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Lessons from Expert Focus Groups on how to Better Support Adults with Mild Intellectual Disabilities to Engage in Co-Design

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ABSTRACT

Co-design techniques generally rely upon higher-order cognitive skills, such as abstraction and creativity, meaning they may be inaccessible to people with intellectual disabilities (ID). Consequently, investigators must adjust the methods employed throughout their studies to ensure the complex needs of people with ID are appropriately catered to. Yet, there are a lack of guidelines to support researchers in this process, with previous literature often neglecting to discuss the decisions made during the development of their study protocols. We propose a new procedure to overcome this lack of support, by utilizing the knowledge of “experts” in ID to design a more accessible workshop for the target population. 12 experts across two focus groups were successful in identifying accessibility barriers throughout a set of typical early co-design activities. Recommendations to overcome these barriers are discussed along with lessons on how to better support people with ID to engage in co-design.

CCS CONCEPTS

•Human-centered computing ~ Accessibility ~ Accessibility design and evaluation methods •
Human-centered computing ~ Human computer interaction (HCI)

KEYWORDS

Intellectual Disabilities; Co-Design; Accessibility; Alternative and Augmentative Communication

1 Introduction

Including potential users throughout the design of a digital tool increases the likelihood of the final product being better suited to its stakeholders needs and preferences [1]–[4]. Yet previous research [3], [5], [6] suggests that this process is scarcely applied within the domain of accessible technologies for persons with cognitive disabilities, thus leading to the employment of inappropriate aids. For example, Prior suggests that device abandonment rates may rise as high as 53.3% [3], meaning poorly designed interfaces are preventing this population from utilizing potentially life-changing technologies.

One possible reason for omitting people with cognitive disabilities is the lack of guidelines to support researchers in employing appropriate design techniques [5]. Those commonly used by human computer interaction (HCI) practitioners are often inaccessible to people with cognitive disabilities, due to an overreliance on skills that may be impaired [3], [5], [7]. For example, many target higher-order cognitive skills such as abstraction, conceptualization or creative thinking [8]–[12] and therefore require adjustments before they become usable. Nevertheless, investigators who are less rehearsed in interacting with their target

populations may find it difficult to carry out these adjustments without guidance, since their own life experiences differ significantly from those of their participants [5].

In response to this dilemma, Hendriks et al. [5] issued a call for researchers to make explicit the rationale behind their methodologies, as opposed to simply fixating on results. Such an approach enables a body of best practices to be composed, which future investigators can utilize to increase the accessibility of their own studies. Consequently, we aim to address Hendriks et al.'s [5] call by discussing the development of a design workshop for an application to support adults with mild intellectual disabilities (ID) to communicate more effectively with general practitioners (GPs). During this process we utilized the views of "experts" in ID to overcome our previously limited knowledge of how such a population may respond to HCI techniques. We argue that the experts were proficient in identifying, and subsequently mitigating, major accessibility barriers throughout the proposed techniques and will discuss the impact their views had on the final workshops conducted in [13]. Some of the lessons learned may also be applied to other techniques and in different contexts.

Throughout the remaining sections of this paper, we will answer the following three research questions:

1. What co-design techniques are appropriate during the design of clinical augmentative and alternative communication (AAC) technologies for people with mild intellectual disabilities?
2. What common adjustments are required to make co-design techniques more accessible to people with mild ID?
3. What impact can experts have on ensuring co-design workshops are accessible to participants with mild ID?

2 Background

In this section, we will frame the context of our work by presenting the definitions of intellectual disability and co-design used throughout the study. We will also discuss the basis for the proposed workshop, before introducing some of the more common impairments experienced by people with ID that may negatively influence the outcome of co-design methodologies. Prior studies that have utilized co-design techniques with the ID population will be discussed in the first results section, since they were identified as part of a literature review – see Methodology Overview.

2.1 Intellectual Disability Definition

We consider ID using the following World Health Organization (WHO) definition [14]: *“[people with intellectual disabilities have] a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.”* There are a number of manifestations of ID, with the impact on an individual's social and cognitive functioning ranging from mild to severe [15]. The workshop discussed throughout this paper is aimed at adults with mild ID who can, in general, live independently but may require support to complete complex tasks such as managing their finances. This was under the hypothesis that people with more severe ID would have difficulty using the proposed clinical AAC application autonomously, meaning the overall accuracy of the extracted results would be reduced. Previous literature has suggested that the over involvement of caregivers can lead to the collection of observations that differ from the views of the patient [16]–[18].

2.2 Need for Clinical AAC Technologies

People with ID are subjected to various health inequalities [17], [19]–[23] that have a significant impact on the length and standard of their lives [20], [21]. Heslop et al. [20] clearly demonstrated this in 2013 whilst examining the deaths of 247 patients with ID across three hospitals in the Southwest of England. 42% were classified as premature, with a further 27.5% directly attributable to change, providing better quality care was

administered [20]. In other words, circa 68 deaths could have been avoided if the patients received the level of care they were legally entitled to.

With such trends continuing to the present day [21], it is clear that the methods being employed by medical professionals are not wholly accessible to patients with ID. One reason for this may be the lack of training practitioners receive on intellectual disability. Trollor et al. [24] found that the depth and quality of content being taught within undergraduate medical courses was both limited and highly variable. Consequently, many professionals lack the knowledge required to make reasonable adjustments to their consultation techniques [16], [25].

