

## 3 Interviews with people with Down's syndrome

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### 3.1 Introduction

The qualitative interviews of people with DS had the aim of gathering more information about their daily lives in the areas: Education/Work, leisure time, socializing, mobility, wellbeing and the usage of modern technology. The interviews were focused on:

- Why and how is technology used?
- Why is a specific technology good or not good?
- How can POSEIDON be developed to meet the user's needs?

The idea was to discuss the use of technology with the interviewee and gain an insight into how she/he uses technology; what is important or difficult for that specific person. To be valuable for POSEIDON it would not have been enough to discuss these things when referring to a normal household appliance or a toy. The main purpose was to understand the user's experience with using modern technology, what they like, don't like, use and would like to have, and their level of competency in using the technology they own.

The guideline for the Interview has three main parts:

#### **Part 1 – overall information**

This part was mainly meant to be an "icebreaker" to establish a rapport with the interviewee and to get information about their lives and family background.

#### **Part 2 – daily routine**

The purpose of this section was to discover the daily routine activities of the interviewees: education/work/day activity/leisure activities/socialising/wellbeing.

The barriers to independence they have to face, the technology they use and the changes they would like to see for the future.

#### **Part 3 – use of technological (especially smart) devices**

From our online questionnaire we have already sufficient information about which technologies people with DS use. Therefore we wanted greater detail about how they use these technologies. What do they like or dislike when using them? Which device is difficult/easy to use and why? What functions of the device do they use? Where and how

much help do they need using them?

29 interviews were conducted by the NNDS in Norway, the DSA in the UK and the ADS in Germany from January to March 2014. Most of the interviewees were visited at their homes. The interviews were conducted (with the agreement of the interviewee and the carer) using audio / video recording. Usually a parent or carer took part in the interviews.

For documenting the interviews and making them easier to evaluate we used record sheets.

### 3.2 Sample description

Of the 29 interviewees 16 were female and 13 were male. The age range was from 14 to 38 years. 17 participants were living with their parents and 12 in sheltered homes. There is no significant difference between countries regarding their living circumstances. Most interviewees had sisters and brothers.

**Table 5: Overview on gender and age of the interviewees in the three participating countries**

	UK	Germany	Norway	All
Gender	4 female/ 6 male	5 female/ 4 male	6 female/ 4 male	15 female/ 14 male
Age (average)	27.9	23.6	20.8	24.2

Below is a record of the interviews and comments from BIS. BIS will not present a differentiated evaluation which can only be carried out by specialists on DS.

In the context of our requirement analysis we have only tried to find out more detailed information than could be gained from the questionnaire and if there is another perspective to consider.

Besides, reading the interviews gives a good impression of the lives of people with DS and the use of technology embedded in their daily activities and routines.

### 3.3 Main results

The daily routine of the interviewees is obviously related to their age, hence the daily routine of children of school age is centred around the school routine, while the daily routine of those out of school is centred around their working schedule. In addition to the routines around this activities (school / work), there are also very elaborate and detailed weekly schedules regarding a high number of different leisure activities, e.g. sports, music, cultural activities.

They have tight schedules, getting up early in the morning, going to school or work. Some of them have different jobs on different days. This demands managing time, destinations and distances. They use smart phones as alarm clocks and they go by bus or metro, but more often students are transported by their relatives or by taxi, which is comfortable and safe. Logistic support is given by parents or carers. They call the taxi, they know the timetable of busses and so on. Travelling by bus / metro is possible when the person is able to read the destination and bus number. Sometimes it means counting the bus stops to get out at the right station. Walking on foot is possible for short distances.

Mobility seems to be a central issue for people with DS. Most interviewees say clearly that they wish to be more self-dependent in their mobility. They would like to go out on evenings alone or travel abroad alone.

Everyday activities like housework, preparing meals, shopping, cleaning the room / flat, washing the dishes, using the vacuum cleaner or washing machine is possible with assistance.

