Designing with and for People with Intellectual Disabilities

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People with intellectual disabilities often experience inequalities that affect the standard of their everyday lives. Assistive technologies can help alleviate some of these inequalities, yet abandonment rates remain high. This is in part due to a lack of involvement of all stakeholders in their design and evaluation, thus resulting in outputs that do not meet this cohort's complex and heterogeneous needs. The aim of this half-day workshop is to focus on community building in a field that is relatively thin and disjointed, thereby enabling researchers to share experiences on how to design for and with people with intellectual disabilities, provide internal support, and establish new collaborations. Workshop outcomes will help to fill a gap in the available guidelines on how to include people with intellectual disabilities in research, through more accessible protocols as well as personalised and better fit-for-purpose technologies.

CCS Concepts: • **Human-centered computing** → Mixed / augmented reality; **Accessibility design and evaluation methods**; *User studies*; • **Social and professional topics** → **People with disabilities**.

Additional Key Words and Phrases: Design, People with Intellectual Disabilities, Communication, Methods, Assessment

ACM Reference Format:
Leandro Soares Guedes, Ryan Colin Gibson, Kirsten Ellis, Laurianne Sitbon, and Monica Landoni. 2022. Designing with and for People with Intellectual Disabilities. In *The 24th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '22), October 23–26, 2022, Athens, Greece.* ACM, New York, NY, USA, 10 pages. https://doi.org/10.1145/3517428.3550406

1 BACKGROUND

People with intellectual disabilities (ID) may benefit greatly from the use of assistive technologies or apps that can support their participation/inclusion in a society that is still learning to become inclusive; these technologies can also support their overall independence and wellbeing [8]. Many designs seek to address independence, in line with the definition of the World Health Organisation [37], which states that 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."*. However, end-users are rarely involved in the early stages of the design process [26], thus resulting in rigid systems that do not meet their interests, abilities, or their support needs, with abandonment rates for assistive technologies remaining high (50%+). In order to promote the use of co-design, Hendriks et al. [18] have called upon researchers to share the lessons learned and adjustments needed when employing traditional

Manuscript submitted to ACM

methods with participants with cognitive disabilities. This body of literature will then help to drive more accessible research in the future.

In our half-day workshop, we aim to focus on community building by offering a venue for researchers who are spread far and thin worldwide to come together, establish networks, and share their expertise in designing for and with people with intellectual disabilities. The workshop should also contribute to the call of Hendriks et al. [18] by producing outputs based on the two themes:

- The considerations to include people with intellectual disability in research both as participants and co-researchers; and
- The methods and practices that can enhance the participation of people with intellectual disability.

1.1 Towards a More Inclusive Society

In recent years, worldwide emphasis has been placed on improving the quality of life of people with intellectual disabilities [38]. This includes aspects such as: the introduction of disability-focused government policies and laws e.g [14, 24, 25]; the abolishment of segregated institutions, like healthcare and education, in favour of public inclusion [35]; and the wider (yet not quite sufficient) availability of assistive technologies and services [8]. In terms of the latter, Boot et al. [8] suggest that an increased focus on the development of assistive products for and with people with intellectual disability may accelerate the advancement of this population's health and the realisation of their basic human rights. The ACM SIGCHI and SIGACCESS communities have therefore begun to explore the co-design of technologies to support people in: navigating the web [2, 4, 27]; learning early and continuous life skills [1, 3, 9, 20, 29]; visiting cultural heritage sites in-situ or virtually [31, 32]; utilising public transport [30]; and communicating medical symptoms [15, 16]. Nevertheless, there is still much to be done to reduce the experience of everyday inequalities.