In response to this gap in knowledge, Bell [26] and Raemy and Paignon [27] called for the introduction of mandatory on-site training sessions centering on both the behavioral traits/communication strategies practiced by patients with ID [26], [27], in addition to their health trends [27]. Nevertheless, doctors and nurses are increasingly overworked [28], [29] and could find it difficult to attend training sessions, even when they recognize the need to do so. Furthermore, some countries have yet to implement a national ID strategy [30], meaning healthcare and educational institutions lack the incentives and resources to change their pathways regarding patients with ID.

In contrast, the implementation of AAC technologies could result in much more immediate effects, as discussed by Menzies et al. during the development of a tool to support dental practitioners to communicate with patients with ID [31], [32]. First, these technologies can help to increase the accessibility of complex medical information. In addition, they may capture the treatment preferences of the individual, which can assist practitioners in providing improved, person-centered care [31], [32]. Consequently, there is scope to explore the impact similar technologies may have on primary care consultations, with paper-based aids e.g. [33]–[36] remaining the most prominent tools in use despite the request for more high-tech aids being made as far back as 1997 [37].

2.3 Co-Design Definition

Kleinsmann defined co-design as a procedure in which researchers and stakeholders alike come together to share their expertise on the design process, as well as its content [38], [39]. This approach therefore compels investigators to consider the ability of target users when developing data extraction instruments – an action that may lead to more representative requirements being identified. Similarly, the direct involvement of stakeholders throughout the design phase, should result in more usable technologies that are better suited to the accessibility needs of potential users. Despite these advantages, Rogers and Marsden [40], [41] suggest that there is a tendency for developers to overlook co-design methodologies when creating technologies for people with a disability. Instead, they utilize their own assumptions of what stakeholders may need, which often leads to the development of compensative technologies, as opposed to those that enhance the ability of their users [40], [41].

2.4 Barriers to Co-Design

In 2015, Hendriks et al. [5] explored the potential development of a dedicated methodological approach to enhance the participation of people with ID in co-design. Nevertheless, after consulting with experts, they quickly concluded that their goal was too ambitious, due to the heterogenous nature of people with cognitive disabilities. This then led to a change in mindset, with the authors advocating for an individualized approach to the adjustment of co-design techniques based on the skills and impairments of participants [5]. Key lessons learned whilst carrying out these adjustments should also be disseminated widely to increase the knowledge of other researchers [5]. Yet this body of work may take several years to sufficiently accumulate, meaning investigators are required to seek out other avenues of support.

On the other hand, there is a wealth of literature that highlights the possible impairments participants with mild ID may experience e.g. [3], [5], [7], [39], [42]. Researchers can use this information to determine potential accessibility barriers throughout their proposed data-extraction techniques. For example, speech is often at the heart of co-design methodologies, yet adults with mild ID may find it difficult to present their views using this modality, particularly when complex or unfamiliar topics are being discussed [3], [5], [7],

[39], [42]. Consequently, participants will be more inclined to answer closed questions [43], which could limit their overall contributions, with many tasks relying upon more open-ended queries. In such an instance, it may be more appropriate to extract an individual’s opinion using picture-based frameworks such as Talking Mats™ [35], [44]. Short-term memory impairments [45] can also affect an individual’s ability to follow verbal instructions and operate intricate technologies. Additionally, people with ID tend to have impaired higher-order cognitive skills, such as abstraction and creativity [5], [7], [12], [42], meaning they are unlikely to be able to envisage the potential use of novel technologies. Finally, people with ID are also more likely to develop physical impairments (e.g. motor impairments or short-sightedness [46], [47]) that may limit their ability to participate in hands-on tasks.

Researchers who have limited experience interacting with the ID population may rely upon caregivers to facilitate their study. Nevertheless, there is a lack of consensus regarding the exact role caregivers should play. Part of the literature suggests that the goals and motivations of people with ID differ significantly from that of their caregivers [5]. As such, paid carers, as well as family members, should remain in a purely supportive role during co-design tasks [5]. In contrast, other researchers have found caregivers to be knowledgeable about the experiences and needs of people with ID [39], [42], [43] and have therefore advocated for this population to be directly involved within studies [42].

3 Overview of the Methodology

As discussed previously, the aim of our study was to develop an accessible design workshop that assists adults with mild ID in disseminating requirements for a clinical AAC application. The tasks to be included throughout the workshop centered on three main aspects of the proposed application: (1) its functionality; (2) the design of the user interface; and (3) pictures of medical symptoms, since there is evidence to suggest that imagery can support people with ID to better understand complex concepts [48], [49]. A two-stage process was employed by the authors to identify suitable design tasks to address these aspects. Stage one involved a review of previous literature to gauge the methods used in similar projects, whilst stage two focused on the evaluation of design tasks to mitigate potential accessibility barriers. The final two stages shown in Fig. 1 are not explicitly reported as they lie out with the papers scope of increasing the accessibility of design techniques prior to their implementation with people with mild ID. Nevertheless, section six contains a summary of the key lessons learned throughout their application, with a complete account being found in [13].