Most participants are using modern technologies such as mobile or smart phones, tablets, PCs. Looking at DVDs or the TV or playing games is one of the favourite leisure activities.

The mobility and the independence varies from case to case, thus some of the primary users travel independently on well-known routes, while others reach their destinations via assisted travelling or transport.

Handling money properly was a problem which occurred very often in the interviews.

A major difference to the results of the online survey with carers is that the people with DS often claim to manage things on their own while carers are more reluctant concerning the range of their abilities. Carers may both over- and underestimate the independent skills of a person with DS. But people with DS are likely to overestimate their competencies. They may not be aware of a monitoring by carers taking place. Support provided might be so subtle that they don't realize it. Some of them may want to emulate their peers and are therefore embarrassed by their lack of independence trying to cover this up.

Generally, more or less all interviews show clearly, that the wish to be more self-dependent and autonomous is very strong. Therefore offering a new technology which is of help in their daily life will be accepted willingly.

### 3.4 Interview guideline

#### Overall aims of the qualitative interviews

- Experiences in daily life in the areas: Education/Work, leisure time, socializing, mobility, wellbeing
- Experiences in using modern technology: What they like, don't like, use and would like to have

#### Criteria (soft) for participation:

- The interviewee should go to school / work / sheltered workshop / day activity center
- In each country 4 persons will be interviewed between 13 (depending on the level of development) and 20 years, 2 persons between 20-30 years, 2 persons older than 30 years; male / female balanced
- If feasible: uses and owns a smartphone, tablet, PC or mobile phone AND has it with him/her during the interview  
If considered needed the secondary user should complete the questionnaire before or in the beginning of the interview.  
If considered needed by the interviewer or wanted by the primary user, the secondary user should be present during the interview.

#### Recommendation:

- a) Before conducting the interviews
  - The information sheet and a questionnaire for the carer should be sent by mail in before. The carer should explain the information sheet to the interviewee in before
  - The printed out online-questionnaire should be completed by the carer (could also be while the interview)
  - The information sheet for the primary user should be sent to the primary user (if the primary user has an e-mail address) and the secondary user.
  - When meeting for the interview give oral information about POSEIDON and the interview.
  - Make sure the consent form are signed (both by the primary user and guardian if needed and when secondary users are completing the questionnaire by the secondary user).
- b) Conducting the interviews
  - The interview is arranged in three parts:
    - Part 1: Icebreaker (information not necessary, but important for the atmosphere)
    - Part 2: Experiences in managing daily life
    - Part 3: usage of specific technology (Tablet, Smartphone, PC, mobile phone - alternative)
  - Part 1 should be used as an icebreaker, establishing confidence and creating a good atmosphere for conversation
  - Part 2 contains the central topics of their daily life: How do they get from A to B, what are they doing at work/school/in their leisure time, how do they socialize

- Part 3 contains specific questions about modern technology (Tablet, Smartphone, PC, mobile – if feasible): How is it used, which features are used? Which do they like/dislike, find difficult/easy to use and why? What additional features should be included?
- The interview will be conducted (with the agreement of the interviewee / carer) using audio / video recording
- Before you prompt, please give the person a bit time to think about the question. Wait a while and guide with a prompt, if there is no answer

In (brackets) you find alternatives of initial questions, e.g. if you dont get an answer to that.

In [brackets] you find hints on how to proceed or behave. This is mainly part 3.

- The sequence of questions is flexible. The response mode of the interviewee is the most important point. It is good to repeat/sum up the answers trying to clarify what is meant.
- While talking about technology in part 3 please ask for a demonstration of the usage of the device; please try to make comments on the things you see or experience then (to catch these things on tape, if just audio-recorded)
- If possible please fill in the record sheet directly after the interview. The fresh impressions, experiences and observations should be documented.
- If the secondary user is present, make it clear that you want answers directly from the primary user. If you get no answer to a question, the secondary user can help you to ask in another way. If the secondary user gives an answer to a question it should be noted that this is given by the secondary user.