1.2 Designing with People with Intellectual Disabilities

Developing technologies that comprehensively meet the needs and abilities of people with intellectual disabilities is not a trivial matter. As end users, all individuals should participate in the design and evaluation of products [5, 6, 13, 16, 30, 31, 33, 34], yet traditional co-design and user-centred methods often rely upon a standardised set of participant skills, which may not reflect those employed by the individuals to express themselves or conceptualise their experiences, or for which participation may be conditioned by adjustments [18]. Without guidance and reassurance from the community, researchers may not feel competent to engage people with intellectual disability in the co-design process [28]; this may also be a result of their inability to relate to the life experiences of participants [18]. Hendriks et al. [18] therefore explored the potential development of a dedicated methodological approach to enhance the participation of people with cognitive disabilities, including intellectual disability, in co-design, through the review of previous literature and workshops with experts. Nevertheless, they quickly came to the realisation that such a single approach was not reflecting the importance of the diversity of life experiences of people with cognitive disabilities. This led to a change in mindset towards advocating for an individualised approach to the development of design techniques centered on the abilities of participants [18]. As mentioned previously, the lessons learned whilst designing the methods themselves should also be shared widely to build a body of literature that may improve the accessibility of future research [18].

1.3 Workshop Topics

In order to contribute to the call of Hendriks et al. [18], and facilitate the sharing of expertise, the workshop's community-building exercises will focus on the following topics:

1.3.1 Design and Evaluation Methods. As highlighted, traditional human-computer interaction techniques often rely on a unique and generic skill set that may not reflect the diverse abilities of individual participants with intellectual disabilities [10, 18]. For example, speech is typically at the centre of co-design methodologies, yet participants may find it difficult to present their views on complex or unfamiliar topics using their voice or natural language, or to people they do not know and trust [11, 12, 18, 23, 26, 30]. Hands-on tasks often expect participants to master fine-motor skills, whilst verbal instruction or the operation of intricate technologies relies on participants having a good short-term memory [36]. Furthermore, co-design activities, such as analysis and ideation, tend to rely on participants' higher-order cognitive skills (e.g. abstraction and creativity) [7, 11, 12, 18] which may not be how participants prefer to evaluate the potential use of novel technologies. Finally, common evaluation methods such as Likert Scales are open to response bias, with participants typically selecting the most positive options [17]. Therefore, we welcome contributions from researchers who have experimented with alternative and respectful design and evaluation techniques in both a group and one-to-one setting. Consequently, the details that are often overlooked in publications in favour of results can be shared in depth with the wider academic community.

1.3.2 Communication. Communicating is central to participation in research, or in design, and people with intellectual disability may chose to communicate in a range of modalities, which should be equitably recognised. Researchers need to carefully consider representing the views of all their participants; some participants may be able to present in-depth feedback, whilst others may only utter basic sentences, rely on signing languages such as Makaton [22], or provide yes/no responses. In addition, some participants are likely to make use of augmentative and alternative communication to share their views, which can range from physical, picture-based artifacts, such as Talking Mats [21], to intricate text to speech technologies.

Researchers also need to carefully consider the context in which participants with intellectual disability are sharing their views, as some people may not be comfortable expressing themselves as part of a group, or towards people who are not familiar to them. Communication may be mediated by people who know participants well, as they can support the condition of participation, and support the researcher in correctly capturing the meaning of what participants chose to share. It is, however, unclear how alternative forms of expression, including mediated communication, should make their way in the structure of research data collection. Consequently, there is an opportunity to build upon existing reflections, such as Prior's commentary on the involvement of people with complex communication needs in the design of a patient hospital profile [26].

1.3.3 The Role of People with intellectual disability and their Caregivers. Due to the shift in emphasis towards co-design [5, 6], people's role in research is changing from largely participant based (or even as a bystander) to a more prominent position where they are actively involved in leading activities and making decisions. Nevertheless, much of the discussion surrounding the inclusion of people with intellectual disability focuses on the former approach. Consequently, we will encourage participants to also share experiences that will support others in working with people with intellectual disability as part of a steering committee, or as fully fledged co-researchers.