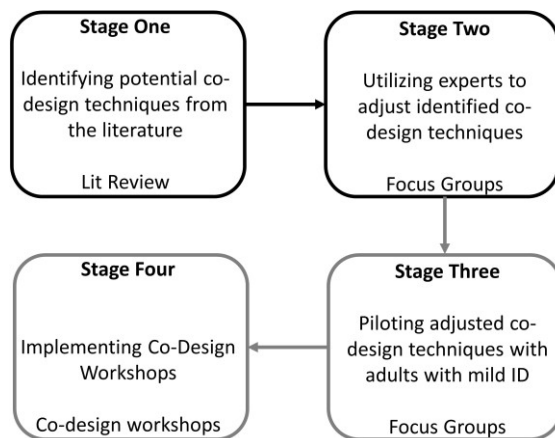


Figure 1: Four-stage design process used to develop the proposed AAC application. Stages one and two focused on the creation of an accessible co-design workshop to ensure representative requirements were extracted from patients with mild ID.

4 Results: Stage 1 – Review of Literature

Stage one was conducted in April 2018 and involved the extraction of potential tasks to be employed throughout the design workshops. The lead author queried three databases (PubMed, Google Scholar and ACM) using the phrase “*co-design AND intellectual disability*” to ensure relevant articles were extracted from both the health and technology domains. The first 100 results returned by each search had their abstracts screened to determine whether they met our inclusion criteria i.e. they discussed the use of co-design techniques with adult participants who had mild ID. We made the decision to limit each query to the first 100 articles, since the relevance and quality of the literature diminished as the search progressed. Eight papers were reviewed in full (see Table 1) to identify potential tasks to support adults with mild ID in addressing the three aspects of the application discussed previously. Some key similarities and differences emerged from this literature that shaped the protocol employed in stage two.

4.1 Ethnography Vs. Interviews

Many of the studies [7], [41], [50]–[52] used some sort of ethnographic technique to extract initial requirements for the proposed technologies. Such methods enabled researchers to bypass traditional interviews in favor of identifying problems that occur naturally in their stakeholders’ lives. Prompts on how technology may be used to overcome these problems could also be made in real-time [41] thus alleviating potential higher-order cognitive impairments such as abstraction. From there, concrete probes [53] / prototypes were developed and subsequently evaluated by potential users in order to identify better representative requirements. Additional methods of extracting initial requirements included interviews with proxies (e.g. family members or caregivers) [7] and the review of previous literature [43].

In contrast, some researchers utilized focus groups and interviews with people with ID to identify how their technologies can mitigate potential barriers [3], [50], [52]. A variety of adjustments were made to ensure these techniques were appropriate to the needs of the participants involved. Prior [3] interviewed several individuals who required AAC devices to communicate and therefore issued resources in advance of the study to allow participants to prepare in-depth answers. Zisook and Patel [50] overcame potential short-term memory and communication impairments by capturing important themes live via the use of sticky notes. This process reminded participants of the topics discussed previously and allowed them to challenge any misconceptions made by the researchers.

In the context of our project, there is a wealth of literature on the potential communication challenges faced by patients with ID e.g. [16], [25], [27], [54]–[57]. As such, we felt it was unnecessary to observe patients with ID interacting with GPs and instead opted to implement a focus group session during stage two. The focus group would enable us to extract the previous communication experiences of participants with mild ID and subsequently identify potential opportunities for AAC devices to mitigate such barriers.

4.2 Low Vs. High Fidelity Prototypes

As highlighted previously, some of the identified studies discussed the use of high-tech probes / prototypes to extract initial requirements from participants with ID [7], [39], [41], [43], [52]. This literature therefore followed the approach of “design after design” advocated by Brereton et al. [41] who suggest that people with ID become better engaged and more enthusiastic when interacting with pre-developed prototypes, as opposed to starting from scratch. Nevertheless, there is a possibility that the introduction of prototypes early in the design phase may restrict or bias the views of the participants. In contrast, other researchers focused on the extraction of requirements via the co-production of paper prototypes [3], [7]. Standard user interface objects (e.g. buttons) were provided to support participants during this process. In addition, Prior [3] utilized storyboards to provide participants with example scenarios of when the proposed technology may be required, therefore assisting them to envisage its overall functionality and design. Since there were pros and

cons to both approaches, we felt it was appropriate to present a paper prototyping task and a high-fidelity evaluation to maximize the potential requirements extracted – see section five.

Table 1: An overview of the studies identified in stage one.

Article	Aim	Co-design Techniques	Discussed Adjustments
Dawe (2007) [7]	Develop a picture based remote communication system.	Interviews with proxies; ethnography; paper mockups; technology probe evaluations; nightly voicemail diaries.	Iterative probing process where additional features were implemented as participants gained experience with the artefact.
Francis et al. (2009) [51]	Co-design digital assistive technologies for people with high functioning autism and aspergers.	Video ethnography; self-photography; think-aloud; role play	Use of concrete examples.
Prior (2010) [3]	Develop a digitized hospital passport for patients with complex communication needs.	Focus groups; storyboard walkthroughs; paper prototyping; medium-fidelity prototype evaluation.	Research materials (questions etc.) issued in advance of study. Example features provided during paper prototyping.
Zisook & Patel (2014) [50]	Understand the most important aspects of communication to improve the design of assistive technologies.	Ethnography; individual interviews; image boards; iterative prototyping ranging from paper-based to high-fidelity.	Live capture of key topics being discussed during interviews via the placement of sticky notes in full sight of participants.
Brereton et al. (2015) [41]	Develop an app to support users with ID to express their goals.	Ethnography; High-fidelity prototype testing.	Initial requirements were gathered from proxies familiar with the needs of the target population.
Wilson et al. (2016) [52]	Develop a goal-setting app for young adults with ID.	Participant and environmental observations; semi-structured interviews; technology probes.	Iterative probing process where additional features were implemented as participants gained experience with artefact. Use of proxies to facilitate interviews.
Sitbon & Farhin (2017) [39]	Develop an app to support people with ID when using public transport in large cities.	Initial prototype evaluations; non-finito features (features with no defined action) to promote creativity.	Caregivers used as proxies to facilitate tasks but also included as full research participants, meaning they were able to provide their own views.
Sitbon (2018) [43]	Develop applications to support people with ID in using public transport in large cities and using search engines.	Low and high fidelity prototype evaluations.	Initial prototypes developed using requirements from the literature. Caregivers used as proxies and research participants.