Don't forget:

Again a consent Form and Information sheet (just in case they lost it) for the primary user and another for the secondary user.

Audio- or video-recording device

## **Part 1: Icebreaker**

**What is your name?**

**How old are you?**

**Whom do you live with in this house?**

**Are you going to school / work?**

**Tell me about your day/weekend, what are you typically doing?**

Could be ANY question to get familiar with each other, if the person is unknown. Could also be a question about the environment, like «You have such a nice garden. Do you like to play outside? What do you play then, what is your favourite game.» Could be the T-Shirt, an obvious hobby, a pet... Just start a smalltalk.

## Part 2a: Education/work/day activity centre

### General

**What kind of school/work is this? What do you do there?** (alt. School: For example, is it an integrated kind of school? Work: What are your daily tasks there? Do you have specific tasks you do every day? Day centre: Do have regular activities there? Trips? Visiting things?)

**How do you remember what to bring to school/work/day activity centre?** (Are there some things you need to take with you regularly/every day? Who ensures that you bring these things? If done himself/herself: Do you just know, do you have a list, do you have a picture or another system?)

**If going to school: How do you know where to be for different lessons?** (Do you use a timetable and then know where to go? Is it written there where you should be for different lessons? Does somebody tell you? Do you follow a teacher/assistant or other pupils?)

**If going to school: how do you know your homework?** (Is your homework given day by day (or by week) on a sheet of paper? Is it given on a platform like Fronter or electronically in another way (like e-mail, transferred to your laptop or tablet by the teacher)? ) Does your teacher tell you and you write down the homework yourself on paper? Do you never have homework?)

### Mobility

**How do you go to school/work/day activity centre?** (Do you use a taxi, public transport, will your parents drive you... etc.?)

**Is this the way you prefer to go there?** If not: **Which way would you prefer?** (Would you prefer to go by bus/taxi/bike/walk with a friend....?)

A) If using *public transport*: **Are you going on your own or with company? Who joins you?**

- **How do you know when to leave for the bus/tram/taxi?** (Do you know it yourself? Does somebody remind you? Who? Do you use an alarm? Do you always have good time so you just go and wait until the bus/tram/tube comes?)
- **How do you know when the bus/tram/tube is coming?** (Do you look at an electronic information table at the station? Do you check the timetable and look at your watch? Do he/she know when the bus/tram/tube should come and check your watch? Do you ask somebody?)
- **How do you know which bus/tram/tube to take?** (Do you ask someone? Do you see it from the bus/tram/tube number? Do you see it from an electronic table?)
- **How do you pay for the bus/tube/tram?** (Do you have a monthly ticket? If so who, buys this ticket? If the primary user: do you use money or a credit/Visa card? Where do you buy the ticket? Do you pay per route? If so, do you pay with money or a card or your smartphone?)
- **How do you know where to get off the bus/tram/tube?** (Do you ask someone? Do you recognize things on the station? Do you count stops? Do you look at an electronic table in the bus/tram/tube saying the name of the stations?)

B) If using *taxi*: **Are you going by taxi alone? Does anybody accompany you? Who?**

- **Who has arranged the taxi drive/Did you call for the taxi yourself?** (Is your mom calling the taxi each day? Or is it something fixed/arranged, so it comes automatically?)

- **How do you pay for the taxi?** (Do you pay with money, a card, a coupon system or do you not pay?)
- **What do you do if the taxi does not come?** (Do you know an alternative way to go to school/work/day centre? Do you call someone familiar then? Do you call the taxi central?)

C) If driven by *parents*:

- **Who drives you?** (Is it your mom, dad...?)
- **Would you prefer to go on your own? If yes, how would you like to travel?** (For example, is there any public transport nearby you would like to use?)

D) If going by *bike/walking*: **Do you drive/walk alone? Does anybody accompanies you? Who?**

- **Do you know the route on your own?** (Or does somebody remind you, how to drive/walk? If alone: Did you practice it?)

