Towards Designing Mobile Apps for Independent Travel: Exploring Current Barriers and Opportunities for Supporting Young Adults with Down's Syndrome

Al Majed Khan

Computer & Information Sciences, University of Strathclyde, Glasgow, Scotland,
majed.khan@strath.ac.uk

Dr Mark D. Dunlop

Computer & Information Sciences, University of Strathclyde, Glasgow, Scotland,
mark@textentry.uk

Dr Marilyn Lennon

Computer & Information Sciences, University of Strathclyde, Glasgow, Scotland,
Marilyn.lennon@strath.ac.uk

Dr Mateusz Dubiel

Computer & Information Sciences, University of Strathclyde, Glasgow, Scotland,
mateusz.dubiel@strath.ac.uk

ABSTRACT

Performing daily independent activities can be a challenge for people with Down's Syndrome (DS). This paper investigates how to better support these activities with smart devices based on three cycles of a collaborative participatory action research (PAR) process. The first cycle involved semi-structured interviews (*n=4*) with parents and an online survey (*n=39*) with people with DS and their parents to explore barriers and opportunities for independent activities. This cycle highlighted that travelling independently was a common challenge among discussed barriers to independent activities for young adults with DS, an issue that smart devices have the potential to overcome. The second cycle involved seven focus group discussions (*n=20*) with parents (*n=13*) and young adults with DS (*n=7*) for gaining deeper insights into barriers to independent travel. We explored key barriers to independent travel and gathered design requirements for smartphone apps to overcome these barriers. In the third cycle, we designed a digital prototype based on participant recommendations and conducted seven focus group meetings (*n=19*) with caregivers (*n=12*) and individuals with DS (*n=7*). This final cycle reviewed the proposed digital prototype and also validated the key barriers found in the second cycle. Overall our studies confirmed that mobile technology can support people with DS in performing daily life activities that increase social inclusion. The studies resulted in identified barriers and requirements along with co-designed solutions for independent travel apps.

CCS CONCEPTS

• **Human-centered computing~Human computer interaction (HCI)** • Human-centered computing~Accessibility technologies • Human-centered computing~Participatory design • Human-centered computing~Smartphones

KEYWORDS

Down's Syndrome 1, Assistive Technology 2, Smartphones 3, Smartwatches 4, Support for Independent Living 5, Navigation 6, Map design 7.

1 Introduction

Down's Syndrome is a relatively common genetic condition caused by an extra copy of chromosome 21. The Worldwide occurrence of DS is approximately 1 in 1,000 with about 6,000 children born each year with DS [4]. DS affects the development ability of both children and adults [76, 78], typically suppressing their cognitive and physical functional ability [3]. The cognitive and physical features of DS can be wide-ranging but often manifest themselves in some form of communication and learning difficulty along with characteristic physical features. Learning difficulties can be caused by linguistic, cognitive and management effects of DS, and can be compounded by sensory and motor skill effects [19]. As a result of these symptoms, performing daily activities can be challenging and frequently require assistance by caregivers, some of which might be easily provided by modern technology. Independent activities can range from their personal life to leisure and work. While the range of activities that require support is individual and varied, some particularly common issues for people with DS are planning, self-managing, remembering, and sustaining continuous attention to tasks [55]. Parents and caregivers typically follow a traditional process to teach and train people with DS to perform daily independent activities that involves repeating a task/activity multiple times and monitoring the performance to ensure the goal is achieved [36]. A list of images/texts, textual and oral instructions are the main instructions that are provided by the caregiver during this traditional process. This instruction-based support training process requires extra time and money to provide and presents some challenges to people with DS who often find difficulties with interpreting instructions and information when performing multiple tasks/activities at the same time. These issues inspired us to study how to provide technological support for performing daily independent activities for people with cognitive disabilities, such as people living with DS.

The main purpose of the studies reported here is to investigate the potential of smartphone and smartwatch assistance to enhance the daily living experiences of young adults with DS, particularly focusing on overcoming barriers to independent activities using smart devices. Through our investigation, we aim to answer the following two questions:

RQ1. What are the main barriers to independent activities for young adults with Down’s Syndrome?
RQ2. How could smart devices (smartphones, smartwatches or smart-clothing) and apps help young adults with Down’s Syndrome to perform independent activities?

In section 2, we present a brief overview of the background with the aim to determine the scope of the study. In section 3, we describe the process of participatory action research that was adopted throughout the study. In section 4, we describe a study that identified key barriers to independent activities for people living with DS and the potential of smart devices to overcome these barriers. Later in section 5, we describe the co-design process and prototype generation toward supporting barriers to independent travel and potential to support this activity. We also present a summary of the design requirements and low-fidelity sketches to prototype an assistive smartphone app. In section 6, we describe a study that evaluated hi-fidelity design validation of proposed digital prototype and bridge the design gaps and requirements to support independent travel. In section 7, we present the implications, limitations of the study and future work, with our conclusion in section 8.

2 Background

We focus on those factors that affect everyday activities and potential technologies that are available to provide support in daily activities of living for an individual with DS.

2.1 Impact of Down’s Syndrome

Cognitive disabilities [37] are common among people with DS. In general, a young adult with DS is better at capturing and preserving visual (visuospatial) short-term memory compared to text and verbal (morphosyntax) short-term memory when performing joint tasks which require low processing levels [19, 33, 47, 55]. However, impairments of visual (visuospatial) short-term memory are also prevalent when joint tasks are increased among young adults with DS [48, 73]. Similarly, people with DS face intellectual development problems that create difficulties in thinking and learning, which results in a lesser capacity of judgment ability; undesirable behaviour, such as a tendency to be resistant and unfriendly [35]; delay in language learning; as well as a lower capacity for attention and reaction [16]. Likewise, working memory, planning, set-shifting, organising, inhibition and emotional regulations are a complex combination of executive functions in the cognitive skill that all can be affected due to DS [17, 39, 60]. The deficit of executive functions is not uncommon for people with DS which create obstacles with multitasking [46, 52, 63]. These issues often lead to depression, confusion, concern and forgetfulness among people with DS [11, 26]. The presence of these symptoms in a person with DS often prevents them from performing daily independent activities. Although there is no cure for DS, given that the condition is caused by a chromosomal abnormality [72], treatment can be provided with other methods by taking special care and providing support. As, cognitive disabilities are now better understood and quality of care, support and treatment have improved, the life expectancy and opportunities to achieve independent living have recently increased substantially for people with DS [30]. Therefore, people with DS require special care at home and outside as they are likely to have a variety of symptoms including unfamiliar behaviour, less control with cognitive function and the high percentage of illness [66]. Consequently, cognitive disorders, intellectual problems and deficit in executive functions lead an individual with DS to depend on a caregiver for help in reminding, completing complex tasks and personal daily activities.

2.2 Assistive Technology

Assistive devices and smart apps can aid people with DS in basic learning and performing daily activities [75] However, implementing such assistive devices and apps according to users needs is a challenging issue. [45, 59]. Dawe [25] has identified the assistive technology devices (AT) into the following categories: communication; writing; reading; prompting; scheduling and educational. De Joode et al. [43] listed examples of AT devices including Personal Digital Assistants (PDA), smartphones, alarm watches, smartwatches, iPads, tablet, voice recorders and pagers. According to Reis and Almeida [62], people with DS often find it difficult to gain good literacy skills, which gives room for technology to aid them with the use of mobile devices such as tablets, laptops, and smartphones suggested to support digital learning through apps for those with DS. Assistive apps can help with the recognition and improvement of learning skills [41] and can guide users through each step suggesting how to finish the task and how to recover from a mistake or hindrance in a step [23]. Currently, most of the AT studies (e.g. mobile phone, tablets and iPads) are used to increase the learning ability amongst students with DS by improving cognitive skills [33]. For instance, Disability Credit Canada suggested ten best AT for people with DS, most of them are used to provide educational support except the smartphone [1]. Dibia et al. considered that both smartphones and smartwatches have strong potential [27] to assist daily independent activities of people with DS, as they have functionalities including GPS, gyroscope, accelerometer, magnetometer, proximity sensor and barometer sensors which can be used in monitoring health condition and tracking locations. Therefore, assistive technology like smartphones and smartwatch can help individuals with DS to support their weaknesses and assist them to perform daily activities according to needs without distress.

2.3 Support for Activities of Daily Living

Remembering general activities from graded memory and performing basic daily routines, such as making meals, housekeeping, and grocery shopping [3], can turn out to be quite complex for people with DS. Furthermore, it is often challenging to improve an individual's performance solely through technology literacy [19]. Nevertheless, based on the results of the study, assistive technology offers a promise to aid individuals with cognitive limitations, and support them with basic common cognitive skills, e.g. organising daily planning, managing schedules/tasks, self-supporting and problem-solving [55]. Lazar et al. [51] stated that the use of computer and smart devices to perform daily activities by people living with DS can be improved through training to use these skills in their workplace. Authors observed 10 users with DS and found that they were capable of using different types of applications both on the computer and on mobile phones for education, communication and entertainment activities. According to Dawe and LoPresti et al. [25, 55], technology can make a significant difference in the lives of those facing difficulty in organising their daily routines and managing agendas. They suggest that it is possible to make use of external prompting systems to aid people with cognitive limitations. This can take place by helping one to remember the right time to undertake an activity, or through providing prompts regarding the stages of task completion [19, 28].

2.4 Self-navigation and Access to Public Transport

Independent travelling when using public transport presents new challenges for users who require support and assistance from smartphone and smartwatch devices [2, 64]. Although several studies support travel on public transport [47, 67], this issue remains a significant barrier to people with cognitive and intellectual disability [24, 68]. Difficulties in wayfinding limit the employability of those with DS, particularly for those who work a considerable distance from home [36]. Common characteristics of reduced working memory ability, attention disorder, poor literacy and decision-making skill can considerably hamper tasks such as managing travel timetables, leading to restrictive public travel [14, 38]. Augusto et al. [7] suggest that it is possible to use sensor-based technology to guide navigation. Davies et al. [24] expressed transportation inaccessibility as a barrier that affects employment and all independent activities of an individual with cognitive and intellectual disability, thus isolating them from the community. The results of their experiment with a GPS device revealed that 8 out of 11 participants completed one journey successfully. However, the use of generic bus images on the PDA screen to identify the correct bus from the bus colour (green and yellow shuttle bus) might confuse participants when there is more than one bus at a time. Sposaro et al. [67] introduced a navigational app on the Android platform for people with dementia called iWander. Google maps navigation API and GPS sensors were used to provide remote monitoring service to their caregivers. They also used Bayesian network (a probabilistic graphical model) techniques to evaluate collected data and to detect if the patient was wandering before taking appropriate actions e.g. sending alerts, directing to home, calling a caregiver or the emergency services. The authors raised concerns about accuracy issues with GPS and some of the extra features (e.g. calling 911 and alert protocol). Sitbon and Farhin [65] reviewed the literature and assembled the initial design criteria and prototype for a GPS based mobile app for their co-design exploration with several functions e.g. alert user about the journey, notify users about next bus arrival, remaining stops, time and walking navigation between home/target destination and the bus stop. Three participants with intellectual inability were observed during the co-design process. They observed that participants who used both paper and digital prototypes reacted and commented on the features of the developed prototype and even suggested some changes and modifications. Likewise, Kramer et al. [47] introduced a navigational app in their POSEIDON project for people with DS to support independent travel without distress and increase social inclusion. Six individuals with DS travelled a 2 km-long route using a navigation app for the experiment. Though the overall result was positive, the concerning issues were difficulties to interpret the turning points while using the map for navigation on their phone and too much attention being focused on the mobile screen which led to a reduced concentration on the road.

2.5 Outdoor Safety and Voice Assistants

Safety is a concerning issue to parents and caregivers with lack of safety being identified as the main barrier to independent travel for people with cognitive disabilities. For example, Vukovic et al. [74] presented a smartwatch application with a location-based reminder and safety zone concept for monitoring and tracking children with complex communication needs. The designed application's feature was to track current locations and defined safety zones of smartwatch users and notify both users and their caregiver when they are about to leave the predefined safety zone. The application was evaluated through real-life test cases. Although the application successfully alerted caregivers when the user tried to leave the predefined zone, primary concerns raised were poor GPS service and short battery life.

Speech difficulties are one of the key factors that affect an individual with DS's ability to communicate with others and eventually impact the free movement in local settings or around a city [15, 36]. The advancement of voice assistance revealed the possibility of using such technology to support people with cognitive disabilities [31, 70, 77]. Carroll et al. [18] designed a speech-based prototype of a context-aware assistive application called Robin on Amazon's Alexa platform to support routing activities by prompt audio for people with dementia. The user experiences were positive except for issues with remembering the activation word to continue the conversation with Robin by participants. Similarly, Balasuriya et al. [9] observed 18 participants with intellectual disability and understood the user experiences of Voice-Activated Interface. Participants were asked to perform four different activities (search images, voice query, managing calendar and finding direction) using Siri and Google voice assistants. The positive impact of using voice assistances was noticeable - as 55% of users completed all tasks successfully and the rest were able to complete three tasks. Furthermore, those voice assistants that are running on their own domain can be used on third-party applications by using the provided framework (e.g. Alexa Skills Kit framework). Consequently, voice assistants can be eventually enabled in the assistive app. Tarakji et al. [70] proposed a prototype of the framework to create Voice User Interfaces (VUIs) on top of existing applications to enable voice assistance with mobile applications such as YouTube, WhatsApp and LinkedIn.