4.3 Image Boards

Imagery was used as a main source of feedback in just one of the studies [50]. Zisook and Patel [50] implemented the image board methodology to extract potential solutions for an everyday AAC application. The participants were required to select images of interest from a series of magazines before combining these artefacts together to form a collage representing their views. We therefore felt that this approach could be adapted to assist people with mild ID in identifying effective medical imagery. Consequently, task two (see section five) was presented to the experts in the next stage to determine whether such an approach was accessible to the target population.

5 Results: Stage 2 – Focus Groups with Experts

Reviewing the literature enabled us to identify potentially suitable tasks to employ throughout the proposed design workshops. Yet not all of the authors accessibility concerns were addressed in stage one. For example, during the prototype evaluation, it was not clear whether a “Think Aloud” procedure would be suitable for the cognitive skills of people with mild ID. Thus, the decision was made to first pilot the four design tasks shown in Fig. 2 with experts (during a series of focus groups) to ensure all major accessibility issues were mitigated prior to the introduction of adults with mild ID.

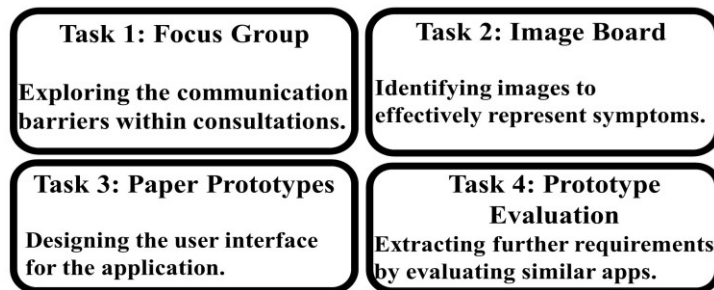


Figure 2: The four activities presented to experts in stage two.

5.1 Methods

Guest et al. [58] suggest that 80% of all themes will be discovered within the first two to three focus groups. As such, we used this recommendation to form our recruitment strategy, which was then implemented during the months of June and July 2018. Invitations to participate were distributed via email to appropriate members of academic institutions and ID charities within four cities across Scotland. During this procedure, potential participants were issued with information sheets to support them in their decision to take part. We were able to recruit enough individuals from two cities (Dundee and Glasgow) to approach our goal of six to eight participants per focus group – see Table 2 for demographics. A separate focus group was conducted in each city in a venue and date that was convenient to the participants involved. To be eligible for the study, the experts had to have five+ years’ experience working with or caring for the target population i.e. individuals who adhered to the ID definition described in section 2.1.

Prior to the commencement of the workshops, participants were reminded of the goals of the study, as well as their individual rights. They then signed a consent form before completing each of the four tasks listed in Fig. 2 – see [59] for the extracted design requirements. Whilst conducting these tasks, the experts were asked to identify potential accessibility barriers for people with mild ID, along with ways to mitigate such barriers. The study then concluded with a discussion on how to overcome common obstacles to conducting research with the mild ID population. The use of focus groups in this context enabled a range of experts to approach the problem from different viewpoints, thus increasing the number of potential barriers identified. Institutional ethical approval to conduct the study was obtained from the Department of Computer and Information Sciences Ethics Committee, University of Strathclyde, ID: 747. The focus groups averaged around 78 minutes.

Table 2: Participant Demographics

Focus Group	Profession	Sex
1	Researcher in the health and wellbeing of people with ID.	F
1	Researcher in the health and wellbeing of people with ID.	F
1	Researcher in the health and wellbeing of people with ID.	F
1	Employee of an advocacy charity for people with ID. Has mild ID.	F
1	Employee of an advocacy charity for people with ID.	F
1	Former ID nurse. Manager of ID activity centre.	F
1	Digital inclusion assistant – Teaches basic digital skills to people with disabilities.	M
2	Community ID nurse.	F
2	Employee of an advocacy charity for people with complex communication needs.	F
2	Community ID nurse.	F
2	Employee of anonymous ID charity. Supports people with ID in pursuit of employment	F
2	Community ID nurse.	F

5.1.1 Description of Tasks

The tasks were developed based on the findings of sections 4.1 to 4.3. Task one aimed to establish the manner in which technology may be used to overcome the communication barriers grounded within the literature. As such, it consisted of a focus group centering on four main themes: preparing for consultations; positive and negative communication encounters with GPs; previous experience in using touch screen technologies; and the implementation of technology to support patients with ID throughout primary care consultations. The sticky note process employed by Zisook and Patel [50] (see section 4.1 and Fig. 3) was also utilized to capture the key concepts being discussed.