In addition, there is a continuing debate on the role caregivers should have in research involving people they support. On one side, researchers suggest that the goals and motivations of people with intellectual disability differ significantly

from that of their carers, meaning the contributions of paid and non-paid caregivers should be limited to support only [18]. In contrast, other researchers have found caregivers to be knowledgeable about the experiences and needs of people they support, and have therefore advocated direct involvement within studies [11, 28, 30]. As such, there is an opportunity to add further empirical evidence to this debate.

1.3.4 Enhancing the Participation of Marginalised Communities. Like other fields, researchers in ID often find it difficult to obtain primary or secondary data from marginalised participants. For example, NHS England's 2020 LeDeR Report (Learning from Lives and Deaths - People with a Learning Disability and autistic people) highlighted that the Black, Asian, and Minority Ethnic (BAME) people with ID and autism represented a significant under-reporting, as well as increased health inequalities [19]. Therefore, the ACM SIGCHI and SIGACCESS groups could benefit from additional discussions on improving the participation of more marginalised sub-populations. Also, by allowing different types of submissions - see Section 3 and 7 - and taking measures to make the workshop as accessible as possible, we are making it possible for different people to participate in the workshop. Extending the invitation from colleagues and people they are working for and with.

1.4 Workshop Outcomes

The main outcome of the workshop will be community building, where networks will be established in an otherwise relatively thin and disconnected field. This could lead to future collaborations, support, mentorship, etc. The workshop's community will also contribute to the call of Hendriks et al. [18], by sharing commentaries on the best practice methods and procedures when designing and evaluating technologies with people with intellectual disabilities. For example, there is an opportunity to combine the knowledge of participants to prepare a checklist of factors researchers should consider when reporting on study designs and results. The availability of such a checklist may therefore support and encourage other academic and industry professionals to share their experiences. Finally, the workshop will set the foundations for a recurring series of workshops in other specialised conferences such as MobileHCI and IDC, which may help to improve the accessibility of research being conducted in those disciplines, e.g., the development of mobile technologies, and that of innovative child computer interactions so that people with intellectual disability may begin to be considered in future developments equally. We also plan to use SIGACCESS Newsletter to disseminate the results of the workshop while also proposing contributors be part of a special issue on the main topic of the workshop.

2 WORKSHOP PLANS

We propose a highly interactive workshop to coincide with our focus on community building, thereby promoting active discussions among industry and academic participants.

2.1 Format

In accordance with the submission guidelines, the workshop will be held entirely online using the ASSETS' recommended video conferencing software. This will support the participation of an extended network of researchers and professionals, by allowing the opportunity to contribute for those who are unable to attend the physical conference.

2.2 Structure

We propose a half-day workshop. To accommodate different time zones and needs, we plan to have a 4-hour synchronous session (from 9 am to 1 pm Athens time) on the day of the workshop and asynchronous activities to meet participants,

provide materials, and network before the event. Afterwards, we expect to have a report on the outcomes of the workshop and keep connected with the participants in an online channel, fostering research collaboration. Here are the details of the expected workshop synchronous schedule:

- Opening and Introductions - 30 minutes. The organisers will outline the goals of the workshop, including the agenda for the day. Participants will then have the opportunity to remind each other of their own background, and motivations for taking part. Note that initial introductions will occur in the pre-workshop activities - see Section 6;
- Keynote + Questions - 30 minutes. We will invite a keynote speaker to introduce their work with and for people with ID during a 20-minute presentation session, followed by 10 minutes of Q&A (Questions and Answers) from our participants;
- Break - 10 minutes. A 10-minute comfort break will be provided for our participants;
- Experience Reports - 40 minutes. This session will exhibit the experience reports submitted by the workshop participants during their expression of interest, along with the materials developed by the organisers with our target group. These reports may include various formats such as audio, video, and text, meaning the organisers will be in touch with participants in advance to agree on the best style of presentation. For example, captioned video submissions could be replayed verbatim, whereas a PowerPoint presentation may be needed to replace a textual submission. The resources produced during this session should help other researchers gain a deeper understanding of the needs, and preferences of people with ID in human-computer interaction research;
- Break - 10 minutes. Another 10-minute break will be provided for our participants;
- Breakout rooms - 50 minutes. The group of participants will be divided into breakout rooms, based on everyone's submissions and interests. The purpose is to discuss different topics relating to the design of technologies in a more intimate session. At least one organiser will be available in each room to serve as a facilitator and note-taker, and to create discussion points that provoke conversation;
- Break - 10 minutes. The last 10-minute break will be provided for our participants;
- Reflection and Closing Remarks - 1 hour. The final session will summarise the findings from the breakout rooms, with the participants agreeing on the design considerations and practices that should be shared with the wider academic community. Lastly, we will identify opportunities for further dialogue and collaboration beyond the workshop.

3 DIVERSITY AND INCLUSION CONSIDERATIONS

We are planning a workshop that will include not only researchers and participants interested in the topic but also people our research seeks to include and support: people with intellectual disabilities. Our workshop will aim, through experience reports, to exhibit accessible media developed by diverse workshop participants and the organisers. We will work closely with our already established networks to identify and then support people with intellectual disabilities to share their pre-developed recollections of participating in co-design. We will also invite associations, such as charities and disability service organisations, to attend the workshop and offer their valuable experience with all of us.

This workshop is an opportunity for people with different perspectives to meet. Furthermore, by definition, we do not want to impose a clear submission length, format, or guidelines that could limit any form of participation. During the invitation process, we will ask participants to list the reasonable adjustments needed for their successful participation in the workshop, which will be carried out on the day. Those who wish to participate also have a number of avenues to

express their interest, rather than being limited to the traditional paper submission process. For academic applicants, we will provide accessible guidelines - see Section 7. Lastly, we can wave registration fees and arrange special grants in agreement with ASSETS organizers, to extend the participation of people with intellectual disabilities and practitioners.

4 ORGANIZERS

We have assembled a multidisciplinary team with expertise in Accessibility and Human-Computer Interaction. Our organizing team has experience working with People with Intellectual Disabilities, ranging from hardware to software.

- **Leandro Soares Guedes**[1] is a Research Assistant and Ph.D. student at USI (Switzerland) and an Assistant Professor at IFMS (Brazil). He holds an M.Sc. in Computer Science from UFRGS (Brazil) and a B.Sc. in Computer Science from UFPEL (Brazil) with an exchange program at U.Porto (Portugal). His current doctoral project involves People with ID in the Museum context, seeking to enhance their user experience into three branches: Augmented Reality, Accessible Applications, and Multisensory Experiences. He is mainly interested in Human-Computer Interaction, Accessibility, User Experience, Inclusion, and Education.
- **Ryan Colin Gibson** is a postdoctoral Research Fellow in Computer Security in the Department of Computer and Information Sciences, University of Strathclyde. His main research interests lie in the design and evaluation of accessible technologies for vulnerable populations, with a particular focus on intellectual disability. His Ph.D. work on "Designing Clinical AAC Tablet Applications with Adults who have Mild Intellectual Disabilities" received a Best Paper Award at CHI'2020.
- **Kirsten Ellis** leads the Inclusive Technology Lab at Monash University in the Faculty of Information Technology. She is working with the community to use cutting edge technology to solve real-world problems for people living with a disability. Her current research focuses on optimising creative technology engagement opportunities for people with Intellectual Disabilities.
- **Laurianne Sitbon** is a Future Fellow of the Australian Research Council (ARC), and associate professor in the school of Computer Science at the Queensland University of Technology (QUT) in Brisbane, Australia. Her research expertise spans human computer interactions (with a focus on co-design and cognitive accessibility), natural language processing (with a focus on semantics), and information retrieval. She has conducted and supervised research through co-design with people with intellectual disability to guide the design of information access technologies and their potential to support inclusion through visual communication.
- **Monica Landoni** is the leader of the Laboratory of User Experience, Interaction & Accessibility, LUXIA at the faculty of Informatics at Università della Svizzera Italiana (USI). She has worked on several national and European projects investigating how technology can support user groups with special needs when searching, writing, and reading for education and pleasure. While doing that, she has happily designed and conducted many collaborative design sessions in formal and informal settings, carefully taking into account the needs, requests, roles, and points of view of varied stakeholders.