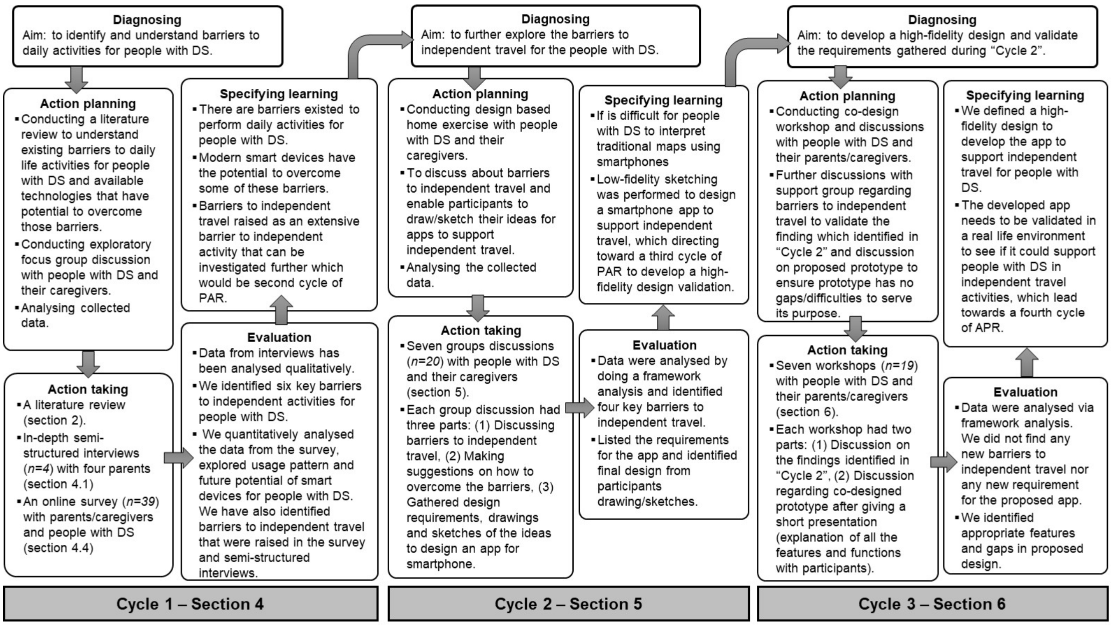
Many studies have been carried out that involved people with cognitive disability to evaluate how to increase their independence. However, few studies focused on participants with DS and considerable parts of such studies have not been conducted in the context of the independent activities, focusing on the individuals with DS's own goals and needs. Currently, there is a significant gap between what we know about effective interventions of smart devices/apps and what technologies are currently used by people with cognitive disabilities including those living with DS to support their daily living activities. Consequently, it makes it difficult to assess how smartphone and smartwatch devices can provide support to people with DS in achieving their expected goals in real-life settings. Further studies which focus on the use of technology and segregating them into different types of cognitive disabilities (as attempted by Dawe [25]) would be beneficial especially if they incorporate not only the individual having DS but other stakeholders as well. Although Augusto [7] proposed an advanced environment building system through the User-Centred Software Development Process (UC-SDP), there is still a dearth of research and tools available in the field of software development routines for constructing and employing intelligent conditions [6]. There is also a need for further nuanced research that focuses on a specific age group, especially the young adults, to assess their employability and condition needs further, in order to incorporate this information into a system design.

3 Methodology: Participatory Action Research

Many of the studies reviewed focused only on people with cognitive disabilities rather than focusing on the interest of a particular group of people, for instance, people with DS, Autism or dementia. For our study, we focused on people with DS. In order to explore their own needs and experiences of technology usage and adoption, we require a methodology that is best suited for this demographic. We conducted participatory action research (PAR) [10, 12] throughout the design processes of the study. PAR ensured the effective involvement of participants throughout the study and enabled us to ensure that we were working with the interest of the community (i.e. people with DS and their caregivers). The PAR cycles were followed in this study, namely identifying the problems (diagnosing), action planning (solution planning), action-taking (implementation of solution), evaluation/observation and specifying learning (reflection) [22, 58]. Furthermore, effective participation of the community from active stakeholders during each cyclical process allowed for the active involvement of people to use their own knowledge and experience, that eventually outlined the design and research agenda [12].

Empowering for participation: One of the goals of our research was to ensure the best involvement of participants with DS and their caregiver in the design and research process during each cycle of every study. We focused on providing freedom and confidence for empowering people with DS and their caregivers and actively involving them in the design and research process by allowing them to articulate their needs, suggestions and solutions. Our research was conducted in three main PAR cycles (illustrated in Figure 1). The cycles are described in the following sections: Cycle 1: section 4, Cycle 2: section 5 and Cycle 3: section 6.

All studies were conducted under institutional ethical approval. All studies are reported anonymously as agreed with participants. Where names are quoted for ease of reporting, these have been changed to preserve anonymity.



Diagnosing
Aim: to identify and understand barriers to daily activities for people with DS.

Action planning
- Conducting a literature review to understand existing barriers to daily life activities for people with DS and available technologies that have potential to overcome those barriers.
- Conducting exploratory focus group discussion with people with DS and their caregivers.
- Analysing collected data.

Action taking
- A literature review (section 2).
- In-depth semi-structured interviews (*n=4*) with four parents (section 4.1)
- An online survey (*n=39*) with parents/caregivers and people with DS (section 4.4)

Evaluation
- Data from interviews has been analysed qualitatively.
- We identified six key barriers to independent activities for people with DS.
- We quantitatively analysed the data from the survey, explored usage pattern and future potential of smart devices for people with DS. We have also identified barriers to independent travel that were raised in the survey and semi-structured interviews.

Specifying learning
- There are barriers existed to perform daily activities for people with DS.
- Modern smart devices have the potential to overcome some of these barriers.
- Barriers to independent travel raised as an extensive barrier to independent activity that can be investigated further which would be second cycle of PAR.

Diagnosing
Aim: to further explore the barriers to independent travel for the people with DS.

Action planning
- Conducting design based home exercise with people with DS and their caregivers.
- To discuss about barriers to independent travel and enable participants to draw/sketch their ideas for apps to support independent travel.
- Analysing the collected data.

Action taking
- Seven groups discussions (*n=20*) with people with DS and their caregivers (section 5).
- Each group discussion had three parts: (1) Discussing barriers to independent travel, (2) Making suggestions on how to overcome the barriers, (3) Gathered design requirements, drawings and sketches of the ideas to design an app for smartphone.

Evaluation
- Data were analysed by doing a framework analysis and identified four key barriers to independent travel.
- Listed the requirements for the app and identified final design from participants drawing/sketches.

Specifying learning
- If is difficult for people with DS to interpret traditional maps using smartphones
- Low-fidelity sketching was performed to design a smartphone app to support independent travel, which directing toward a third cycle of PAR to develop a high-fidelity design validation.

Diagnosing
Aim: to develop a high-fidelity design and validate the requirements gathered during "Cycle 2".

Action planning
- Conducting co-design workshop and discussions with people with DS and their parents/caregivers.
- Further discussions with support group regarding barriers to independent travel to validate the finding which identified in "Cycle 2" and discussion on proposed prototype to ensure prototype has no gaps/difficulties to serve its purpose.

Action taking
- Seven workshops (*n=19*) with people with DS and their parents/caregivers (section 6).
- Each workshop had two parts: (1) Discussion on the findings identified in "Cycle 2", (2) Discussion regarding co-designed prototype after giving a short presentation (explanation of all the features and functions with participants).

Evaluation
- Data were analysed via framework analysis. We did not find any new barriers to independent travel nor any new requirement for the proposed app.
- We identified appropriate features and gaps in proposed design.

Specifying learning
- We defined a high-fidelity design to develop the app to support independent travel for people with DS.
- The developed app needs to be validated in a real life environment to see if it could support people with DS in independent travel activities, which lead towards a fourth cycle of APR.

Figure 1: PAR cycle use in this study to inspire research participation of people with DS and their caregivers. Cycle 1: were initial starting points to explore barriers to independent activities for people with DS, cycle 2: was to explore barrier to independent travel and cycle 3: was finalised the design needs and validated requirements for the app. The phases of the PAR process adapted from Gerald Susman [71].

4 Cycle 1: Identifying Current Barriers to Independent Activities and the Potential of Smart Devices for People with Down's Syndrome: an Exploratory Cycle.

4.1 Exploring Current Barriers of Daily Living for People with DS Through Interviews

In this exploratory study, our primary purpose was to understand the current challenges and impediments to perform daily life activities for people with DS. Additionally, we were interested in how people with DS and their caregivers perceive mobile and wearable technologies and how they could help with performing those activities. In the process of the participatory design, caregivers are one of the main sources of information [42] as they regularly provide support to people with cognitive disability in performing daily life activities. We involved people with DS during the next cycles of the study to ensure their voices are heard as recommended by the participatory design approach.

4.2 Interviews Method

We conducted semi-structured interviews with four parents of young adults with DS (see Table 1). Participants were recruited through Down's Syndrome Scotland (a non-profit charity organisation). Initially, we attempted to conduct requirements capture through focus groups with parents and caregivers. However, it was difficult to arrange a suitable time for all participants to attend the focus group at the same time as parents and caregivers were simply too busy with their daily life commitments, therefore, making individual appointments instead was more convenient.

4.2.1 Procedure

Two interviews took place in a city-centre university office and two via telephone at the participants' request. A participant information form about the interview questions and procedures were given to parents before the interviews took place. The first joint interview with two participants (see Table 1, 0.1 and 0.2) was conducted at a university office by the first and second authors and took 55 minutes. The other two interviews (see Table 1, 0.3 and 0.4) were conducted via telephone and took 25-30 minutes each. All interviews contained the same questions and a short presentation of smart technologies (for phone interviews the presentation and an online video link were given to participants prior to the interviews). We asked two main questions, Q1. what are the main barriers to independent activities in Glasgow for a young adult with Down's syndrome? Q2. How could smart devices (smartphones, smartwatches or smart-clothing) and apps help people with DS to perform independent activities?

Table 1: Caregivers Demographics

Interview IDs	Caregivers' IDs	Caregivers Gender	People with DS Gender
1	0.1, 0.2	F, F	M, M
2	0.3	F	M
3	0.4	F	F

4.2.2 Participants

Participants were aged between 51-54 years and were all mothers of individuals with DS who have provided full-time care support to people with DS for more than 15 years. The average age of young adults with DS was 22.5 years with mild cognitive disabilities.

4.2.3 Data analysis

All interviews were audio-recorded, transcribed by a third party then qualitatively analysed using thematic analysis [15]. This process involved familiarising with the interviews' data, searching and coding the text to identify themes within the data, and then reviewing and confirming final themes. Data were coded manually by the first author. Notes, memos and initial categories were created using the first interview's data, followed by the second and third interview's data. Once completed, all related codes were then condensed into single categories by reassembling and recognised these categories to form tentative themes in terms of their properties and dimensions. These tentative themes were then reviewed and ordered appropriately to confirm final themes. Similarly, the fourth author reviewed the interview transcripts, independently coded them to identify themes and then met to agree on final themes. The differences between the two coders were on the first two themes. The first coder resolved this by creating one theme called "care supports" which then split into two separate themes as "personal security and safety" and "communication" (see Figure 2) after discussions with the second coder (fourth author). Later, these themes were discussed with first, second and fourth author together and confirmed.

4.3 Interview Results

We identified six key barriers to independent living activities (Figure 2); each of those is discussed briefly along with supporting quotes from caregivers listed in Table 1. Caregivers are referred to as "C" with their ID to quotes.

4.3.1 Security and safety:

Security and safety in both indoor and outdoor conditions were one of the main barriers for people with DS. All parents expressed their desire that their sons/daughters be able to go outdoors on their own. However, parents raised the issues of lack of security and safety. C0.1 stated concern about the vulnerability of her son that caused fear about the safety of the outdoor condition as she always has to be with her son when her son meets his friends in the town centre. Similarly, C0.3 expressed her desire that as a mother she wants her son to be independent, to be able to travel alone to the town centre for shopping. However, she also raised her concerns about the vulnerability of her son which leads her to worry about his security and safety outdoors. Furthermore, people with DS are often not considered safe to do certain activities at home without supervision from parents, as they sometimes have difficulties understanding the unsafe activities and are unable to recognize hazardous situations. For example, C0.2 raised concern about the lack of understanding of the hazardous activity in the kitchen.

> C0.3: "*Because as a parent, I very much want him to be out and about. I want him to be as independent as possible. I certainly want him to be safe and secure, but there are situations in… City Centre that I would be concerned about.*"

> C0.2: "*There was one time I had jumped in the shower, I came out and Bob had the frying pan on full, so although he can do things he thought he would do something different but would have no understanding of how hot, how high or how dangerous… I think with his little sandwich making and toast making, that's absolutely fine. But, there wouldn't be the ability to understand danger and understand heat, just anything that hadn't been taught, he wouldn't get.*"

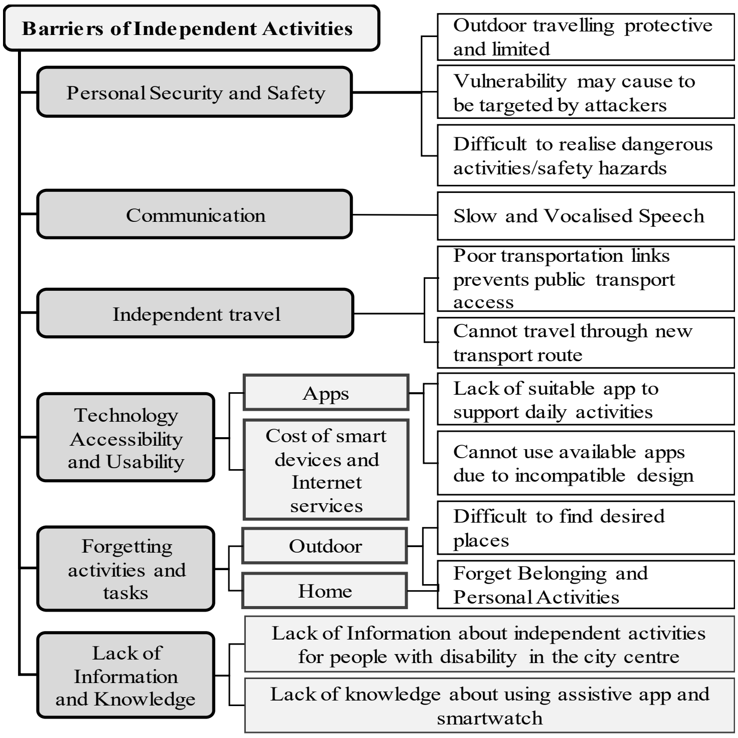


Figure 2: Categorisation of barriers to independent activities.