Figure 3: Example outputs of the design tasks. 3.1 demonstrates the sticky notes captured throughout task one, 3.2 highlights a produced image board, and 3.3 captures a developed page during the paper prototyping session.

Task two involved the image board methodology discussed by Zisook and Patel [50] to identify appropriate pictures to represent medical symptoms. The experts were required to individually critique pre-existing

images of medical symptoms and separate them into one of two categories: those that accurately represented the symptom conveyed; and those whose meaning was more obscure. All symptoms were conveyed via three or more different images (including basic black and white symbols, colored cartoons, and real-life photographs), with each image incorporating a short textual description to ensure the participants know what it is trying to depict – see Fig 3. A group discussion then occurred on why some images are more accurate in describing symptoms than others, before the pictures deemed effective were collated to form an image board. Images that had similar reasons for their inclusion on the board e.g. clear facial expressions, were grouped together to allow the investigators to form themes on aspects that accurately depict medical symptoms.

Task three aimed to develop an appropriate interface for the proposed application by utilizing paper prototypes. The experts were required to nominate a leader who was responsible for describing initial features to include in the interface. Once the group came to a consensus, mock-up objects were then placed onto a paper representation of a tablet to demonstrate their needs. Similar to Prior and Dawe [3], [7], the objects included general usability features such as skip buttons, as well as those more specific to the application. Blank objects were also provided to allow the inclusion of elements unforeseen by the investigators. Participants were required to develop a paper representation of each screen and describe what actions occur when certain elements are selected, for example a potential symptom.

In task four, participants were required to evaluate a previously developed tablet application [60]–[62] to discern requirements that may not have been identified during task three. A “think-aloud” [63] protocol was utilized where the participants were asked to complete two exercises using the application and describe the reasons behind their actions during real-time. Once again, the group nominated a leader to initiate a discussion on what action should be conducted, yet progress was only made once a consensus was reached.

5.1.2 Analysis of Tasks

All tasks were recorded with participant consent and transcribed verbatim by the lead author to further their understanding of the data captured. The resulting transcripts were then subjected to a framework analysis [64] to extract the primary barriers and facilitators to conducting co-design activities with adults with mild ID. Key phrases / findings were initially tagged by the lead author, before being reviewed by the second author to limit researcher bias. Any discrepancies between the two investigators were resolved by the third author prior to the development of a final working analytical framework. Previously tagged transcripts were then updated to adhere to this framework, at which point the identified excerpts were transferred to their set positions in the framework analysis table. This table has been made available via the following doi:10.15129/76f97730-a5fa-49da-973f-995373cee7ad.

5.2 Focus Group – Exploring Participants Views on Consultations

5.2.1 Accessibility

Overall, the experts found focus groups to be accessible to people with mild ID. In particular, three key themes emerged that may assist adults with mild ID in disseminating their views within a group setting.

5.2.1.1 *Appropriate Use of Language*

Experts across both focus groups stressed the use of accessible language guidelines (such as NHS England’s [65]) to increase the participants’ ability to both comprehend and answer the questions being presented. The use of simple and plain language was disclosed as being particularly important within the proposed focus group due to the complexity and unfamiliar nature of the topics being discussed. Questions that are concise, focus on solitary ideas and avoid the use of jargon should assist in easing the cognitive load placed on participants, which may increase their ability to provide in-depth answers that accurately match their views.

5.2.1.2 *Supportive Caregivers*

Support workers and family members are often familiar with the individual traits of people with ID. As such, they should be able to recognize when inappropriate communication strategies are being implemented by the researcher and subsequently suggest alternative approaches. For example, a caregiver may rephrase overly

complex passages of speech or advise the investigator to avoid specific concepts – see section 5.2.3 for additional methods to overcome complex language.

5.2.1.3 Sticky Notes

The experts were also optimistic about the use of sticky notes to capture the views of participants in real time. They suggested that the notes may act as a concrete referent for the topics being discussed, thus helping to alleviate any short-term memory impairments. Participants are also able to elaborate on or challenge any of the produced notes, meaning the spontaneity of discussion may be increased, which matched the findings of Zisook and Patel [50].

5.2.2 Barriers

The experts identified three barriers to the implementation of focus groups, two of which centered on the questions proposed and one focused on the involvement of caregivers.

5.2.2.1 Response Bias

The participants involved in focus group two revealed that response bias tends to be prominent within the ID population. They suggested that adults with ID are often “people pleasing” and may provide the answers they believe are expected, rather than their own views, as discussed by participant 2.3: *“One member in particular, he went to the doctors and say he had pain in his shoulder but also had pain in his knee...He gets across that it was in his shoulder and the doctor was like “oh is there anything else” and he’d be like “no I’m good” even if he had this horrendous pain in his knee”*

The above example highlights response bias occurring in open-ended questions; however, the experts also suggested that it may be a prominent issue within closed questions, such as rating scales, where the most extreme options tend to be selected. Caregivers may therefore play a positive role in pinpointing response bias, since they should be familiar with the life experiences of the individual with ID and recognize when their answers are inaccurate.

5.2.2.2 Complex Concepts

It was not possible to avoid complex concepts within all the questions presented. One instance was the use of the word “symptom”, where many of the experts in focus group one felt that its meaning could be difficult to comprehend for people with ID. Another example was the concept of time. Each of the ID nurses revealed that their patients had issues determining when a symptom first occurred and suggested a similar barrier could occur throughout the focus group. Strategies to overcome these barriers will be discussed in section 5.2.3.

