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POSEIDON – Bringing Assistive Technology to People with Down Syndrome: Results of a Three Year European Project

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Abstract. The POSEIDON project aimed to increase the independence and autonomy of people with Down syndrome with the help of technical assistants. It followed a user-centered approach by involving people with Down syndrome and their parents, carers etc. A requirement analysis was the first step of the project. It became clear that people with Down syndrome especially need support in the areas of time management, mobility and money handling. Different applications were developed which were tested and evaluated in two field tests in three countries. Results indicate that POSEIDON can help to overcome daily challenges and that it can increase the autonomy and independence of people with Down syndrome.

Keywords. Down syndrome, smart environment, ICT, inclusion, integration into society, autonomy, user-centered design

1. Introduction

The project POSEIDON (PersOnalized Smart Environments to Increase Inclusion of people with DOwn's syNdrome) focused on an increase of inclusion of people with Down syndrome into society and a greater independence with the help of IT-technology.

Down syndrome, also known as trisomy 21, is caused by extra genetic material in chromosome 21. Infants with Down 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. According to the World Health Organization (WHO), Down syndrome affects 1 in 1,000 to 1 in 1,100 live births worldwide. People with Down syndrome usually are more likely to have health problems e.g. heart diseases [1]. Down syndrome also affects mental areas responsible for cognitive, linguistic and sensomotoric skills [2]. There is a general perception that people with Down syndrome are poorly integrated into the society in which they live. One reason might be that they have problems in expressing themselves [3]. Problems in expressive language can cause an underestimation of intelligence and other competencies of people with Down syndrome [4]. Meanwhile it is established that the abilities of people with Down syndrome differ widely [5]. With appropriate support, they often exceed the expectations of their environment [for example, 6]. It has not been widely explored what form of support could be helpful. POSEIDON aims to support people with Down syndrome since they can achieve much

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more than they are expected to, especially when help is provided. In some cases, they successfully complete university [6] and become as independent as possible. The idea of POSEIDON is to support people with Down syndrome with the help of modern information technology. Nine partners[2] from the United Kingdom, Norway and Germany were involved in this project. It was founded by the European Commission from 2013 to 2016.

2. The POSEIDON applications

In the POSEIDON project, different applications were developed for people with Down syndrome and their carers to support them to manage their daily activities as independently as possible. POSEIDON provides support in the areas of time management, mobility and money handling. The developmental process followed a user-centered approach and involved Primary (people with Down's syndrome), Secondary (e.g. caregivers, parents) and Tertiary Users (e.g. teachers). The 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 the awareness of the necessity of a greater personalization of all apps.

The POSEIDON app supports daily planning, traveling, shopping and personal video clips (see Figure 1). The main menu gives the user with Down syndrome the following options:

- Routes – Start navigation by using planned routes
- Preferences – Turn on/off position tracking and choose colour themes
- Calendar – View planned events and add new events
- Videos – View videos that are uploaded by the carer
- Training – Access the Money Handling Training app
- Shopping – Access the Money Handling Assistance app

In order to support the competencies on time management, an easy usable calendar was developed. Carers are able to add, change and delete appointments with the help of an online platform (Web for carers). Appointments can be personalized with videos, instructions, voice recordings and symbols or signs according to the needs and abilities of their protégées. Carers can also add pictures of items people have to take with them when going to school, to work or to appointments (e.g. an umbrella). People with Down syndrome receive notifications on their smartphone when they have appointments. These notifications come up half an hour before the appointment starts. A time bar highlighted with different colours indicates how much time is left. If they want to and are able to, people with Down syndrome can add, change and delete appointments as well. The Primary Users also receive weather notifications based on the weather forecast. These messages are connected with recommendations what to wear according to the temperature outside and can be personalized by the Secondary Users.

An additional feature is the possibility to add routes to appointments. This leads to the next area which is supported by the POSEIDON project: Mobility. People with Down syndrome often have problems to get from A to B. Carers can create routes with the help of a Route Creator app. These routes can be rehearsed with the help of the Home

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Figure 1. POSEIDON app

Navigation system on the PC and they can be used on smartphones to navigate outside. Carers can add pictures of certain places to this route to make the navigation easier and they can customise the steps of a journey by adding text and speech. To strengthen their competencies regarding money handling, a money handling game for smartphones was developed. With the help of this app we want to increase their knowledge about the value of money and how to pay for certain products. The game is about choosing the correct amount of money for the priced product being displayed on the screen. Carers can make shopping lists on the Web for carers by adding product images and prices. The shopping lists are automatically transferred to the Money Handling Training App in which the user can practice before going to the shop. Moreover, a Shopping App (on smartphone) was developed which supports the users on the spot – when they are out shopping. The app gives an overview of which products to buy (the created shopping list), the price for each product and the total price including what type of coins and notes to pay with. On the web the carer can not only make personal calendar events, shopping lists and add videos to the app, the carer can also track the user´s position (if the person with Down syndrome has switched on this function in the app) and mark important places on the map. Since the abilities and needs of people with Down syndrome vary to a high extent, all applications and functions can be personalized. The POSEIDON apps are available in the Google Play Store (only for Android phones) in three languages (English, German and Norwegian). Figure 2 gives an overview about POSEIDON´s framework and all functions.