4.3.2 Communication:

All parents specified that poor communication ability when outdoors was also a barrier to performing independent activities for people with DS. C0.1, C0.2, and C0.3 stated that their sons/daughters have speech difficulties and are unable to communicate successfully with someone new. Similarly, all parents stated that phone calls and text messages were the main ways to keep in contact with each other when the individual with DS was outside or alone at home. The main purpose of communicating was to ensure safety and check their location when going to school or way back home.

> C0.3: "*He speaks. Sometimes not fully clearly, so it would maybe take you a bit of time to tune into him. But, he is verbal and he vocalizes.*"

> C0.4: "*I always call her [my son] or she will call me, you know, just to make sure she arrived at school safely"*

Likewise, failure of communication can cause serious concern to both caregivers and people with DS when neither of them are able to communicate with each other. Due to concern of communication failure parents stated that this leads to limits on independent activities.

4.3.3 Independent travel:

All participants expressed the desire that their sons/daughters become independent traveller and that they believe that increased independent travel would make significant changes to their son'/daughters' daily life. However, participants raised concerns about vulnerability in remembering and decision making, which were perceived barriers to independent travel for their sons/daughters. A strong concern raised by all participants was that their sons/daughters are only able to travel through known and established routes. C0.4 stated her daughter was not able to follow unknown routes except between home and school.

> C0.4: "*She can't travel independently, no. She can't find a new route, even incredibly easy. She can't do that on her own. She's very reluctant ..."*

> C0.3: "*Follow transport road is a real difficulty. There is somebody needs to help to get into the correct bus and on the way coming home he does one independent journey at the moment, it's only one journey and way coming home, because we have to cross a very busy main road we actually have somebody meet him on there he gets off to help him in crossing the road and gets into correct bus.*"

Consequently, self-travelling was reported to be quite challenging through new routes with public transport. All participants showed high concern when more than one form of transit is required while travelling by bus or train. C0.3 stated that travelling by bus with many transits was challenging for her son.

4.3.4 Technology accessibility and usability:

The parents specified that lack of suitable apps and cost of both smart devices and internet/mobile-data services restricts potential mobile support for daily independent activities. C0.4 expressed her concern that there were no suitable apps she found that specifically designed to aid her daughter's in daily activities. C0.4 also used a tracking app to know her daughter's location but even after practice, her daughter had difficulties due to the poor design quality of the app. Similarly, C0.1 tried a GPS location tracking app for her son, but faced many technical hitches e.g. updating location information was not quick enough and drained the smartphone's battery while using GPS service. C0.1 had also tried an AAC app to teach communication but found that it was difficult to use for her son due to low sound quality and poor interface design.

> C0.4: "*That's where mobile technology appears. We've got Life360 [tracking app], which means that she takes her phone and we're able to follow progress on the iPhone, so we can see where she is at. But, from her [her daughter] point of view, she got problems to use it, as it appears with lots of information together.*"

Parents also reported that motor skills could be a barrier to accessing smart devices. C0.3 stated her concern that the screen size of devices were too small as were the size of the buttons/tabs of any app. Parents sometimes put restriction on to access smart devices because of the high cost of the devices, apps and internet services. C0.3 and C0.4 stated the cost of devices and internet services as barriers to technology access.

> C0.3: "*The only thing I would say is manual dexterity. Particularly for people with Down's Syndrome, their fingers tend to be a bit podgier. Manual dexterity, particularly fine motor control,*

> *can be an issue. So, if it's very, very small taps on the smartwatch, that can actually be a barrier to them successfully managing to use the technology.*"
>
> C0.4: "*We are quite wary of expanding too much of her use of a phone because then she's going to use a lot of data. In that respect, we've not allowed her to search the internet on her phone because we don't want her not realizing she's not in a Wi-Fi area and then starting using data left, right and center and therefore costing an awful lot of money*" (most young people in this study were using pay-as-you-go packages with limited included data and high costs for extra data).

4.3.5 Forgetting activities or tasks:

Participants reported that forgetting activities and managing particular tasks as key barriers to independent activity. C0.3 stated that forgetting about belongings was not uncommon for her son. Furthermore, doing something that involved multiple steps was not possible for her son on his own. Likewise, C0.2 reported that her son has the issue of remembering to perform any particular activity with multiple tasks e.g. in baking or cooking something with multiple steps.

> C0.3: *"Probably the big issue is personal belongings. Remembering to take the right things, not leaving things. He regularly loses his wallet and leaves things on buses*". "*Yes. ... that's something we very much encourage in him in terms of his independent living. To be able to put on his own washing, ... to be able to cook his dinner. But there is usually somebody there to support him as he is doing that. May need to remind him of the steps that he following*"
>
> C0.2: "*But, in the kitchen, that's probably as much as he'd do, make a sandwich, he would just do it from beginning to end. Whether that's because it's quite a short spell, and because each step is quite short, I'm not sure, but he would stay focused on that. But cooking or baking something like a cake, he cannot stay focused on*"

4.3.6 Lack of information and knowledge:

Gaps in knowledge and information were found to be a barrier to independent activity as all participants reported a lack of knowledge using modern smart devices/apps that are available on the market. All of them stated that they do not know much about assistive apps and smartwatch usage, and they were not sure how such devices could support a person with DS. All participants except C0.4 mentioned that they cannot find information about any independent activities that are available in Glasgow city centre for people with disabilities. C0.2 expressed her lack of knowledge about activities in Glasgow that are accessible for her son. Similarly, C0.3 mentioned that there is a lack of resources for her son in the city centre.

> C0.3: "*I would say, are lack of resources. Whether those resources are physical space, or places to go where people would be supported, or even financial resources, or clubs. There is particularly a distinct lack of social clubs for people with disabilities.*"
>
> C0.2: "*At the moment we don't know of any activities in Glasgow that he would go to. A lack of knowledge of activities that are in Glasgow, I suppose, would be something because we don't know or have any support to take him to some. Him being able to access what's available to see if it's something we'd like to… To know what's out there. I think it's lack of knowledge and how to access.*"

4.4 Understanding the Potential of Smart Devices to Support Independent Activities Through an Online Survey

To balance the detailed focussed interviews, we also conducted an online survey to explore the current usage of smart devices and apps by people with DS and the activities that are supported by smart devices and apps.

4.5 Survey Method

The online study took place in the Scotland region. We distributed the online survey to young adults with DS (mild cognitive disability) and their parents/caregivers through the mailing list of Down's Syndrome Scotland (a charitable company).

4.5.1 Survey design

A page with an introduction and consent form were included at the beginning of the survey. There was no restriction applied for questions to be answered so that participants could skip. The survey questions were developed based on the literature review and the questions categorised in two sub-sections. First sub-section (see Figure 3) for people with DS asking questions about the type of devices and apps, also the purpose of those devices/app usages. Furthermore, parents/caregivers were requested to help them to understand and answer questions. Second sub-section (see Figure 4) for parents/caregivers asking their views on the potential of smart devices and technology to support independent activities for people with DS. The survey was distributed using Qualtrics [32] and included a combination of multiple-choice questions (with only one/many options to be checked), Likert scales and close-ended questions (each multiple-choice questions included with a text box as other option). The origin of the respondents was not collected to maintain anonymous participation.

4.5.2 Data analysis

Statistical analysis conducted for the descriptive results of the study data, e.g. population, activities, devices. A cross-tabulations were reported to illustrate the number of responses for each used item. Also, to illustrate data from the 'other' option (each multiple-choice questions included with a text box as other option) that were collected as words and phrases which analysed by conducting a content analysis of each response and grouped accordingly [42]. Consequently, a numerical analysis was conducted on second sub-section questions (see Figure 4) for descriptive results.

4.6 Survey Results

4.6.1 Participants

A total of 39 caregivers responded to this survey, 32 were family members (mostly parents) and 3 were clinicians. There were 2 caregivers from charity organizations, 1 from the education centre and 1 from public health service. All caregivers provided support to at least one individual with DS and were from Scotland: 28 caregivers provided support in the home setting for more than 15 years while other caregivers had provided support for between 0 and 2 years. 27 of the caregivers (mostly parents) provided support to one individual; two professional caregivers supported less than 10 individuals and one clinician more than 10 individuals every year. About half of the responders (44%) supported people with DS aged between 21-30 years, 24% between 31-40 years, 24% between 10-20 years, 4% between 41-50 years and 4% less than 9 years old.

4.6.2 Smart devices usage

It is important to understand usage patterns and current levels of technological support in order to know what types of smart technologies and devices are currently being used by people with DS in their daily life activities. Figure 3 illustrates the result of the survey in which young adults with DS were asked about their regular use of smart devices that are currently being used to support daily living activities. We found iPad/tablet as the most frequently used smart device followed by smartphones. Three responses included other devices (radio and camera). Additionally, only three responses (out of fifty-eight) responses counted on the usage of Augmentative and Alternative Communication (AAC) technologies to reduce verbal communication difficulties.

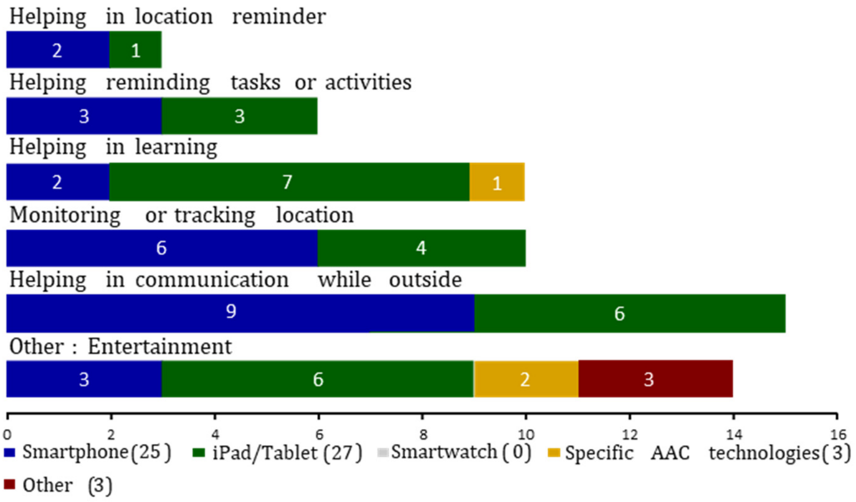


Figure 3: Usage of smart devices and supported activities with smart devices by people with DS. Note: Some of the participants reported using multiple devices; hence the 'total responses count' 56 and a total of 39 participants counted.

Since iPad/tablet and smartphones are most popular smart devices, it can be observed that the vast majority of young adults with DS used some kind of smart device to support their daily life activities, enabling their use to support daily life activities of people with DS.

4.6.3 Tasks and activities supported with smart devices

To gain a better understanding of device usage, we also asked about what purposes these devices were used for. Figure 3 also shows the activities supported using those smart devices by individuals with DS.

The result indicated that to 'retain communication with parents, caregivers and family members' was one of the main essential activities for people with DS while in outdoor condition (15 responses), a topic also raised in the earlier study (section 4.3.2). The activity of 'location reminder' (3 responses) and 'tasks/activities reminder' (6 responses) was quite the opposite with low responses, despite these activities were being identified as relatively important to live independently according to literature. Subsequently, 'activities of learning' (10 responses) and 'monitoring/tracking location' (10 responses) were both found to be equally needed as the need for communication with users with DS was assisted by smart devices. Nevertheless, other activities (e.g. listening music, watching films, looks for information through the internet and use of apps to motivate communication) that are not directly linked with independent activities were also raised (14 responses). We confirmed that users with DS operate many different types of applications (e.g. CBeebies, YouTube, Hangout, keep safe Scotland app, Spotify, Picture Exchange Communication System etc.) and smart devices. Overall, this finding indicates that the main context of smart devices usage was supported in outdoor activities.

Parents, caregivers and family members were asked to provide their views on those three important independent activities (Figure 4) where smart devices and apps have the potential to provide assistive support to user with DS.

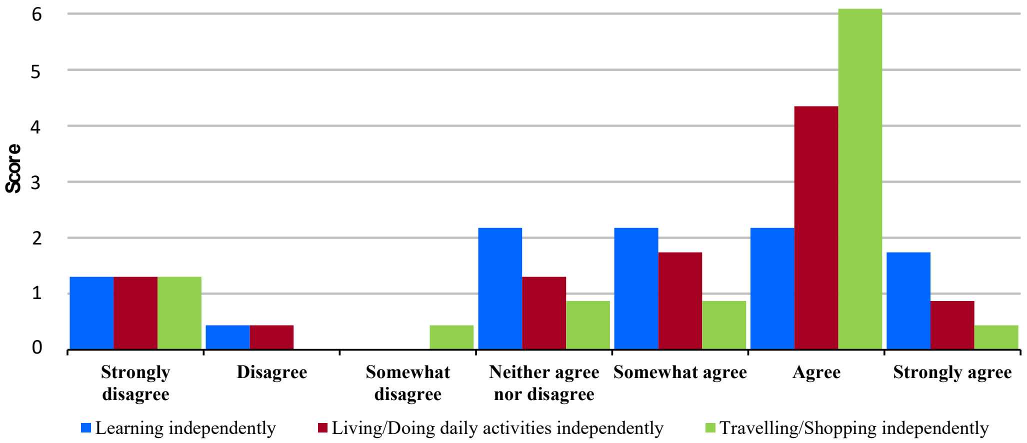


Figure 4: parents/caregivers agreement of independent activities on 7 points Likert scale. A total of 21 participants counted. Learning independently: Self-prompting studies and communication studies. Living/Doing daily activities independently: cooking/baking and washing up own clothes. Travelling/Shopping independently: self-navigating with or without using public transport.

"Learning independently" (*Median=5, Standard deviation=1.93*), "Living/Doing daily activities independently" (*M=6, DS=1.95*) and "Travelling/Shopping independently" (*M=6, SD=1.88*). These three activities did not differ from each other meaningfully. Most common was "Agree" (=6) same as "*Range*" in all three activities. The result indicated that the level of agreement was satisfactory, and these three activities were equally important for people with DS.