5 WEBSITE

The website for the workshop will be developed following accessible guidelines and will be hosted in the following URL: www.luxia.inf.usi.ch/dpid/.

[1]Main contact author

Information regarding the goals of the workshop and key dates will be provided on the homepage to entice potential participants into exploring the site further. There will also be a page dedicated to the "Call for Participation" that will elaborate on the information discussed in section 7, whilst a link to accepted submissions, experience reports, and media (audio, text, videos etc.) will be uploaded to a "Program" page (with permission from authors) along with the finalised schedule. Details on the organising committee will be included on an "Organisers" page. Finally, a "Results" page will be added on completion of the workshop to provide a space to update people on what happens next e.g. further community building through Slack/Discord, paper publications, etc.

6 PRE-WORKSHOP PLANS

We are pleased to announce that this workshop is open to everyone interested in the topic, regardless of experience, role and expertise level. We will share workshop calls between our contacts and primary e-mail listings to attract interested participants. It is expected to have attendance from researchers, students, industry and third-sector employers, and last but not least, people with intellectual disabilities. We acknowledge that while we want to encourage and support the participation of people with ID in our workshop, this can be challenging due to several reasons, such as communication language and the online setting. We are ready to give it a go and learn with this process, exploring such uncharted territory, and will share the lessons learned with the wider academic community. All participants will be able to apply in multiple ways to promote the accessibility of the workshop:

- Filling in a form expressing their interest
- Sending an abstract by e-mail
- Submitting an experience report via video, text, or audio

After sharing the list of the accepted participants, we will contact each individually to propose asynchronous activities via community building apps such as Discord or Slack. These activities may include: introductions; expertise sharing; expectation building for the workshop; breakout room theme development etc. We will also ask participants about their preferences and accessibility requirements for the workshop platform.

7 CALL FOR PARTICIPATION

CFP: Designing with and for People with Intellectual Disabilities (DPID) Workshop @ ASSETS 2022

This half-day workshop aims to focus on community building, enabling researchers to share experiences on how to design for and with people with Intellectual Disabilities, provide internal support, and establish new collaborations. Our pre-workshop plans propose asynchronous activities to support networking and to understand participants' preferences and needs. Workshop outcomes will help fill a gap in the available guidelines on including people with intellectual disabilities in research, which should lead to more accessible protocols and personalised and better fit-for-purpose technologies.

Areas of interest for the workshop include, but are not limited to, the following topics:

- Verbal and non-verbal communication (e.g., language, AAC, signals, feedback)
- Methods for working with participants (e.g., experience reports, co-design, focus groups, scaffolding, active support)
- Design and development of hardware and software (e.g., inclusive applications, assistive technology, multisensory experiences, AR/VR)
- Assessment techniques (e.g., cards, multiple choices, open-ended questions, satisfaction surveys)

We are pleased to announce that this workshop is open to everyone interested in the topic, regardless of experience and expertise level. Participants will be able to apply in multiple ways:

- Filling in a form available on our website expressing interest
- Sending an abstract by e-mail
- Submitting an experience report via video, text, or audio by e-mail

Please, keep in mind that the requirement is that at least one author of each accepted submission must register for and attend the workshop.

You can find more information on our website available at www.luxia.inf.usi.ch/dpid/.

Thank you, The DPID Workshop Organizing Committee 2022

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