5.2.2.3 Caregiver Barriers

We have previously discussed the positive impact caregivers may have in supporting people with ID to complete the activities presented to them. However, the experts also highlighted the potential dangers of incorporating carers within research: participant 2.5: *“You’ll get some [caregivers] who will take over or direct them [the participant] more and others will be very supportive...I would try to get them to just sit back.”*

Carers can range from family members who have known the individual for the entirety of their lives, to paid employees who have been hired for a short period of time. As such, they may differ in terms of their familiarity with the needs of the participant, as well as their enthusiasm to get the best outcomes for the individual. For example, family members often care deeply for the participant and this may lead to them becoming overinvolved. As such, the results of the study may be skewed, with caregivers providing opinions that may not match those of individual with ID: participant 1.3: *“I think you need to think about whose perception is it you want to capture during your research. Is it people with intellectual disabilities or is it carers? Cause you might get quite different outcomes.”* Consequently, it is important to clarify the role in which the caregivers have and enforce that they stick to this role.

5.2.3 Adaptations

The experts advocated for the implementation of concrete examples across three separate scenarios to help ease the cognitive load placed on participants. Firstly, those in focus group two suggested shortening any Likert scales used to a maximum of five points and further supplementing them with symbols to clearly define each option, thus matching the findings made by Hartley & MacLean [66]. Concrete examples should also be employed to assist in the clarification of difficult language. For example, a diverse range of symptoms may be presented to the participants to support them in processing what a symptom may entail. The ID nurses also suggested that this strategy may be used to help an individual overcome complex concepts such as time: participant 2.5: *“Things like how long have they had this problem [for] is hard for our clients. So, this is where we use, right, if it’s the summer was it there before Christmas time?”*

5.3 Image Board – Exploring Effective Medical Images

5.3.1 Accessibility

The experts found this activity to be less cognitively challenging than developing images from scratch: *Participant 1.3: “I think it’s better to have these to work with rather than [coming up with your own]” - Participant 2.5: “I couldn’t draw what some of these look like.”*

This was particularly true when more abstract symptoms, such as numbness of a limb, were presented. As mentioned previously, people with ID tend to have impaired higher-order cognitive skills such as abstraction and creativity [8]–[12]. Consequently, their ability to describe how certain symptoms may look could be affected, especially if they have not experienced such symptoms before. It was therefore considered to be more appropriate to present potential options to the participants and have them share their needs by critiquing these options.

5.3.2 Barriers

Two potential accessibility barriers were identified: the labels placed on the images; and the heterogeneity of the participants.

5.3.2.1 Labelling images

The experts in focus group one advocated for the use of labels to assist participants in critiquing the accuracy of the image: *Participant 1.3: “I think it’s good with that and then you have headache at the bottom. And I think if it didn’t have headache at the bottom it would be quite confusing ‘cause it could be is she burned, has she burned her face?”*

However, this quote suggests that the participant initially found the image to be ambiguous, and its intention only became clear after they had read the label. As such, there is a possibility of response bias occurring and this was a concern raised by the experts in focus group two: *Participant 2.2: “if you have the words there it would be very much what answer you’re looking for rather than what they actually think or what [they would see] without guidance.”* The use of labels may therefore detract from the natural first impressions of the participant and could potentially lead to the development of images that are less effective in describing symptoms.

5.3.2.2 Heterogeneity

The experts were unable to agree upon the style of image that best represents medical symptoms. Those involved in focus group one preferred images that incorporated real life instances of conditions within them. On the other hand, the ID nurses involved in focus group two revealed that they are more familiar with the simplistic black and white line drawings and believe that such a style would be more effective. Participant 2.5 predicted that this scenario would occur throughout the co-design workshops: *“You’re going to get*

different people saying different things. Be prepared for them disputing the best one 'cause everybody has got their own things as to what they like.'

5.3.3 Adaptations

The experts suggested also implementing an image board on which to capture the ineffective pictures (versus simply discarding them), as a way to promote discussion on the features of the pictures that the people with ID find inaccessible. Additionally, researchers must be wary of the heterogeneity of the ID population and adjust various resources to account for this heterogeneity. An example implemented by us was the inclusion of a range of image sets within task two, as opposed to just one. A discussion on the inclusion of image labels will be provided in section six.

5.4 Paper Prototype – Design of User Interface

5.4.1 Accessibility

The experts believe that the low-fidelity prototype process is more accessible to people with ID in comparison to hi-fi prototypes. Those involved in focus group two explained that many people with ID come from a household affected by poverty and, as a result, may not interact with tablet technologies frequently: *Participant 2.2: "We understood that you meant "click on that and it'll go to the next section" but for people who are not familiar with iPads or apps, that would just blow their mind."*

As such, it may be initially daunting for the participants to interact with an application or device they are unfamiliar with. Additionally, people with ID often require support from their caregiver when interacting with technology, meaning they can be entirely dependent on their carer being tech-savvy to complete the task. Some participants may therefore be more comfortable when interacting with paper prototypes, yet our own research suggests that most people with mild ID have access to smartphones (due to their declining costs), with up to 50% also owning tablets. Ramsten et al. [67] came to a similar conclusion, therefore indicating that digital exclusion may not be a prominent barrier within this population.