4.7 Discussion Cycle 1 – Survey and Interviews

We identified six key barriers that are common and affect the daily life of individuals with DS: (1) safe use of mobile devices and travel safety concerns, (2) communication difficulties, (3) inability for self-navigation and access to public transport (e.g. changing buses), (4) finding suitable technology that can support independent activities (5) difficulties for remembering tasks/activities, (6) lack knowledge and experiences about the current advancement of smart devices and technology. All these barriers are discussed briefly.

The issues of safe use of mobile devices and concerns about travel safety were identified in previous research by Dawe and Vukovic et al. [25, 74]. Similarly, communication difficulties due to speech intelligibility problems were identified in previous literature, i.e. Balasuriya et al., Carroll et al., Chang et al. and Tarakji et al. [9, 18, 19, 70]. Likewise, the need for staying in touch with caregivers via phone calls were described by Carroll et al. Dawe et al., Lazar et al. and Lazar et al. [18, 25, 50, 51]. Additionally, barriers to independent travel, arising from difficulties in accessing public transport, inability to take multiple transits and being unable to travel through a new route were other problems discussed by Davies et al., Kramer et al. Sitbon et al. and Sposaro et al. [24, 47, 65, 67]. Finally, the obstacle of finding suitable technology to assist the needs of people with cognitive and intellectual deficits is not new, as similar issues were previously identified by Dawe and LoPresti et al. [25, 55].

Our finding indicates that participants felt insecure about performing activities in outdoor conditions by people with DS that were not discussed in the related study of literature. Similarly, failure to recognize hazards by people with DS was not directly discussed in the literature. Likewise, lack of knowledge from parents and people with DS about new smart devices (smartwatches) and assistive apps (e.g. tracking and monitoring, activities supported apps) was also not discussed directly in the literature. Our findings provide in-depth insights in relation to barriers to independent activities for people with DS and their implications of daily life.

While our study highlighted a few technologies (smart devices and apps) along with barriers, it was not clear what other technologies are currently being used by people with DS and for what purpose. Therefore, a further study was required to gain deeper insights into technology use and how activities of daily living can be supported using technology.

Our results provide initial usage pattern of smart devices (Figure 3) for the daily routines of people with DS. The findings of the survey confirmed our expectations, as most of these smart devices were already identified in previous research (e.g. Dawe [25] and Kramer et al., [47]) and have the potential to support people with learning disabilities. additionally, our study revealed several activities that were also observed in previous research, e.g. reminder tasks/activity [74], learning [41], communication and entertainment [51]. However, new aspects identified by our results include the usage of smart devices in outdoor conditions e.g. location tracking/reminder and communication were noteworthy in relation to performing independent activities along with parents' agreements (Figure 4).

We explored six key barriers to independent activities identified in Figure 2 and highlighted that iPad/Tablets and smartphones are popular smart devices commonly used by people with DS (in Figure 3). Overall, our study found that people with DS had good knowledge and positive user experiences of operating smart devices (iPad/Tablet and smartphone). We took it as a positive indication to do further research to overcome the barriers identified in this study to eventually enhance independence and quality of life for people with DS.

Overall, our findings revealed a link to outdoor activities with safety and security concerns with performing outdoor activities, verbal communication problems, and difficulties in finding desired places were related to outdoor activities among six barriers identified in section 4.3. Similarly, "*helping in communication while outside*", "*monitoring/tracking location*" (see Figure 3) and "*travelling/shopping independently*" (see Figure 4) were also related to outdoor activities. Our findings also revealed that smart devices were recognised to have a strong potential to overcome barriers to independent travel by DS and their caregivers (see section 4.3.3). Furthermore, the usage of smart devices (smartphone) to provide support in outdoor conditions by parents (see section 4.3.4) and the second-highest smartphone usage by people with DS revealed in the survey (see Figure 3), indicated that people with DS and their parents have positive experiences of smartphone usage. Therefore, it would be realistic to investigate barriers to independent travel. Also, it is possible to focus on some of the other barriers by investigating barriers to independent travel e.g. communication difficulties during travel and forgetting tasks/activities. We then decided to investigate this topic in more detail as our exploratory study (interviews and surveys) revealed independent travel as a common problem.

5 Cycle 2: Co-design and Prototype Generation to Support Barriers to Independent Travel

The first cycle investigated barriers to independent activities by young adults with DS in general and explored the opportunity of smart devices to overcome these barriers. We also found through the exploratory survey that one of the substantial independent activities was "*travelling/shopping independently*" (figure 4) and the highest number of responses was to provide communication support in outdoors using smart devices. These findings indicated a common link to independent travel. In the remaining cycles, we focus on barriers to independent travel and the potential support for this activity using smart devices and intelligent technologies.

5.1 An Investigation on the Barrier to Independent Travel and Develop Low-fidelity Sketching: A Design-based Home Exercise.

This study aimed to investigate further the barriers to independent travel so we understand them better and to reveal the possibility of overcoming these barriers for people living with DS. We also wanted to explore the current uses of smart devices and technologies to support independent travelling, and to gather the design requirements to design a smart app to support barriers to independent travel for people living with DS and their caregivers.

5.2 Co-design Method

We carried out seven group discussions in home settings with young adults with DS along with their parents and caregivers. We recruited participants via mail through Down's Syndrome Scotland (a charity organisation) and the contact list from our previous studies. After our experience of difficulty in recruiting for traditional co-design style workshops, we decided to investigate further through home-based group discussion with parents and young people with DS. Again, studies were conducted under Institutional Ethical Approval and are reported anonymously (with substitute names as needed).

5.2.1 Procedure

At least one person with DS and both parents/caregivers were present during each group discussion, except for one interview with one person with DS and one caregiver. Full information about the group discussion and procedure was given to parents and family members beforehand and they were asked to explain the procedure of the interview to the young adult. During the discussion with group 1 and group 7, parents and caregivers were requested to repeat some of the words or sentences that were not understood by the interviewer due to occasional problems with understanding the voice of some young people with DS.

Each discussion group was split into three sub-sessions (see Figure 5):

1. In the first sub-session, we explored the current barriers and experiences to independent travelling by public transport, and current usage of smart devices and apps to support independent travelling. We asked two questions during this session, Q1: "*what are the main barriers to independent travel using public transport for a young adult with Down's Syndrome?*" and Q2: "*what are the main benefits and usability issues to use technology (smart devices and apps) for independent travelling?*" We discussed these questions separately with participants with DS, and their parents and caregivers. First, we discussed with young adults with DS and after then these same questions were discussed with their parents and caregivers.
2. In the second sub-session, participants were asked to provide suggestions on how those barriers (discussed in the first sub-session) could be overcome with or without the use of smart device and technology. One question was asked to discuss, Q3: "*how the identified barriers from above (discussed in the first sub-session) could be overcome with (e.g. smartwatches and smartphone apps) or without using technology?*" This session was a joint discussion together with parents, caregivers, and their son/daughter with DS.
3. In the third sub-session, the interviewer briefly introduced routing and navigating technologies, apps and features. Participants were then engaged jointly in a short design session to sketch an interface of their own ideas for an app to prototype. All sketches were drawn collaboratively by parents, caregivers, and their son/daughter with DS. Participants with DS were asked and confirmed by their parents/caregivers about the features that they want to include in the app or if they do not understand any feature drawn by parents/caregivers. All drawings and sketches were described by parents/caregivers at the end of the session.

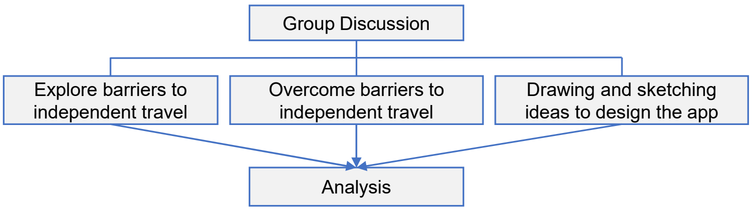


Figure 5: the study design process.

5.2.2 Data analysis

All discussion group were audio-recorded and transcribed by a third party before being qualitatively analysed. The analysis was done using framework analysis [40] to identify themes. The first author read the transcriptions numerous times to increase familiarity and to apply framework analysis. After then the transcript's data were coded manually and initial categories were created from the first interview's transcript, followed by second and subsequent interview's transcripts with similar codes grouped together to form overarching themes. The interview's topics were used as a starting point for creating overarching themes and recognise these themes (see Figure 6) as an initial thematic framework. Subsequently, the fourth author reviewed the framework and any inconsistencies were resolved by the second and third author. Finally, the coded themes were tagged and transferred to their suitable positions in the final framework.

Table 2: Participants with DS and Caregivers Demographics

Focus Group IDs	People with DS and caregivers' IDs	Caregivers Gender	People with DS Gender
1	1, 1.1, 1.2	M, F	F
2	2, 2.1, 2.2	M, F	M
3	3, 3.1, 3.2	F, M	F
4	4, 4.1, 4.2	F, M	F
5	5, 5.1, 5.2	M, F	F
6	6, 6.1, 6.2	M, F	M
7	7, 7.1	M	M

5.2.3 Participants

In total 20 people took part in the study, including seven individuals with DS across seven sessions. Thirteen parents and family members aged between 22-57 years (average age 49 years) were full-time caregivers and providing support for more than 18 years except for one caregiver (who providing support for 4 years). For people with DS, the level of cognitive capabilities varies widely, as such we only considered individuals with mild cognitive disabilities in this study. All individuals with DS (seven) were young adults (four females and three males), aged between 18-28 years, the average (mean) age of the group 22.1 years. The participant's demography listed in Table 2.

5.3 Findings: Barriers to Independent Travel for People with DS

This section briefly describes the themes of key barriers to independent travel and discusses how to overcome these barriers. Figure 6 presents a summary of the themes and Table 3 presents the requirement's summary to design an app. Figure 7 and 8 present representative sketches to designing an app that were drawn by parents and individual with DS during the design session. The outcomes describe with participants' quotes listed in Table 2 and "P" were referred to participants with DS and "C" referred to parents/caregivers/family members.

5.3.1 Unfamiliarity with route:

One of the difficult activities for people with DS were navigating by foot when they were not familiar with the route e.g. finding new places after getting off from the bus, walking to a shopping Centre or transit and crossing the main road. All parents of participants expressed unfamiliarity with the route as a barrier to independent travel and that circumstances on the route could create an obstacle to independent moving. Consequently, a similar view obtained from the discussion with group 4 that the unfamiliarity create complication to navigate for people with DS.

> C3.1: "*It is very scripted, you know: 'Goes to this bus stop. Gets this bus until this stop. Gets off.' It is very scripted. And if one of those things is knocked off, like say, her walk. If that road is shut…she might not know just to go one street down… she would struggle with that unfamiliarity.*"

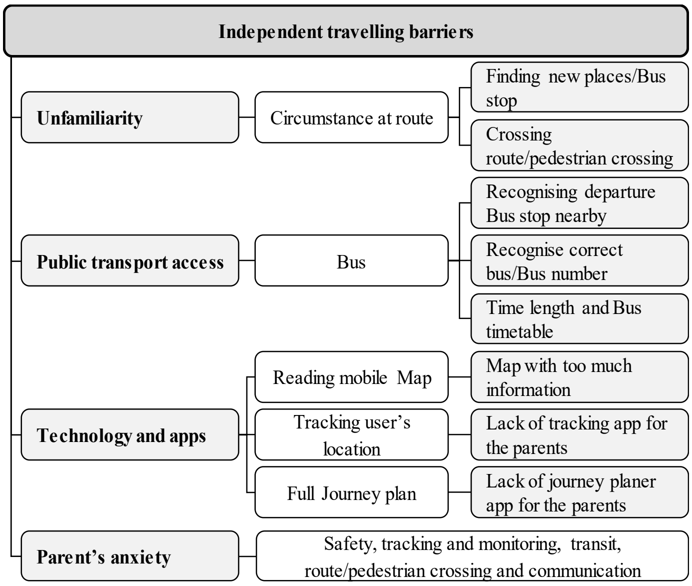


Figure 6: Barriers to independent travelling for people with DS.

A concerning issue raised by group 5 that unfamiliarity could cause to loss of confidence to travel alone by people with DS. Subsequently, crossing busy streets often required support while taking transit, walking home or to a bus stop and executing these tasks in an unfamiliar route become difficult for people with DS.

> P5: "*When I first found out that my mum told me I had to do independent travel to college it made me feel scared.*"
>
> C5.2: "*Yes. You've then got to worry about the hazards on that road. If you're doing one straight line and it crosses four other streets, you need to know that that's a crossing so that you don't just keep walking. Because I look at a map and it's got four roads, I understand there's a crossing there and there's a crossing there and there's a river there.*"

5.3.2 Public transport access:

Public transport access was confirmed as one of the main barriers to independent moving for people with DS by all groups. Finding the nearest bus stop and recognizing the correct location in urban or suburban areas where barriers to access public transport with repeated practice required to find the correct bus stop. Five participants of this study have been trained for one independent journey and had the ability to find the bus stop but raised concerns such as bus stop moving due to roadworks.

> C3.1: "*Just the one thing, in town, there was loads of temporary bus stops which were not exactly where the closed bus stop was, they were maybe like 100 yards further down. That kind of thing can throw her off as well. .... Because she might just see the bus stop go past in the window and then be like, 'Oh, where…?'*"

Furthermore, C5.2 stated that her daughter required someone with her to recognize the bus stop. Recognizing the correct bus is also considered as a barrier to move independently for people with DS. Though, five participants with DS of this study practised recognizing the correct bus except for P4 and P7. However, according to them (those who were trained to recognise the bus stop), it is not always for a young adult with DS to easily identify the correct bus.

> C1.1: "*We regularly have people stopping at the bus stops to give you [individual with DS] lifts. People say, "I stopped and gave her a lift [helped to access the bus]." [but] she's trying to use the bus!*".