**In general: Do you sometimes experience difficulties when travelling? If yes, what kind?** (Do you sometimes miss the bus/tram/tube? Did you experience that the taxi does not come? Did it happen, that your mother/father has no time to drive you to your friends home? Did you lost your way when walking/cycling? Etc.) If yes, what do you do then?

## Part 2b: Leisure Activities and Socializing

### General

**Do you have regular leisure activities?** (Do you go to any clubs every week? Do you do do regular sport activities?)

**Are there other things you love to do in your free time? What is it?** (Sports, cinema, bowling, drawing, listening to music...?) *If not clear: Is it outside home?*

**How do you contact friends, if you want to meet them?** (Do you write SMS, e-mail, use Facebook or call them?)

**How do you generally stay in touch with friends of yours when you do not see them?** (Do you stay in contact by writing SMS/E-Mail/Facebook messages/Calling [depends on answer before] with all of your friends?)

**Is this the best way? Would you have preferred another way of getting/staying in touch?** (Do you would try to write SMS/Facebook etc. instead?)

**How do you make new friends?** (Do you get to know people at school/work, that become your friends then? Or do you meet people at your clubs or sport arrangements?)

**Do you sometimes meet friends outside home? What are you doing then?** (Where do you go then? Do you have a special place you go to together?)

### Mobility

**When you meet your friends or go to your hobby: How do you travel there?** (Is this different from going to school/work/day activity centre?) **Is it always the same way you travel or does it depend**

**on the friend/meeting/hobby place?** (For example, do you have a friend you can walk to to visit him/her? Can you do the hobby at a place nearby?)

**Is this the way you prefer to go there?** If not: **Which way would you prefer?**

*If travelling the same way: Refer to the answers given above, if possible, instead of just repeating these questions below, e.g. «You said, you remember the bus number to catch the right one, when going to work. Does it also work like that when visiting a friend?»*

A) If using *public transport*: **Are you going on your own or with company? Who joins you?**

- **How do you know when the bus/tram/tube is coming?** (Does somebody remind you? Who? Do you use a clock that reminds you to go there in time?)
- **How do you know which bus/tram/tube to take?** (Do you ask someone? Do you see it from the bus/tram/tube number?)
- **How do you pay for the bus/tube/tram?** (Do you have a monthly ticket? Do you pay per route?)
- **How do you know where to get off the bus/tram/tube?** (Do you ask someone? Do you recognize things on the station?)

B) If using *taxi*: **Are you going by taxi alone? Does anybody accompanies you? Who?**

- **Who has arranged the taxi drive/Did you call for the taxi yourself?** (Is your mom calling the taxi each day? Or is it something fixed/arranged, so it comes automatically?)
- **Who pays for the taxi?**
- **What do you do if the taxi does not come?** (Do you know an alternative way to go to school/work/day center? Do you call someone familiar then?)

C) If driven by *parents*:

- **Who drives you?** (Is it your mom, dad...?)
- **Would you prefer to go on your own? If yes, how would you like to travel?** (For example, is there any public transport nearby you would like to use?)

D) If going by *bike/walking*: **Do you drive/walk alone? Does anybody accompanies you? Who?**

- **Do you know the route on your own?** (Or does somebody remind you, how to drive/walk? If alone: Did you practice it?)

**In general: Do you sometimes experience difficulties when travelling? If yes, what kind?** (Do you sometimes miss the bus/tram/tube? Did you experience that the taxi does not come? Did it happen, that your mother/father has no time to drive you to your friends home? Did you lost your way when walking/cycling? Etc.)

## Part 2c: Wellbeing

**Do other persons help you with things you would have preferred to be able to do yourself? If so; which things?** (Do you sometimes feel like you want to do a specific task just on your own? Which task could that be?)