5.4.2 Barriers

In addition to digital exclusion one further barrier was proposed by the experts. Originally, we had planned to utilise abstract elements to represent objects, such as simple "Answer" and "Question" tags. However, all experts felt that this approach would be cognitively challenging. They suggested that the participants would find it difficult to relate to the objects, which may impact their ability to identify their needs. For example, they may believe that the inclusion of six options on the screen could be accessible, when in reality it is overwhelming and hinders their ability to answer the question presented.

5.4.3 Adaptations

Once again, the concept of using concrete examples was brought up by both sets of experts. They stated that the inclusion of example questions and answers within the paper prototype could reduce the cognitive load placed on the participant. This will then allow them to convey their needs accurately as described by participant 1.1: *"It might be better if you give them examples of questions. So rather than "question" and "answer" you can give them your choice of two answers or examples like "do you feel cold." Or if you had six choices with real life examples they could say "oh it's too much I can't decide between these ones."*

Participant 2.2 also discussed using examples to overcome the potential issues that arise from digital exclusion. She revealed that a short demonstration of tablet technologies could be provided to give the participants with ID an idea of how they function. This could also include some time for them to interact with similar accessible health applications. In addition, participant 2.2 also proposed a minor improvement to the paper prototyping process to make technology specific actions explicit to the participants: *"if you just got flip chart paper and put it along the wall, then it was like [the changing of screens]."* The experts in focus group two agreed that this was a good suggestion and believe that the flip chart would

be able to mimic such actions. To elaborate, flipping over the paper may symbolize the changing of screens, with existing elements being replaced by newer ones once an action has occurred. This may help the participants to visualize the consequences of tapping on certain objects.

5.5 Think Aloud - Critiquing Existing Touchscreen Prototype

5.5.1 Accessibility

Overall, the experts found the “think-aloud” session to be inaccessible to people with mild ID. They suggested that the need for the individual to describe their actions is cognitively challenging and will distract them from performing the exercise to the best of their ability: *Participant 2.4*: “*It might be a little bit too much. It would probably be too much for me, oh, how do I touch that and speak at the same time. I think afterwards would probably be [better], like a talk through review type thing.*” Consequently, the authors were encouraged to adapt this process to ease the cognitive load being placed on the individual and this will be discussed in further detail in section 5.5.3.

5.5.2 Barriers

Two main accessibility barriers were cited by the experts when completing this activity: complexity and digital exclusion.

5.5.2.1 Complexity

As discussed in section 5.5.1, the experts believe that the “think-aloud” process is too complex for the mild ID population. Combining the need to describe an action with the need to complete a task using the prototype was deemed to be cognitively excessive and may limit the amount of feedback received. As such, these two processes should be separated, and this will be deliberated further in 5.5.3.

5.5.2.2 Digital Exclusion

In section 5.4.1, the concept of digital exclusion was discussed. This could have a significant impact on the results obtained from the study since the needs of people who are unfamiliar with such technologies may differ extremely from those who are. Consequently, researchers must be prepared to develop products that accommodate for the requirements of a wide range of users. In exceptional circumstances some may be unaware of the technologically specific actions required to interact with tablets - such as swiping and scrolling. This is one scenario where the benefits of allowing the participants to interact with the technologies beforehand may be of use.

5.5.3 Adaptations

To increase the accessibility of this activity, the experts suggested separating the prototype interaction phase from the evaluation phase. As such, a post-task walkthrough methodology [68] may be more appropriate, with the participants answering questions about their actions on completion of the task. One downside to this, however, is the opportunity for the individual to justify their decisions, since they have time to think about what they have done rather than being prompted immediately.

The experts in focus group one also discussed the need to change the accessibility settings contained within the device to suit each individual’s preferences: *Participant 1.7*: “*I think one thing that might take a bit of time as well is the setting up. Like if it’s on the tablet then setting the tablet up for their [accessibility] needs, [for example], maybe a screen reader so they can tap on things for [the interface] to speak to them.*” This may include aspects such as: changing button activations to occur on the end of a tap; updating color schemes to account for color blindness; increasing contrast etc. Yet, identifying and setting up accessibility settings for a large focus group may be an extremely time-consuming process, meaning investigators could benefit from completing this task in advance of the study. Nonetheless, such a process may be crucial to the participants ability to use the prototype effectively.

6 Discussion

Stages one and two (see Fig. 1) resulted in the identification and subsequent adjustments of co-design tasks to support adults with mild ID in discerning requirements for a clinical AAC application. The implementation of these tasks with ten participants with mild ID has been reported elsewhere [13], yet we will now discuss their effectiveness to demonstrate: (1) common adaptations that may be applied to other projects; and (2) the success the experts had in ensuring the design techniques were accessible.

6.1 Targeting a Range of Modalities

It was clear throughout that the experts advocated for a mix of different tasks to be used within the study. People with ID are highly heterogeneous and therefore respond to information in different manners. As such, utilizing workshops that rely heavily upon a single modality is an ineffective strategy and may severely limit the amount of feedback being received by participants. For example, in the design workshops employed in [13], several of the participants took a back seat in the more verbal tasks (i.e. the focus groups and think aloud's) due to being less comfortable in a group setting. Yet their feedback was well-received in the tactile image boards and paper prototypes. Additionally, targeting a range of modalities assists in capturing the participant's attention, particularly during extended studies. Such a practice was evident throughout previous literature [3], [39], [48], [50], with researchers combining a range of techniques such as storyboarding, interviewing and prototyping etc. to extract the needs of their participants.