In addition, concerns were raised over understanding bus timetables, journey times and the impact of weather for those living with DS. Group 3 described the difficulties of understanding time duration and group 2 described impacts due to weather conditions. Likewise, getting off the bus was identified as an issue for people with DS during the discussion. All groups discussed the issue of getting off the bus.

> C3.2: "*When she finishes early from college, she will walk to the bus stop and then I think she immediately phones me and says, "Where is the bus? The bus is not here." So, usually, I have to say, "It's okay. How long have you been there?" And she is not good with [time]… "Half an hour." Everything is half an hour*".
>
> P2: "*Last time when I was in a bus, I fell asleep by accident and I missed my stop.*" P2's parent C2.2: *"…I know how difficult it would be for John to get off the bus and explain to somebody what he was doing …. So that was a big issue, but fortunately the driver was able to get him back.*"

5.3.3 Technology and apps:

Lack of suitable technology and apps to support travelling was again raised as a barrier. Only one participant (P1) with DS used a mobile app called 'Bus & Tram' to recognise the bus number while travelling by bus. Although the app comes with the general map, the user cannot interpret it because too much information was displayed. Also, the app does not have the tracking feature for the parents, C1.1 stated that identifying locations using a map would be a useful feature as he often used the 'Find My iPhone' app to see his daughter's location. He also mentioned an unexpected experience when his daughter lost the way back to home where he (C1.1) used the app (*Find My iPhone*) to identify her location.

> C1.1: "*I think if I didn't know from the map [using Find My iPhone feature], I wouldn't have known where she was*". And C1.2: "*It's quite easy to read, isn't it? Because all that just says is a big bus number, which you know, and then it tells you whether it's due [commented on 'Bus& Tram' app].*"

Due to reduced distance judgment and sense of direction, people with DS often struggle to identify their current location or identify how far they are from home [23]. C5.2 specified technology should provide every stage of journey progress, which eventually will increase the confidence of parents to encourage self-travelling. Interpretation of mobile maps was found difficult for people with DS due to excessive information causing confusion and preventing navigation. Similarly, P3 claimed not to be a map user. Parents and caregivers had tried a number of apps with GPS sensor to support travelling by bus and to know the current location of the traveller, but none of them found any suitable app that actually met their needs. 'Find My iPhone', 'Find My Friend' and other bus apps were mentioned by participants.

> C5.1: "*Any technology, any additional information to know that she's got on the bus, arrived, got off, these would make a huge difference to our comfort and reduce the nervousness*".
>
> P1: "*No, I don't know how to use map*". And C4.1: "*Google Maps is probably a little bit too dense" "A bit more simplified, but the same basic thing might work for her.*"

5.3.4 Parent's anxiety:

All parents in the groups revealed that their fear was one of the main barriers to independent travel for people with DS. This fear intensified when any unwanted circumstance occurred during travel. As with our exploratory study, safety was a concern in public places raised by all participants and caregivers. People with

DS can easily be targeted if, for example, they carried expensive phones, hence group 5 felt that wearable devices could improve safety on a journey.

> C2.2: "*I worry about him and his phone. I worry about people using a daily trip, recognizing that he's on his own, he's a bit vulnerable… Another time, he lost his wallet. There was some money in it, but also travel card, cinema card, lots of things to replace."*

> C5.1: "*Yes, continually, which is where the watch would be an advantage because you can wear it [smartwatch]. You've lost it, so there's that. Yes, absolutely, stolen because they are expensive, and they are a target.*"

Likewise, parents and caregivers have expressed their views about losing an expensive smart device that can be caused that limit independent travel. Further, any unexpected circumstance on the route can create anxiety for parents. Also, those parents were concerned about the reliability of transport and transit.

> C5.2: "*We're just nervous of new circumstances." "As far as Bob concerned, I think the biggest problems will come when something goes wrong. When the bus doesn't turn up or when the bus breaks down halfway into town or something like that.*"

5.4 Overcoming Barriers

Group discussions started with a discussion of the barriers to independent travel. We followed this up with a discussion of how these barriers could be overcome and identified several solutions to overcome such barriers from participants with DS and their parents/caregivers.

5.4.1 Notification and alert

All participants and their parents/caregivers talked about reminders and notifications before getting on and off buses, or any changes (e.g. due to road works) in the planned route of the journey [61, 65, 67]. Our findings revealed from discussion with all groups that the notification and alert with vibrations to get users' attention would be more convenient.

> C5.2: *"Sometimes they move the bus stops… so that's really useful if that information could be available, 'Your bus stop is not here today, it has moved.' 'Yes, get on the bus,' notification so that whoever is in charge of that day they know Amy's on the bus. Absolutely. Notification.*"

5.4.2 Dealing with circumstance

We revealed that dealing with unforeseen circumstances that can occur during a journey is often challenging for people with DS Caregivers required to intervene for dealing with some circumstances that are not possible by people with DS. All participants (P1–P7) emphasised the importance of contact with parents/caregivers when people with DS are unable to deal with a particular situation [47, 61, 67]. Consequently, parents/caregivers and people with DS suggested a help button for emergency contact if something unusual occurs.

> C3.1: "*Well, even maybe the option of if something could flash up to say, phone, ... 'If you don't know what to do, phone Mum'." or "Phone James", "Go into shop", "Go back to college," you know, just to remind her…*"

5.4.3 Smart Map with voice assistance

All groups insisted that the information or instruction to support navigation should be easy and simple for people with DS. A simple journey plan could be customisable from parents'/caregivers' phone was suggested by parents/caregivers.

> C6.2: "*You have every journey to pick up from. But if you were on another app that just showed her journey that she needs to get to college. So, for instance, if she could click "To college" or "From college to home" and then it loads a pre… like, that would be a pretty good way…*".

Parents and caregivers from all groups except group 2, suggested a voice navigator and assistance with the simplified map. Group 5 (C5.1) discussed walking directions with voice instruction to support navigation [9, 18, 47]. Likewise, group 4 (C4.1) discussed text instructions with images together would provide precise navigational support. Similarly, group 3 (C3.2) discussed voice output to assist the user to notify the current location.

> C5.1: "*Yes, talking instructions, "Walk forward, turn right, turn left," would certainly help or even just a larger display with an arrow, turn left, turn right*".
>
> C4.1: "*Yes, she can do directions no bother. If there was a voice or a visual, like a text thing came up on the screen the same way Google Maps has. Google Maps is probably a little bit too dense*".
>
> C3.2: "*If the smart technology knows where John is and is supposed to be, could the technology tell her where she is? You know, could it actually have voice output?*"

5.4.4 Requirements summary

We summarised the requirements (see table 3) from the group discussions and design session to design an app for smartphones. Most of these requirements were discussed in the literature, however, a few requirements were new in the context to support the travel barrier for people with DS.

Table 3: The app features and requirements identified from group discussions to be included in the travel support app for people with DS and their caregivers.

GROUP IDS	REQUIREMENTS	REFERENCES	IDS
1 – 7	The app should have two types of user: primary and secondary.	[28]	1
1 – 7	A full route plan should include walking directions.	[23, 28]	2
1, 3, 5, 6, 7	The route plan should be editable by parents, with the option to add pictures of landmarks.	[23, 28]	3
1, 2, 3, 4,	Show the bus stop's picture when user is near the bus stop.	[68]	4
1 – 7	Notify user when the bus is near the departure stop and display a pop-up message with the destination name to show the driver to get the ticket.	[68]	5
1 – 7	Notify parents or caregiver when the user gets on the bus.	[62]	6
1 – 7	Notify a parent or a caregiver about users' journey progress with details (location information).		7
1, 5	Notify user to get off at correct bus stop before arriving at destination stop.	[24, 68]	8
1 – 7	Notification must be triggered to both user with DS and caregiver if a user DS reached to a wrong route or missed a bus stop. Also, a help interface must display with simple instructions and phone calls option to communicate with the caregiver.		9

1, 4, 5, 7	The linear bar should contain the full journey outline with the name of bus/train stops and progress of the journey.		10
1, 4, 5, 7	Icons/images of any superstore or landmark while the user is travelling by bus or train to increase the familiarity with the route	[29, 47, 54, 68]	11
1, 3, 4, 5, 6, 7	Textual navigation [20] with voice output to support the user to navigate while walking	[18, 24]	12
1, 6, 7	Save all journey plans in a list with appropriate names	[28]	13
1 – 7	Parents should be able to identify user's locations from their device when user with DS not in the right direction or lost themselves to way to the destination.	[67]	14

One novel requirement was a pop-up message that displayed the destination name (requirements ID: 5) which can be shown to the bus driver to get the right ticket for the journey, This will reduce the verbal communication barrier with the driver and who can confirm by reading the message that the person with DS got the right bus. Another requirement was to notify parents/caregivers about each step of the progress of the journey e.g. when he/she reached the bus stop, when he/she inside the bus, when left the bus and arrived at arrival stop, and when reached the final destination. A continuous notification to parents/caregivers about each step of the journey progress (requirements ID: 7) to reduce parents' anxiety and help to increase confidence in independent travel by public transport for people with DS. Notification triggering (part of requirement ID: 9) has been developed in many commercial navigation apps e.g. alerts when user is not in the right direction [24, 67]. However, dealing with any unforeseen circumstance during travel was a new requirement that requires a simple instruction to support such situations and an option for calling parents/caregivers immediately. The requirement ID:10 (progress bar), were not new and have been used in many commercial navigation apps, however, it is new for supporting people with DS, which appear as a substitute to the traditional mobile map and may open a new door to support barrier to independent travel.

5.5 App Prototype Drawings

Sketches of front-end design requirements were collected from all groups. Parents, caregivers and participant with DS used drawing to demonstrate how to overcome the identified barriers and appropriate use of these features identified above (Table 3).

All participants were given a minimum of five minutes to describe their sketch, which we later analysed sketches along with recorded audio [69]. Two representative sketches are described below. For the first sketch, P7 and his parents sketched together a linear map (Figure 7) of the full journey that included walking points and travel by public transport. This drawing illustrated all the steps of the journey, the messages are displayed for the user when unexpected circumstances happen on the road and how to deal with them as well as, reminders of landmarks for increased familiarity and trigger notifications (e.g. get on and off from the bus) to ensure a smooth journey. For the second sketch (Figure 8), P1 and her parents created a sketch of the full journey plan in a linear bar with GPS tracking ability for users with DS. Parents or caregivers must authorise any journey planed by users with DS before performing the journey. Every place name or name of bus stop and landmark would be highlighted with a circle in the bar. The progress of the journey is shown by changing the bar colour and notifying parents about the progress. A reminder should be triggered when the user is near any landmark or about to get off from the bus to ensure a comfortable journey. A motivational message is also displayed for users after every completed journey.

Other sketches included suggested home screen button and related information for users with DS. All sketches are available at https://doi.org/10.15129/9b946240-b42b-4a3b-8606-7cc87e2254de

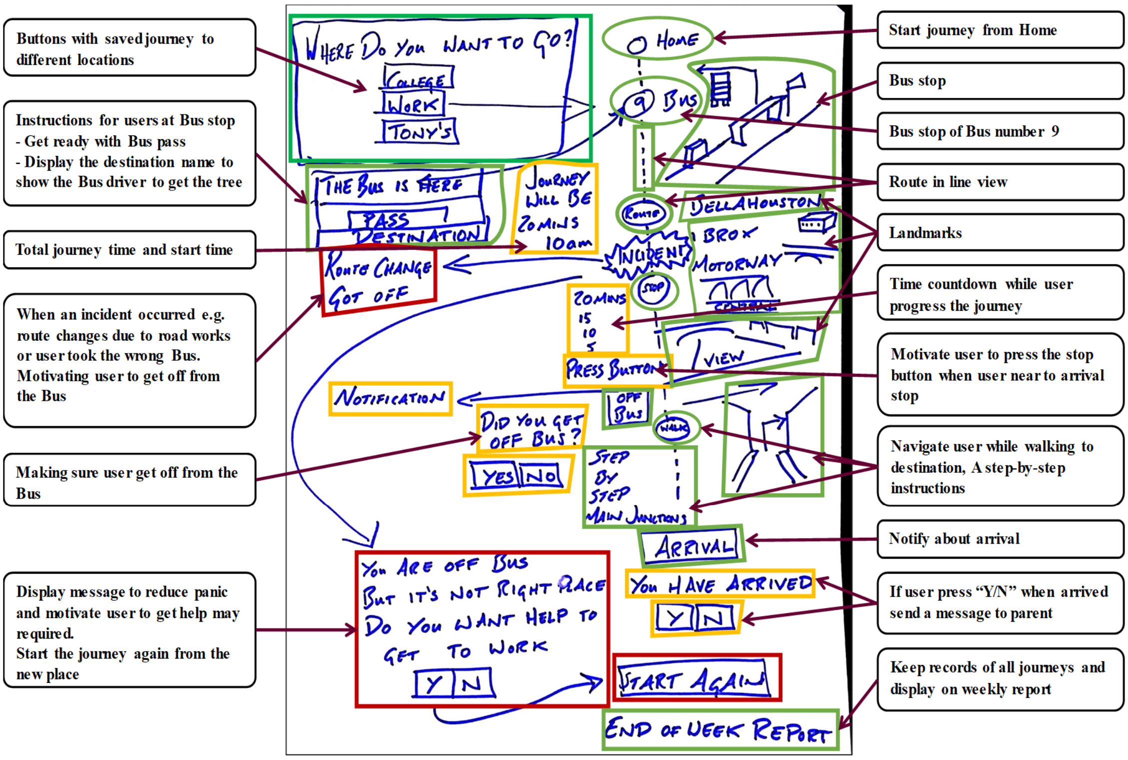


Figure 7: Drawing of a linear map (P7 and parents)