3. Methods

User-centeredness was paramount for the success of the project. This means that from the beginning on, all stakeholders, as there are Primary Users (people with Down syndrome),

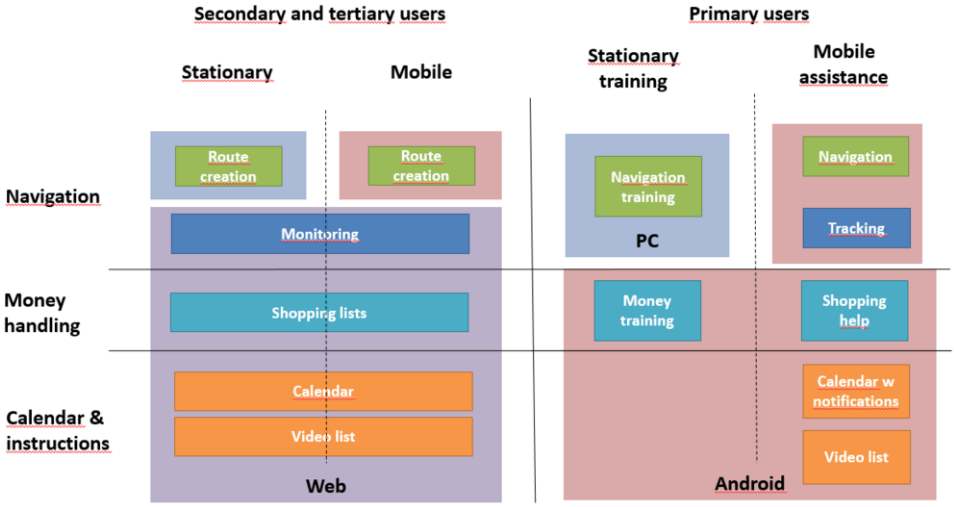

Figure 2. Framework of POSEIDON

Secondary Users (parents and carers) and Tertiary Users (teachers or supervisors e.g.), are included in all stages of the developmental process. The first step of the project was a requirement analysis in form of an online survey. The aim was to assess the needs and requirements as well as the usage of technology of people with Down syndrome. The survey was conducted in six countries (the UK, Norway, Germany, Italy, Slovenia and Portugal) and started in December 2013. The questionnaire[3] addressed everybody caring for people with Down syndrome. All in all, 583 questionnaires were filled. Additionally, face to face interviews with a total of 30 people with Down syndrome were conducted at the beginning of the project. The results led to a set of personas and scenarios that describe the life situation for seven fictional people with Down syndrome. The personas are important for the technical requirements which ensure that the POSEIDON solutions fit the target group.

Moreover, three workshops, which covered topics like the use of technology in general and assistive technologies in particular, the living situation and daily activities of people with Down syndrome, took place with guests from Croatia, Italy, Luxembourg, Portugal, Romania, Slovenia, Switzerland, Ukraine, Scotland and France. These guests were parents or carers from people with Down syndrome or members of national Down Syndrome Associations.

Based on the results of the workshops, the interviews and the requirement analysis which indicated that people with Down syndrome mainly need support to handle time, appointments, money and support for mobility, different technical applications were developed. These applications were evaluated in two field tests and one extended field test in form of a one-day event. The field tests were conducted each time with three families in each country (the United Kingdom, Norway and Germany) in 2015 and 2016. The Down's syndrome associations of each involved country recruited the families that took part in the field tests.

For each family, the field tests lasted four weeks. Members of the POSEIDON project regularly visited the families to rehearse tasks and to consider the learning process.

[3] Available under www.bis-berlin.de/POSEIDON/Quest/RequirementAnalysis.pdf

For data collecting, different qualitative and quantitative methods were used. The carer/parents had to fill in questionnaires for every function in the beginning and in the end of the pilot, interviews were conducted two times with the person with Down syndrome and the parents. Moreover, they were observed during the visits while using the POSEIDON devices and they had to fill in User Protocols. Due to the low sample size, the results of the field tests were analysed in form of case studies, which are based on qualitative data. Therein, the Primary Users are presented in their living context with their daily routines, abilities, challenges, goals and their general use of technology. The Primary and Secondary Users' experiences with POSEIDON are described in detail as well as the outcome of using POSEIDON applications.

4. Results

4.1. Requirement analysis

Results indicated that a majority of people with Down syndrome uses modern information technologies: Tablet-PC 71.2 percent, smartphone 60.8 percent. The easiest seems to be the use of Tablet PCs (only 42.6 percent need help using them) while 65.6 percent of people with Down syndrome need to be assisted when using a smartphone. Modern assistive technology is regarded as helpful to overcome challenges in daily life (57.7 percent), although some of the carers do not seem to be well informed about the chances these technologies offer. Social integration varies highly between work/school and leisure time. 44.8 percent are well integrated at school or work but only 23.3 percent in leisure time. Most important seem to be supporting communication, socializing and school/work/learning; more than 50 percent of participants consider these aspects as very important. These results go in line with the fact that people with Down syndrome need to be accompanied by relatives when going to leisure activities (73.8 percent). Making traveling for them safer and more flexible could result in building and maintaining friendships. More than 75 percent of the carers indicate that checking that the person they care for has reached a destination as well as locating the person would be very helpful features for them.

