. Feng, "Understanding the Computer Skills of Adult Expert Users with Down Syndrome: An Exploratory Study." In The Proceedings of the 13th International ACM SIGACCESS Conference on Computers and Accessibility). New York, NY, USA: ACM, pp. 51–58, 2011.
- [6] Down Syndrom Regensburg, What about the intelligence of children with down's syndrome? (Was ist mit der Intelligenz bei Kindern mit Down-Syndrom?) published on: http://www.down-syndromregensburg.org/das-down-syndrom/was-ist-mit-der-intelligenz-bei-kindern-mit-down-syndrom/, 2016.