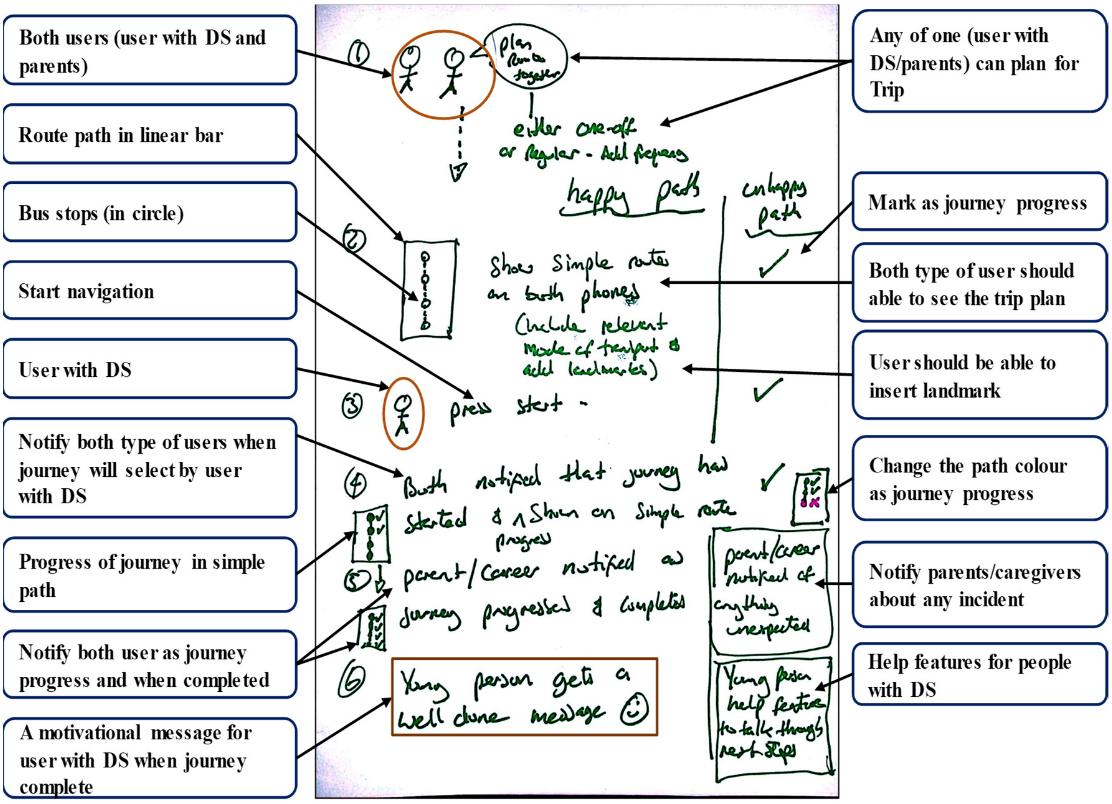


Figure 8: Progress of journey in the linear bar (P1 and parent)

5.6 Discussion of Cycle 2 - Discussion Groups

Our findings indicate that there are four key barriers (Figure 6) that prevent an individual with DS from independent travelling. The first one of these barriers is unfamiliarity with routes, which affects all other barriers. In order to address this problem, travelling with a "travel trainer" can increase DS individual's familiarity with a new route. However, it cannot alleviate parent's anxiety. Alternatively, smart devices e.g. smartphone with a smart app could be used as a substitute for a "travel trainer" and shadow an individual with DS while travelling (c.f. tracking users' activities [47]). The next difficulty was finding the correct arrival bus stop, recognising the correct bus and basic routing with the regular map. These were often mentioned as persistent problems (as reported in Davies et al. [24]). We also saw the importance of notifications for parents and caregivers, providing updates about circumstance on the route, and proving support in unusual situations.

Furthermore, we confirmed that pedestrian crossings and reading regular maps to navigate at a short walking distance were difficult for people with DS. These barriers have been observed in an earlier study of Kramer et al. and Sposaro et al. [47, 67] but remain unsolved. The complexity of standard smartphone maps was raised as a common problem by the participants. The participants suggested that the difficulties in navigating a new route or home to the bus stop could be overcome by simplifying maps and combining them with textual and voice navigation. Participants' drawings also revealed a new way to visualize the full journey by using a linear bar map and voice assistance (see Figure 7 and 8). Correspondingly, one of the key barriers was parents' anxiety, which may possibly be reduced by overcoming the identified barriers (Figure 6), except for the safe use of smartphone in public places without being targeted, lost or stolen. Nonetheless, smartwatch (four participants with DS were smartwatch user found in the study of supporting independent travel) is the only device that can be used safely in public places and is less prone to be targeted.

6 Cycle 3: High-fidelity Validation Workshops and Bridging the Gaps in Design

In the previous study (see section 5.1) we identified key barriers to independent travel and assembled requirements and features along with low-fidelity sketches to design an app for a smartphone. Based on these studies, we designed a digital prototype for people living with DS to overcome these barriers to independent travel. In this study, we return to participants (users with DS and their caregiver) for their feedback on designed prototype. We aimed to validate our findings (four key barriers to independent travel, see Figure 6) and discuss our proposed prototype design for smartphones, and how this same concept can be applied to design a smartwatch app. We targeted young adults with DS aged between 16-35 years old and their parents/caregivers.

6.1 Prototype Review Method

Participants were recruited via email and social media post (Facebook post) of Down's Syndrome Scotland and from the contact list of our earlier studies. As we have experienced difficulties to recruit for the previous study, again we decided to give more flexibility to our participants by visiting them at a place (usually home) of their convenience.

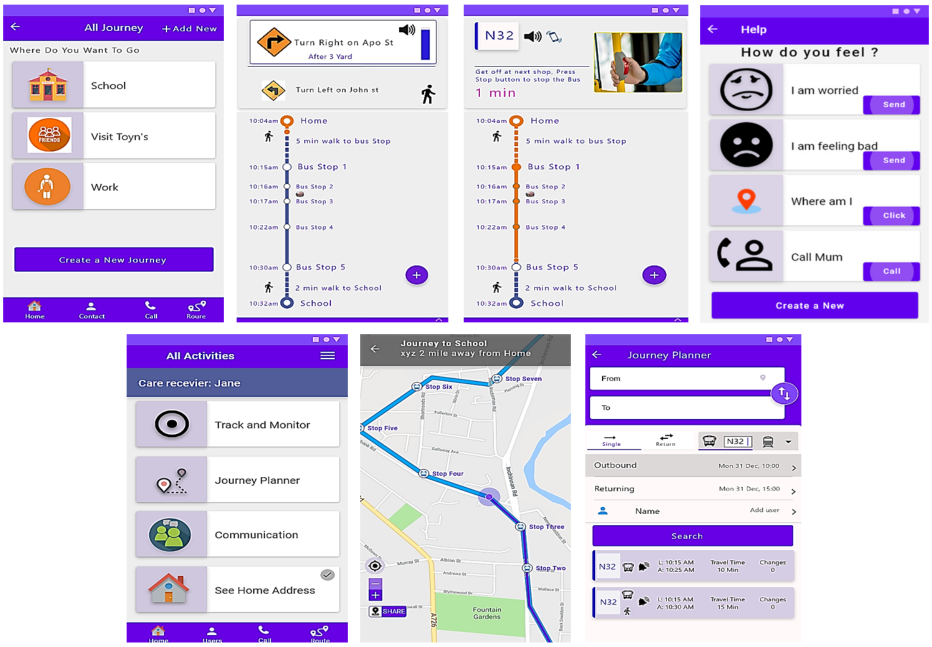


Figure 9: digital prototype designed for smartphone (top four images for the primary users and the next three for secondary users). Help page (top-right) with a short-written message to be sent to caregivers, messages can be customized by users with DS or caregivers.

6.1.1 Procedure

In total, seven group discussions were conducted, three at the university campus (*n=7*, three participants with DS, one married couple, one mother, one brother) and, four in participant's home (*n=12*, four participants with DS, three married couples, one mother and one brother). An easy to read participant's information form about the group discussion and procedure was given to parents and caregivers in advance, and then they were asked to explain the procedure of the group discussion to their young adult. Before we started the group discussion, we presented the prototype in a web browser using a laptop and projector, and explained all features for both types of users. The digital prototype: the prototype consists of two types of users— people with DS as primary users and their parents/caregivers as secondary users. The prototype was designed in Adobe XD and used Google material design concepts [20] (e.g. cards, buttons, navigation panels, etc.) for smartphone users. For the primary users (people living with DS), the interfaces were designed to support overcoming travel barriers. The design consisted of a directional panel, instructional messages and a linear map to aid easy navigation and ease selection of the right bus/train (see Figure 9). A total of 26 screens were created to represent a journey from home to school. For the secondary user (parents and caregiver) the interface was designed to enable parents/caregivers to shadow users with DS. Parents/caregiver were given access to admin controls, e.g. planning for the journey, tracking locations, monitoring journey progress, checking journey history, receiving update or any circumstances occurred while the individual with DS performing the journey (see Figure 9). All the screens of the designed prototype were printed on an A4 size paper [8, 13, 44] with narrow margin layout and landscape orientation and were used to gather feedback from both types of users (first set for primary users with DS and second set for secondary users parents/caregivers). The group discussion was divided into three sub-sessions. The first sub-session was to understand and observe usability issues of the designed digital prototype for users with DS (primary users). We let participants with DS use the digital prototype on a smartphone (Samsung Note 3, screen size 5.7-inch). The task was to navigate through the whole prototype (this task represents a journey from home to school). Participants were allowed to ask questions and discuss with their parents/caregivers if they do not understand any interface or find difficulties to navigate. The purpose was to observe the usability issues and take notes to discuss these issues using the paper prototype in the second sub-session. The second sub-session was a detailed discussion of overcoming those usability issues that were raised in the first sub-session and we used a printed version of the digital prototype to record their feedback. This sub-session was a joined discussion with parents, caregivers and participants with DS. A third sub-session was a short discussion with parents and caregivers on the user requirements and usability issues on the designed prototype for secondary users. Though we started the discussion by mentioning to participants our findings from the earlier study (four barriers to independent travelling) and asked for their feedback on this, we also stated that they were not restricted in discussing any other barriers that were not found in our findings (see section 5.3). Each group discussion lasted around 90 min (SD = 70 – 100 min) and was audio-recorded. The main discussion comprised of three elements 1) Comments and feedback on the designed prototype, what do participants like/do not like and what features to include/remove from the prototype? 2) *What are the accessibility issues on the designed application for a young adult with DS?* 3) *What aspect of the app overall is useful to support overcoming travel barriers and why?* These questions were formulated based on the literature review and findings from the previous studies [19, 23, 28, 44, 53].

6.1.2 Participants

The criteria stated during the recruiting process were that participants with DS should be aged 16 years and above, able to move physically, keen to learn independent travel by public transport, and have no worse than mild cognitive disability (i.e. excluding those with a moderate or severe level of cognitive disability). Seven young adults with DS took part in the study (three male and four female), four participants were new and three took part in our earlier study (Referred as "R" e.g. group ID=11R, see table 6). The average age of participants with DS was 21 years (age between 17 - 28 years). Also, twelve parents/caregivers (five male and seven female) took part with their average age of 52 years. All participants with DS were smartphone users. All parents/caregivers were full-time carers of a young adult with DS, except one who was a part-time carer.

Table 6: Participants with DS and Caregivers Demographics

Focus Group IDs	People with DS and caregivers' IDs	Caregivers' Gender	People with DS Gender
8	8, 8.1	F	M
9	9, 9.1	F	F
10	10, 10.1, 10.2	M, F	F
11R	11, 11.1	F	M
12R	12, 12.1, 12.2	M, F	F
13R	13, 13.1, 13.2	F, M	M
14	14, 14.1, 14.2, 14.3	F, M, M	F

6.1.3 Data analysis

To familiarise himself with the data, the first author read each interview transcript several times and carefully examined each set of paper prototypes (printed paper prototype used during discussions to record the feedback). The quotes were retrieved from both transcripts and paper prototypes, and the retrieved data were analysed by following the same process described in section 5.2.2.

6.2 Findings

Outcomes of users with DS (primary user): In this section, we present the design gaps of the proposed prototype for people with DS and describe briefly with participants quotes. Again, "P" refers to participants with DS and "C" for caregivers.

6.2.1 Most appropriate designs features

Linear map: the linear map was one of the key features developed based on the participants' suggestions (discussed on 4.3.3). Our findings revealed positive views from both participants with DS and their caregivers. Parents and caregivers from all group described as a novel feature to support travel barriers. Nevertheless, the participants with DS felt familiar with the linear map quickly as revealed while observing with the digital prototype in the smartphone. The only issue was the displaying of the name of bus stops in between departure and arrival stops, as these stops are not their stops to get off and lead to confusion because of the unfamiliarity. On the other hand, P11 and P13 had no objection to the inclusions of these stops and argued that the inclusions of the name of these bus stops will help them to increase familiarity with the route. Additionally, parents of P12 recommended the instruction for on and off the bus alongside departure and arrival stops name in the linear map as noted.

> C10.1: "*Like the linear map*". And C9.1: "*Emma*[1] *will not know the names of the stops so noting them here will not be helpful*"
>
> C12.2: "*Bus stop 1 – add text → "Get on bus here". Bus stop 2 – add text → "Exit bus here or get off bus here." "*.

Help interface: Our designed prototype consists of a help feature (see Figure 9) for users with DS to send a message instantly to their caregivers while outside. Both people with DS and their caregivers from all groups stated the importance of this feature and described that the capability of sending this message will increase confidence among user with DS while performing travel and decrease loneliness.

6.2.2 Features with design gaps

Instruction features: the instruction features was one of the key features of the designed prototype discussed by all participants and their caregivers. Based on this finding we further categorised instructions into three sub-sections: turn-by-turn instructions for direction (e.g. turn left, turn right); prompt instructions to take action (for example, "did you get the right Bus, action = YES/NO", "press the stop button to stop the bus"); and alert messages to notify the user or provide important information (landmark notification e.g. "you are passing by Tesco now").

Ordering the box design: turn-by-turn direction instructions for the navigational instructions contained two instructions at a time, the first instruction was to follow for direction with the next instruction to inform users about the upcoming turn in advance (see Figure 10). However, we found that this created confusion for participants except for P12 while observing participants using the prototype on the smartphone. P8, P9 and his parents suggested one instruction at a time to make sure easy to read and understandable by people with DS.