Concerning the usability and design, especially the motivating and fun aspects are stressed (67.1 percent and 61.7 percent considered them as very important). Very important is also the adaptability to individual needs (62.5 percent), the avoidance of a need for fast reactions (58.1 percent), and the aspect that the device should be robust (57.8 percent). Other aspects, such as large buttons (22.7 percent), a display with strong contrasts (22.2 percent), a flexible change between icons/symbols and text (29.3 percent), are not frequently regarded as "very important".

4.2. Pilot studies

The general impression of the first pilot study, which was conducted in summer 2015, was that all participants seem to like the idea behind the POSEIDON applications and the POSEIDON vision itself. During the first pilot phase, a lot of problems had to be overcome, but the participants were aware of the limitations of the system. However, they mentioned a lot of advantages: They liked to learn how to handle money on a new device with the help of a gamification approach. They also considered the calendar app as helpful for a better structure of their daily life. Most of them can imagine that the

Home Navigation System can help to learn new safe routes to home, and they very much liked the idea of having a navigation app using routes which can be adapted to their needs. However, there was still room for improvements. Especially usability and user experience, safety and personalization aspects had to be considered for further developmental activities.

In both pilots, the applications sometimes did not work properly or bugs occurred while testing. This was very frustrating for the Primary Users but also for their carers. Most people with Down syndrome have a lower frustration tolerance. This increases the tendency to give up when problems cannot be solved immediately and the tendency to become bored or annoyed. Carers often had to encourage their protégées to use the applications.

The second pilot study started in Summer 2016. The POSEIDON functions had been revised based on the experiences of the first pilot, the extended pilot and the workshops and some new functions were integrated. New functions in pilot 2 were the shopping assistance and the integrated video function in the POSEIDON app, a new Route Creator app and a social network.

The system worked more reliable than during the first pilot. One of the most important results of pilot 2 was that all participants see the potential of POSEIDON to increase the independence and autonomy of people with Down syndrome, the potential for a better organization of daily tasks and for a higher mobility.

The Primary Users were able to master their individual challenges and to reach most of their goals they mentioned beforehand, even though a longer period of usage might be necessary for some goals: With the help of the calendar app, they achieved their goal remembering appointments and bringing all necessary things to school or work, through the money handling and the shopping app they were able to achieve a better understanding of the value of money. The navigation app made traveling more secure for the Primary Users and was reassuring for the carers who easily could inform themselves about the whereabouts of their protégées. By combining different POSEIDON apps the users could organize and conduct different daily tasks. They could for instance do a shopping tour completely on their own: creating a shopping list, organizing the money for the planned purchase, planning and training the route to the shop, using the navigation app to go there, doing the shopping, paying on their own and going back home again with help of the navigation app.

Most participants were also very open-minded and excited to learn new things. Their ability to master POSEIDON made them proud and they had fun testing POSEIDON for four weeks and were pleased to be an important part of the project.

Nevertheless, many problems occurred in the pilot and there was still much room for improvements. Participants mentioned a lot of ideas for improvement and recommendations for further development. These recommendations were used to make some last improvements until the project ended in December 2016.

5. Discussion

POSEIDON contributes to the field of smart environments where little has been done before for people with Down syndrome. Not much is really known about their interaction with technology.

Results of the project indicate that information technologies are of great importance for people with Down syndrome and that the developed POSEIDON applications can be

a great support to increase their independence and inclusion into society. All participants see the potential of POSEIDON to help people with Down syndrome to be more independent and autonomous in their daily lives. However, the impact is very individual for each person with Down syndrome. According to their individual challenges and abilities, they consider different functions as most helpful and supportive. For some participants, the navigation training and the navigation app was the most helpful function in order to achieve a better orientation and to be able to go out on their own. Participants who were going to move away from home into supported living considered POSEIDON as a great help to handle this situation. For other participants, the Money Handling Training and the shopping app were most helpful, because they had no understanding of the value of money. All participants could master the technology and this had a positive impact on their self-consciousness. They had fun testing POSEIDON and were proud to be a part of the project. Most participants would also like to use POSEIDON in the future, at least specific functions of POSEIDON.

In the study design, the time schedule of the field tests was limited. Therefore, we could not measure the long-term impact on independence and inclusion in the society. Long-term field tests would be very helpful to measure the psycho-social impact on the lives of people with Down syndrome in terms of independence, autonomy and inclusion. In longer field tests, it could also be measured if POSEIDON increases the chance of employment which was also not possible to measure in four-weekly field tests.

It is planned to continue the development of the applications (like accessibility for Apple phones, not only Android; translation in more languages) in order to bring POSEIDON onto the market. Not only people with Down syndrome, but also people with other cognitive disabilities would strongly benefit from using POSEIDON to increase their quality of life.

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