6.2 Providing Equal Opportunities

Throughout two of the three focus groups conducted with adults with mild ID [13], one participant tended to dominate the majority of the discussions. In such cases, it was important to involve the other participants by deflecting the views of the dominant individual to the others. For example, you could forward on the comments to another person by asking if they agree with what has been said. Another strategy may be to have a set order in which the participants can express their individual views before coming together to have an overall discussion. Nevertheless, it is important that you refrain from singling out a participant who is less outgoing, whilst having a heightened awareness of response bias, since individuals are likely to accept the views of the majority using yes or no responses.

6.3 Use of Concrete Objects

During the focus group tasks [13], the participants with ID appreciated the use of sticky notes to keep track of what was being discussed, yet they were unlikely to challenge any misconceptions made. Instead, the lead author had to prompt the participants to review the accuracy of the sticky notes on completion of the task, at which point some errors were rectified. For individuals who are illiterate, it may also be more appropriate to utilize other modalities such as imagery. Within the image board task, we initially made the decision to pilot images that included short descriptions of the symptom being depicted. We found that the participants were more inclined to assign pictures to the ineffective board, meaning they disagreed with the original statements and response bias would unlikely have occurred. Overall, the experts felt that the use of concrete examples could help people with ID to: understand complex language; overcome potential digital exclusion barriers; comprehend abstract concepts; and answer questions with greater accuracy.

6.4 Prototypes

Several alternatives to extracting requirements from participants with ID were discussed by the literature, including ethnography [7], [41], [50]–[52] and the evaluation of pre-developed prototypes that increased in fidelity [39], [41], [43], [52]. Potential methods of creating such prototypes ranged from the lessons learned from previous literature [39], [43] to the knowledge held by proxies who are familiar with the needs and abilities of the people with ID [41]. In our study [13], the paper prototypes produced by the participants broadly matched the high-fidelity prototype developed using the requirements extracted from experts. This

highlights the potential of proxies in recognizing the needs of people with ID, yet it is still important to pilot any technologies with target users, to ensure all requirements are identified.

6.5 Experts and Caregivers

The most knowledgeable experts across the two focus groups discussed within this paper were the ID nurses. They were able to consistently envision how the design tasks would assist or hinder participants with ID to discuss their clinical experience. Nevertheless, the experts who had knowledge in HCI and digital inclusion also made significant contributions to the identification of potential accessibility barriers - for example, the need to change the user interface settings on tablets before use. As such, the authors recommend a variety of experts be employed within the focus groups to ensure design tasks are approached from different viewpoints and the optimal number of accessibility barriers are addressed before implementation with target stakeholders.

Previous literature suggests that caregivers may have two distinct roles within research involving people with ID: (1) they may support the individual to complete the task to the best of their abilities by performing appropriate adjustments [5]; or (2) they may actively contribute to the task due to their familiarity with the experiences and needs of people with ID [39], [42], [43]. Our research, however, indicates that a combination of these two strategies may be most appropriate. The experts initially agreed with role one to ensure the information obtained is the true views of the participant and not those of the support worker/family member. Nevertheless, they later realized that caregivers may have a positive influence on recognizing the presence of response bias and could therefore rectify the answers provided to match the life experiences of the individual with ID. There may also be scope to employ design tasks with caregivers in addition to people with ID, to extract the similarities and differences that occur between these two populations.

6.6 When to Include Experts?

One possible drawback of the proposed approach is the over-reliance on domain experts to evaluate and adjust potential design methods. As such, it may not always be appropriate due to the overheads involved in recruiting specialist participants who have restricted free time. Researchers should first look to the literature to gauge whether suitable techniques have been used in the past, including those that have been implemented with other populations who have similar needs – for example, participants with limited cognitive functioning due to dementia. Experts may then be contacted if any accessibility concerns remain, particularly when the study focuses on novel technologies in which similar products do not exist.

7 Limitations and Future Work

Two main limitations emerged during this research. First, the scope of the design tasks was restricted to the clinical AAC needs of people with mild ID. As such, there is no guarantee whether the lessons learned will transfer wholly to different domains or populations. Second, all experts resided in Scotland, which has a publicly funded health service with a reliance on GPs to facilitate entry into the healthcare system. Consequently, the findings may not transfer to different care regimes or to countries that have less sophisticated technological infrastructures. The lack of implementation of the proposed design methods may also be considered a limitation; however, as described in section three, this has been presented in [13]. Opportunities for future work may center on the employment of accessible methods in other design contexts; and the dissemination of common guidelines to support researchers in a variety of domains

8 Conclusion

Until a shift in culture towards the explicit dissemination of best practices takes place, researchers are likely to be continuously burdened by the lack of guidelines to support them in conducting studies with people with ID [5]. We have therefore proposed a two-step process to support those who have less experience interacting with the ID population to increase the accessibility of their co-design workshops. First, a literature review may be conducted to identify research techniques that have been employed in similar areas, along with any

reasonable adjustments that have been implemented. The resulting tasks may then be presented to experts in ID to mitigate accessibility barriers that had not been previously discussed. Common barriers highlighted by our experts included: overly complex concepts; heterogeneity within the ID population; digital exclusion; and overbearing caregivers. Potential adjustments, which may also be applied to other research methods, involved: the use of concrete examples; implementing design techniques that apply to a range of modalities; clearly defining the role of support workers / family members; and breaking complex tasks down into more manageable steps.

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