> C9.1: "*I think one instruction box at a time would be less confusing.*" "*I don't think the distance [in yards] notification is helpful.*"
>
> C11.1: "*create space for admin generated photo of next turn. If photo not taken default to street view."*

Parents of P11 suggested keeping both instructions together but upcoming instruction should be in a smaller box (see Figure 10). The instructions were presented with text and images but unfortunately, none of the participants with DS understood the distance when presented in "Yards" (e.g. turn right after 20 yards). Consequently, parents suggested that the distance text should be in meters. Although all participants and caregivers were happy with the instructional images, C11.1 parents of P11 suggested customisable images and direction arrow on the images for the navigation instruction. The panel also contained a progress bar that

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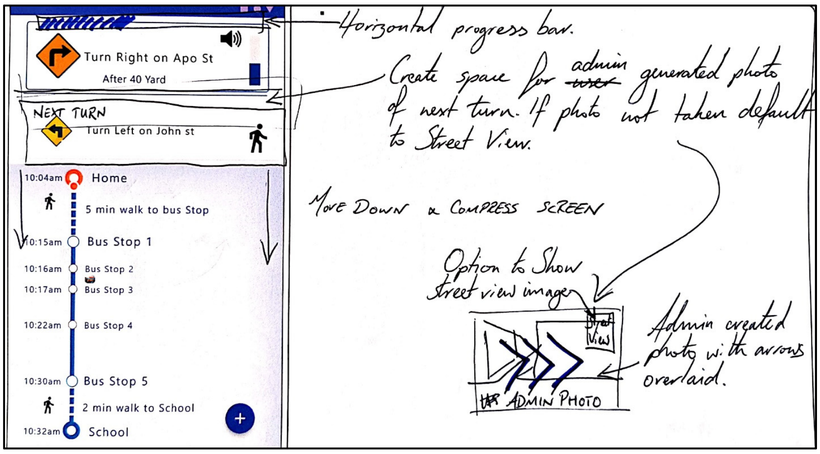
[1] All participant names have been changed to preserve anonymity

fills up while the user is moving towards the next turn. Parents of P8, P11 and P12 suggested a horizontal progress bar (see Figure 10) rather than a vertical on top of the direction instructions box.



· Horizontal progress bar.

Create space for admin ~~user~~ generated photo of next turn. If photo not taken default to Street View.

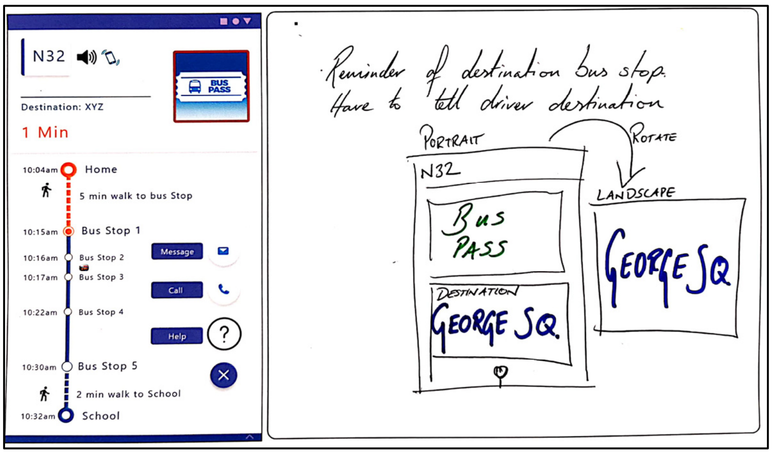
Move Down & Compress Screen

Option to Show street view image

Admin created photo with arrows overlaid.

Figure 10: showing changes made by participants in Turn-by-turn direction (P11R and parents).

Design the interface with correct alignment: action instructions were presented with text and image. While the user is waiting for the bus at the bus stop, the bus pass image will appear on the right side of the panel and, that indicates to the user to get ready with bus pass when the bus is nearby. And the text instructions with destination name as well as the remaining time of the bus arrival are also displayed here. P11 and his caregiver suggested that it would be better for the image better to appear under the bus number rather than the right side (see Figure 11) and the destination name with a separate box below for the bus pass image, by taking more spaces on the screen. And the same change should be implemented for other action instructions e.g. instruction for crossing the road. To reduce the verbal communication with the bus driver this instruction box should also include the destination name. P8, P11, P12 and their caregivers recommended the destination name should be the arrival stop name instead of their final destination as the final destination (users' with DS destination) might be away from the arrival bus stop and the bus driver may not able to recognise the users' final destination name.



· Reminder of destination bus stop.
Have to tell driver destination

Figure 11: showing changes in action instructions by participants (P11R and caregiver).

Contents adjusting and ordering: our finding indicated positive views for the alert messages by all participants and their caregivers except for the colour and text size. Parents have suggested a message to be sent to caregiver, when the user with DS presses "NO" when alerting message display on the screen to confirm that the user got the right bus. Similarly, sending messages to parents about incidents of the route was found as crucial as discussed by group 12R.

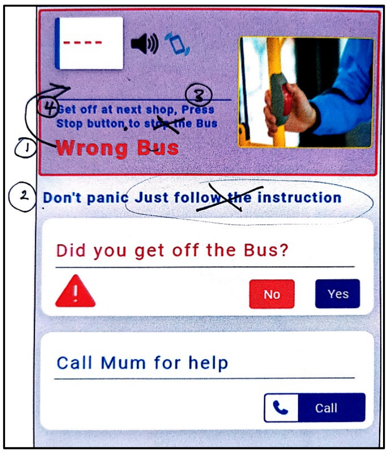
> C8.1: "*If he gets on a bus which doesn't go in the direction the app expects – it would send me a message to alert me.*"

For the designed instruction page on how to deal with such situations (see Figure 12) when users with DS get on the wrong bus. All participants and their caregivers provided constructive views and opinions to deal with such situations. Our observation with the digital prototype on the smartphone indicated that all participants with DS took time to understand this instruction page. All participants and their caregivers also indicated the significance of the call button for help (discussed in earlier study 5.3.2). Parents of P12 also advocated the text instruction and rearranging the current instruction (see Figure 12).

> P13: "*I was a bit hesitant about this page*". And C13.1: "*when pressing YES [in response to: did you get off the Bus?], this takes you to a new journey but takes away the ability to call Mum for help*".

> P12.1 and P12.3: "*Wrong bus", "Don't panic", "press stop button, get off at next stop*"

Nonetheless, all participants and their caregivers assured that the button to send the message to notify caregivers about journey progress will reduce the anxiety of parents and increase the level of confidence of participants with DS to perform independent travel. Parents of P10 (C10.1) recommended an option to customise the message by participants with DS.



Get off at next shop, Press Stop button to ~~stop~~ the Bus

Wrong Bus

Don't panic Just follow ~~the~~ instruction

Did you get off the Bus?

Call Mum for help

Figure 12: showing changes in an alert message by participants (P12R and parents).

6.2.3 Other features (Text size, font style and colour)

Problem to design a suitable interface using appropriate text size, colour and images are not uncommon for people with DS due to their visibility issues. The observation with the digital prototype on the smartphone revealed that all participants with DS struggled to read the text instructions of font size 14. But the instruction with text size 20 was adequate to read without stress. The caregivers were recommended the minimum text size of 18 and bold with a suitable font style e.g. Arial or Tahoma. We changed the font style and the font size accordingly before testing with the last participants P14, where observations indicated no difficulties in reading instructions. Also, our finding revealed that the use of graphical icons and text together for the instructions and buttons were accurate and suitable for the participants with DS. However, the use of inappropriate colour (e.g. red) in the text, icon or alert messages possible cause anxiety to people with DS. Parents of P11 proposed to use yellow colour instead of red in the alert message (see Figure 12).

> C12.2: "*I would use 'comic sans' font for hounded 'a'* ". And C13.2: "*visual marker was what Bob picked up on first*". And C11.1: "*the red colour maybe a little too alarming*"

6.2.4 Additional features

Two additional features were revealed from group discussions. Parents of P11, P12 and P13 raised the issues of battery drain due to the use of GPS sensor that could seriously affect the journey and can increase caregivers' anxiety. To overcome this issue parents of P12 suggested a remote view of battery level on caregiver's app that aware them to mark the last location when users with DS's phone about to off due to low battery.

> C12.1: "*add battery indicator to carer app so that I will know her last location*". And C13.1: "*a mute button will give them an option to turn off the voice instruction when needed"*

Also, parents of P13 suggested an alert message to turn off GPS before closing the app to save the battery energy. Parents of P8, P11, P12, P13 and P14 revealed that the voice alerts/instructions may distract others while participants with DS inside the bus and they recommended a mute button to turn off the voice alerts or instruction.

Outcomes of parents and caregivers (secondary users): in this section, we present the key features that were important for the designed prototype for parents/caregivers and describe briefly with parents'/caregivers' quotes.

6.2.5 Remote tracking and monitoring feature

These features were presented to facilitate parents and caregivers to know their sons'/daughters' (user with DS) real-time location. Our finding revealed an optimistic outcome from all parents and caregivers during the group discussions that the ability to track location, monitor the progress of the journey and receive live feeds (notification and text) about the journey increased self-confidence of parents and caregivers. As we found the significance of remote tracking and monitoring from the previous literature [61, 67]. All these features were marked as excellent features by parents/caregivers and stated that these features will support them to balance the level of anxiety by shadowing their sons'/daughters'.

> C10.2: "*useful if Emma gets loss*". And C11.1: "*tracking facility is an excellent idea, that will make me worry less…*"

6.2.6 Landmark feature

The designed prototype included a 'landmark feature' which allowed parents/caregiver to add multiple landmarks with images when creating a trip plan. Previous literature has shown the impotence of effective use of landmarks for people with cognitive deficit [29, 47, 54, 68]. Our finding revealed that all parents and caregivers were explicit with their views that this was an important feature, and that the landmark feature will help to increase the level of confidence and familiarity of the road for people with DS. For instance, group C14 expressed their views on the importance of using familiar landmark images.

> C14.1: "*it would be good to add Tesco's image for Nikki, she sees Tesco when travels to school*".

Journey history: the interface for the history of the journeys were designed for the parents/caregivers to see the individual with DS's travel history. However, findings revealed that the feature was not deemed important and it seems that the parents were not interested in checking the history of previous journeys. Indeed, parents and caregivers from groups 8, 9, 11R, 12R recommended not to have such a function and group 13R made no comments.

> C11.1: "*I don't like to see her all travels history, I want to help her if any incidence on the road*".

All other features were verified by parents and caregivers throughout all groups that were not deemed important e.g. plan for the trip, edit/delete and save with name and icon. Two screens that were common to both type of users e.g. loading and login screens. All participants recommended that they like to see their name (primary user's name) on the loading screen with the bus image and colourful background. Consequently, parents and caregivers were suggested to highlight the login button with bigger font size for users with DS and the login text (not a button) for the caregivers should be called "admin" and the size should be smaller than the primary users' login button.

6.3 Discussion Cycle 3 - Prototype Review Meetings

We listed a few interface designs that were appreciated by individuals with DS and their parents (the list was arranged based on the quality and significance of meaningful quotes that were used to rank interfaces. The highest-ranked interfaces were placed first in the list followed by subsequent interfaces). The listed interfaces include: (1) the linear map interface (see Figure 9 and 13); (2) progress bar to support walking path (see Figure 10); (3) an interface to get the ticket from the bus driver (see Figure 11); (4) an interface to deal with unexpected situations during travel that has calling option to call parent; (5) help interface to share feelings with parents during travel (see Figure 9); and (6) landmark feature to increase familiarity with the route. These identified six key features that were found relevant and important from both type of users (user with DS and their parents/caregivers). Our findings indicated that there were gaps (see section 6.2.2) in our designed prototype and that it was crucial to revisit participants (under PAR process) to ensure that the result meets their needs and serve the actual purposes.

There are numbers of features that have been discussed in the literature to support the walking path, we designed text instructions on the screen which was also used by Kramer et al. [47] along with images of the turning points but did not use any arrows to indicate the direction on the image as recommended by parents of P11 (C11.1) which discussed on section 6.2.2. We designed turn by turn navigation with an image of the arrow to support direction, the approach which was also discussed by Sposaro et al. [67]. However, we also introduced a few features and concepts in our designed prototype that were not mentioned in the literature. A novel feature that used a `progress bar' to support the walking path for users with DS was much appreciated by participants in the previous study (see Figure 10). The bar gets filled up while the user moves toward the next turn and repeats that process on each turn. An interface designed to overcome verbal communication (see Figure 11) with the bus driver. The designed interface includes instructions of bus number and destination name for the bus driver to read and make sure user that the passenger with DS got the right bus and appropriate ticket for the journey. The interface creates a safeguard that substantially reduces the risk of boarding wrong bus.

The linear map concept (see Figure 7 and 8) was sketched by participants in a previous study (section 5.5) was presented as an alternative to traditional maps. This concept is inspired by the use of rail timetable apps (see Figure 13) for regular users but had not been applied to users with DS. A different concept that involves dealing with unforeseen circumstances (see Figure 11) is yet to be evaluated through an empirical study. Likewise, the concept of a help page (see Figure 9) with written messages to increase the comfort of the journey for people with DS has not yet been addressed in the literature. Nevertheless, as we discussed in section 6.2.3 the difficulties to read instructions from the mobile phone screen by users with DS due to font size and colour lead us to stick on the standard rules (web accessibility) of web designs for people with learning disabilities. Consequently, throughout this study, we have completed another cycle of the PAR process (see Figure 1, cycle 3).

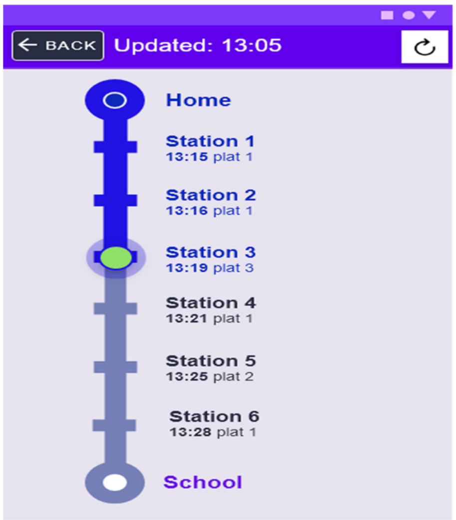


Figure 13: Linear map showing all stops between departure and arrival stops in a linear vertical bar with time and platform number.