**Is there other things you would have like to be able to do on your own?**

### Part 3: Technology

**START: I heard/see you own a tablet (smartphone/ PC/mobile – or other). Can you show that to me?**

*Priority: Touchscreen first! If both – tablet and smartphone – are used, ask for the one, the user prefers and go on with that technology. 3<sup>rd</sup> priority is the PC, last the mobile. We just discuss one of these technologies, not all.*

*Let you show the device, have a look at this together and just go through the different features – just let you show, what he/she does regularly with that technology, what the person is able to do, what the features he/she uses are about and **while** looking at this, ask the questions. It is enough to dig deeper for one or two specific (most used) features, not for all, which are used. If there is time left and if the person wants to talk about that, you can also go through more features. Up to you.*

*ALTERNATIVE: If there is none of these technologies in the household, take the favorite technology and discuss this.*

- **Which feature(s)/apps/programs do you like the most?** (Is there anything you use regularly?)
- **What can you do with that feature?** (if not already clear; What is that able to do? Is it for.... [just guess]...?)
- (When only asked before, if it is used often: **Do you like/is it fun using that feature?**)
- **You said you like using it – what do you like about that?** (Is it because you can do XY [refer to answer above] with it? Is it because it looks colored [use your imagination on WHAT could be attractive about that]?)
- **Do you sometimes have problems using it?** (Is it sometimes difficult to use it or do you find it easy to use?) **What problems were that?** [You can use YOUR experiences with that technology, too. Like “I sometimes have difficulties using that touchscreen/writing SMS/finding letters on the screen/do not know, how to switch it on etc. Do you sometimes feel the same?”]
- **Is there any feature in it you have really difficulties with using it?** (Is there some feature you need help with when using it?) **Which one is it, can you show me this feature? Can you tell me, what the problems you have with that are like?** (In which do you need help then when using it?)
- **Which other features are you using?** (Are there more than the one you just showed to me?)
- **Is there any feature in it you don't like? Why not?** (Is there something you do not use? Why not? Is it for example because you do not need the feature?)

*(If there is no feature they don't like or have problems with, you can ask for another feature they like. If there is more than one they have problems with, then go on with another one, which is problematic.)*

- **Is there any other feature you like to use/ you use regularly?** (AGAIN the questions above)
- **Would you like to have more/other features in it? Which features?** (What else should this Tablet/Smartphone/PC/Mobile be able to do? Games? Music? Notes? Timetables?)
- **What other device would you like to have and why?** (Is there anything your sibling/friend has you also want to own?)

### 3.4.1 Record Sheet

Interview Record
<p style="text-align: center;"><b>Interview information</b></p> <p><b>Name of Interviewer:</b> <b>Country:</b> <b>Date:</b> <b>Interview place:</b> <b>Type of recording:</b> <i>(video/audio/written notes)</i></p>
<p style="text-align: center;"><b>Part 1 Overall Information</b></p>
<p><b>Interview number (interviewee):</b> <b>Gender:</b> <b>Age:</b> <b>Living situation:</b> <i>(alone, with parents, cared living situation etc.)</i></p> <p><b>Profession of parents:</b></p> <p><b>Background:</b> <i>(this should include anything the interviewer considers relevant, communication needs, place of residence, carers, health issues, mobility)</i></p> <p><b>Observations:</b> <i>(this could include parts of the technology use, difficulties you observed; observations on the atmosphere and the condition of the interviewee; anything you noticed when doing the interview and think it is useful to know)</i></p>
<p><b>Icebreaker Information:</b> <i>(either typical day or any other information)</i></p>

Part 2 Daily Routine
<p><b>The purpose of this section is to discover the routine activities involved for this individual. The barriers to independence they face, the technology they use and the changes they would like to see for the future.</b> <i>(please refer to the detailed list of questions available in the guidelines to support your questioning)</i></p> <p><i>Write in the fields any information you get about these areas, including mobility, things they need to know/remember, how they proceed, what they are doing, difficulties they have, activities they have, what they would like to have changed in their lifes etc.</i></p> <p><b>So main questions you should keep in mind: How are things done? How are these things assessed? What is done? What could be different? When do problems occur? Who is involved?</b></p>
<p>Education/Work/Day activity:</p>