User diversity: is an important issue to address in terms of design and research for young adults with DS. Although many studies reported wide individual variation in cognitive, physical and learning abilities among people with DS. We found less wide individual variation skills in using smart devices, as most of the participants were capable of using smart devices and applications for education and entertainment purposes (from survey results). We believe that this was because we only considered young adults with DS (aged between 16–35 years) with mild cognitive disabilities. On the other hand, a few of our participants reported incapability to use applications in smart devices to support navigation and tracking (see section 4.6.2 and 5.3.3). However, two aspects can be considered to provide a broader context of usage. First, the participants had to use traditional digital maps that come with smart devices, for example, Google map, tracking apps (Life360), and bus scheduler apps because participants were not aware of available navigation systems designed particularly for them. Second, even though there are some applications available that were designed particularly for people with DS to support navigation, these applications come with digital maps which are difficult to interpret by this user group (e.g. POSEIDON navigation application for users with DS). If an application with accommodation were available that mitigate their cognitive needs, it is possible that the users with DS might be able to learn independent travelling quickly and their parents can let out for travelling confidently. We observed easy adoption of the linear bar map concept with the progress bar by our participants with DS (see section 6.2.1), which indicate the opportunities to be able to learn the routine using custom designed apps for users with DS. While our studies worked with young adults with DS who have mild cognitive capabilities, our study could have lessons for other users with similar genetic syndromes of sub-groups e.g. young adults with Fragile X syndrome and people with dementia with mild cognitive capabilities that need further investigation.

7 Implications, Limitations and Future Work

Implications for designers: our research revealed several potential design implications for the development of smartphone applications to support navigation for young adults with DS. First, it appears that there is a need for an alternative to traditional digital maps (e.g. Google maps) to support navigation as indicated by our findings. A linear bar map concept (see Figure 9) to support navigation without the use of digital maps has strong potential for adoption by users with DS. The linear bar map should contain a list of all the steps between the start to the end of the journey, presented in order with corresponding step numbers and instructions of each step. The steps should be provided in a single vertical line, with a current location indicator displayed on the vertical line which moves while users move towards their goal. The goal of location indicator with an order list of each step is to assist the group in understanding and identifying their current location in the linear bar map. Second, it is important to understand the concept of the progress bar that gets filled up while the user moves from one turning point to a subsequent point. The concept of this progress bar provides cognitive support to the user by creating a sense of the journey progress and serves as an alternative of following a path in the digital map. Also, the user is not required to remember the upcoming road names and the turning points as it provides notification for turning points based on user's GPS location, and indicates the user proximity from the upcoming turning point based on how much it gets filled. Third, it is suggested that the use of images and icons should be clear and relevant within the context of the journey. For instance, we do not recommend using the bus stop and landmark images from Google street view as sometimes it does not appear with a correct angle from the user's walking path position. Instead, it is recommended to take the bus stop and landmark images by caregivers with the correct angle that helps users with DS to recognise the bus stop without imposing heavy cognitive load. Fourth, design for accessibility should provide more flexibility to the users by making the interaction with the system easier for those with fine motor control inability. Due to the lack of motor control ability in users with DS, the designer should design systems that require less screen touch of smart devices. For instance, our designed system does not require a lot of touching on the smartphone's screen, with the exception of requesting help from caregivers, when the user needs to touch the help icon and send a written message. Furthermore, users are not required to write messages as they can choose from already written and saved in the message list.

Implications for developers: a few important implications for developers can be derived from our findings. Due to the visibility issues of users with DS the size of buttons, text, box panels and borders should be sufficiently large. It is recommended to use at least 18px or 1.125em due to visibility issues for the users with DS. Similarly, the use of appropriate colours for background, buttons and box panels are suggested for the user with DS. Our findings are in line with Alonso-Virgós, Lucía, et al [5] for the usage of colours, but we suggest avoiding using red colour as some of the users with DS in our study found the red colour used in the alert message annoying. One of the important recommendations is to use icons together with text. For instance, the "back" button should include an icon of the back arrow (🡐) together with text written "BACK" and the border with a distinctive bright colour to make sure that the size of the buttons is big enough to help users with DS to tap on the button precisely in smartphones screen.

Implications of co-design in the PAR process: the process of participatory action research methodology was well-documented in our study involving young adults with DS and their caregivers, and potentially persuasive technology. First, due to intellectual disabilities and indistinct voice existed among people with DS, it is recommended for the researchers to involve their parents and caregivers in the study process in order to get a deep insight into their abilities and understand problems. This felt the most natural and safe way to conduct our studies and we believe it did not lead to excessive leading by parents/caregivers. Second, designing methods: An important recommendation is to take separate interviews/discussions of individuals with DS at the beginning of the session (instead of joint interviews/discussions with parents/caregivers) that help to set the focus on them and reveal their actual views/problems. After then, discussions of the same topic with parents/caregivers should be conducted to get their views. Third, designing methods: due to the cognitive disabilities of users with DS, we found that it is effective to involve both parents, caregivers and individuals with DS together in such a co-design session for designing and drawings. We believe such implications will support researchers to disclose the users' needs and understand their individual problems precisely, and eventually ensure the success of the study.

Implications for researchers: we noticed that some of the young individuals with DS felt nervous to start talking at the beginning of the interview. We recommend researchers to start the session by asking participants about general questions, for instance, asking their name, about their study, asking about their day and then slowly moving to the study questions. It is highly recommended not to start with technological questions at the beginning because asking such questions at the beginning of the interview may lead to participants feeling uncomfortable and stressed. Also, researchers should consider involving all those individuals into research who have an influence on the daily life of the participants. For instance, our findings on barriers to independent travel suggested that the bus driver and train staff involved in individuals with DSs' life for a successful journey to be completed, not only their parents/caregivers

Implications for parents and caregivers: parents' motivations play an important role for individuals with DS to perform independent activities by using smart devices. On the other hand, parents' fear creates barriers to performing independent activities due to safety concerns during journeys outside the home and the use of additional internet data in smart devices. First, we recommend parents to practice a short journey by bus together with their son/daughter with DS at least 2-3 times and to help them understand most of the steps of performing a journey e.g. finding bus stop, on and off the bus, getting a ticket. Also, this practice journey will provide a clear overview to the parents on how difficult or easy it is for their son/daughter to perform a journey by bus. We believe that such practice journey will help to increase confidence among parents and to remove some of their fears regarding the safety of their children. Second, parents and caregivers can use the data usage feature under the network settings in smart devices to limit the monthly data plan in order to prevent the use of extra data that will notify the user when the data limit is about to be reached. Third, it is recommended for parents to keep themselves updated about the current development of technology in order to better support individuals with DS in performing their daily activities. The information regarding technology development can be found from various Down’s Syndrome organisations that are local or international for instance, Down’s Syndrome Research Foundation UK[2], Down’s Syndrome Association[3], Down’s Syndrome Scotland[4], Down Syndrome International[5], National Down Syndrome Society[6] and the National Down Syndrome Congress[7] etc. The best way to receive an update from those organizations is to follow their Facebook and Twitter pages. Forth, it brings huge satisfaction and builds up confidence when a parent knows how other parents are helping their son/daughter with DS in performing daily activities. Creating social groups on Facebook and Twitter with other local parents and caregivers would be the best way to involve themselves in social networks and share each other experiences.

Limitations: this paper reports in-depth three studies with a relatively small number of participants and a broad age range amongst young adults living with DS and their caregivers as participants. It provides some crucial insights into barriers to independent travel and potential ways to overcome them. We believe that our findings to overcoming barriers to independent travel will have wider implications for individuals with DS and their caregivers. One of the challenging issues encountered during our research was participants recruitment, as parents were busy with their daily life commitments and people living with DS were not safe to attend the workshops alone. We adjusted our methodology in order to overcome recruitment problems for our co-design workshops by conducting individual, detailed home studies that proved a valuable tool for getting input from parents/caregivers and young people living with DS in a safe environment. Another limitation was the survey accessibility by people with DS. We designed the survey by creating separate sub-sections for both people with DS and their caregivers, and the survey was distributed via the parents’ contact list. Parents and caregivers were requested to help their children with DS to understand and answer the survey questions. However, we cannot guarantee that all surveys were completed with the presence of an individual with DS (as caregivers could have filled the survey themselves without asking opinions of their dependants). Therefore, it cannot be guaranteed that the survey sample (the sub-section of the survey designed for people with DS) is representative of all people with DS.

Future work: our future research will focus on developing the revised prototype system into a fully functional app. We will examine how independent travelling can be better supported using the developed app for smartphones and smartwatches in collaboration with young adults with DS and their parents/caregivers. To execute the study a test route will be selected and people with DS will be asked to walk to the bus stop as well as perform a journey by bus. A list of tasks will be evaluated (e.g. turn-by-turn directions, get on and off the bus, follow instructions from the smartphone screen, use of emergency features) during the travel. At

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[2] https://www.dsrf-uk.org/

[3] https://www.downs-syndrome.org.uk/

[4] https://www.dsscotland.org.uk/

[5] https://www.ds-int.org/

[6] https://www.ndss.org/

[7] https://www.ndsccenter.org/

the same time, parents will be given a smart device to monitor their sons'/daughters' journey progress. In addition, people with DS and their parents/caregivers will be consulted further to gain feedback about the ease of use, accessibility and experience of the developed app during the evaluation process. It would likely be helpful to learn more about app features that are important for both people with DS and their parents/caregivers.

8 Conclusion

In this paper, we reported three design cycles using the PAR methodology. Firstly, the exploratory study, based on our analysis, identified six key barriers to independents living as (1) lack of safety, (2) verbal communication problems, (3) barriers to independent travel, (4) inability to use/access technology, (5) forgetting tasks/activities, and (6) lack of accessible interfaces and information. Also, we presented the potential of smart devices such as smartphone and iPad/tablet as devices that are popular and frequently used by young adults with DS. The study revealed that according to participant's views, independent travelling is an activity that is difficult for young adults with DS and one crucial to their independent living.

Secondly, we identified four key barriers specific to independent travelling as (1) unfamiliarity with routes, (2) barrier to public transport access, (3) lack of suitable technology and apps for travelling and (4) parents' anxiety. We gathered the design requirements from participants (parents, caregivers and people with DS) including drawings of smartphone apps to prototype and a summary of functions and features for the app that can support independent travel.

Thirdly, we offered potential solutions (design of a digital prototype) to overcome travel barriers with a smartphone app that includes a linear Map with voice assistance, special instructions to deal with unforeseen circumstance, notifications and alerts. We revisited participants to bridge the gap between our designed prototype and participant's requirements and we identified solutions to accessibility issues (text size, font style and colour) and usability issues (changes in design e.g. turn by turn navigation and navigational instruction). Also, we introduced features that were brand-new as these features never been applied before for people living with DS e.g. progress bar, visual representation of the linear map (in prototype), overcoming communication barrier to communicate with the bus driver, emergency call button and help page. All these features were described as valuable by participants with DS and their parents/caregivers. Consequently, we ensured that the gathered design recommendations were accurate and met the needs of people with DS to overcome the barriers to independent travel.

With regards to our RQ1 "*What are the main barriers to independent activities for young adults with Down's Syndrome*?", we have identified several substantial barriers to performing independent activities that young adults with DS face on a daily basis (see Cycle 1: section 4, Cycle 2: section 5). In order to overcome these barriers, young adults with DS depend on their parents and caregivers. As for our RQ2: "*How could smart devices (smartphones, smartwatches or smart-clothing) and apps help young adults with Down's Syndrome to perform independent activities?*", we found that smartphones and iPads/Tablets have strong potential to support young adults with DS in performing daily independent activities and to reduce their dependency on parents and caregivers. Taken together, our studies indicate that technology can play a key role in supporting people with DS in daily independent activities and, consequently, increase their social inclusion.

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CONTRIBUTIONS

Khan conducted all the studies reported in this paper as the primary author under the supervision of Dunlop and Lennon. Dubiel was the second assessor who conducted the thematic analysis. All authors contributed to revisions of the paper.

ABOUT THE AUTHORS

AL MAJED KHAN is a PhD candidate in Computer and Information Sciences at The University of Strathclyde in Glasgow, Scotland. His research interests focus on human-computer interaction with smartphone devices particularly to support independent living for people with Down's Syndrome. Author's Present Address: Computer and Information Sciences, University of Strathclyde, Glasgow G1 1XH, UK; majed.khan@strath.ac.uk

DR. MARK D. DUNLOP is a senior lecturer in Computer and Information Sciences at The University of Strathclyde in Glasgow, Scotland. His research interests focus on human-computer interaction with mobile devices with interests in supporting wider mobile accessibility, use of mobiles to support more active lifestyles and improving mobile text entry. Author's Present Address: Computer and Information Sciences, University of Strathclyde, Glasgow G1 1XH, UK; mark@textentry.uk

DR. MARILYN R LENNON is a Reader in Digital Health and Care in the Department of Computer and Information Sciences at The University of Strathclyde in Glasgow, Scotland. Her research interests focus on human-computer interaction and the co-production and co-design and evaluation of digital tools and services for health and care. She also works with health and care organisations to understand their data and to use data analytics more meaningfully to improve patient and citizen care. Author's Present Address: Computer and Information Sciences, University of Strathclyde, Glasgow G1 1XH, UK; marilyn.lennon@strath.ac.uk.

DR. MATEUSZ DUBIEL is a researcher in the Department of Computer and Information Sciences at The University of Strathclyde in Glasgow, Scotland. His research is focused on the design and interactive evaluation of user-centered conversational agents for goal-oriented tasks. Author's Present Address: Computer and Information Sciences, University of Strathclyde, Glasgow G1 1XH, UK; mateusz.dubiel@strath.ac.uk

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