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“I Feel Proud That with This App We Can Help Other People with Intellectual Disabilities”: The Role of an Expert by Experience Digital Inclusion Citizen Advisory Panel

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Abstract: Despite legislation affirming the rights of people with intellectual disabilities to take equal part in society, marginalization persists. Accessibility needs can impact this group’s ability to engage in the digital society and in aspects of daily living, such as employment and socializing. The Digi-ID PLUS study was established with a team of seven people with an intellectual disability. Team members were hired as a diverse group to give insight into their lived experiences in reviewing and validating research findings. Their insights were key to every aspect of Digi-ID PLUS. It has been recognized that user-centered design enhances technology development and accessibility; therefore, the aim of establishing a Citizen Advisory Panel (CAP) in our program design and delivery is to include the critical role of users by experience to review, validate and test our solution to enhance the accessibility of all aspects of the program. Working with Digi-ID PLUS, the CAP spoke of the impact being paid team members had on their lives. Analysis of insights shared indicated that being a part of the team had a positive impact on their self-image confidence and digital skills acquisition. CAP members discussed the importance of supporting each other and the value of being paid for their insights.

Keywords: accessibility; digital inclusion; user-centered design



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1. Introduction

Digital literacy is required to harness the increased opportunities online for supporting health, accessing health professionals, connecting with services, and maintaining connections with family and friends. Research provides evidence that, contrary to World Health Organization sustainability goals, people with intellectual disabilities (est. 8 million in the EU) are being left behind in a time when their increased vulnerability during the pandemic requires more than ever their full participation in our digital society. People with intellectual disabilities also have high levels of communication difficulties, with one in three reporting difficulty talking to healthcare professionals [1].

Additionally, social connections that hold meaning to their participants have been suggested to decrease negative emotions, such as loneliness [2]. Peer interactions can give opportunities for peers to support each other in meaningful ways and have been defined by Mead [3] as ‘... a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful’. Peer support has often appeared as an intervention in the field of mental health [4], where it has been suggested to have multiple benefits both for those providing and receiving peer support. These benefits are suggested to include increases in self-esteem and self-efficacy [4,5].

Another barrier that people with an intellectual disability may face is that of employment. While the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has outlined that people with disabilities have an equal right to work [6], In

Ireland, the 2011 and 2016 Census results illustrate the high unemployment levels in these groups [7,8]. Within the Irish context, in 2017, it was reported that there is a pay discrepancy between people living with a disability and non-disabled peers, with people with a disability earning 21.3% less [9], while for people with an intellectual disability, only 15% of working age were employed [9]. Being employed offers many benefits, including economic independence, personal fulfillment, and social inclusion.

A recent international review [10] of people with intellectual disabilities' digital access experience during COVID-19 demonstrates a lack of prior support and training for both people with intellectual disabilities, support, and health care staff was both a barrier and a challenge to pivot to support online meetings and loss of autonomy and an increased reliance on support for many blocked digital opportunities [11–13].

These recent studies demonstrate how research methods pivoted to adjust to the COVID-19 social restriction regulations. Many of these adjustments included a necessity to connect online, which may have made them more accessible for some people with accessibility needs. However, there are also risks associated with excluding those for whom it is difficult to engage online, as people with learning disabilities continue to face digital exclusion [14]. With modern technologies, there is an opportunity for people with intellectual disabilities to learn to meet independent living needs, especially to enhance health and well-being in a more accessible format [15]. Previous research has suggested that research conducted with people with intellectual disabilities should also involve them in the dissemination of their work. The central involvement of people with intellectual disability in research has also been identified as increasing visibility and potentially shifting societal perceptions to peoples' abilities to participate in society and employment opportunities [16]. It has been recognized that user-centered design enhances the technology development and accessibility.

Digi-ID PLUS is a multidisciplinary European collaborative partnership with people with intellectual disability and autism, disability service user organizations, and advocacy groups, which brings together expertise in the fields of intellectual disability, social science, assistive technology, accessibility, healthcare technologies, public health, inclusive education, speech and language, inclusion health, mental health, and health economics from Ireland, France, Sweden, Spain, and Croatia. Digi-ID PLUS addresses the challenge of digital inclusion and digital literacy among people with intellectual disabilities. At the heart of the project is our Digi-ID Citizen Advisory Panel (CAP), a group of seven individuals with intellectual disabilities and accessibility needs, hired as experts by experience supporting the project. Our first established CAP was based in lead Partner country Ireland and was intentionally established to bring together voices with diverse age, gender, and digital competency. All Panel team members share a passion for learning about technology and an enthusiasm to share their knowledge with others. The aim of establishing our CAP in the design and delivery of our program is to recognize the critical role of users by experience as paid team members to review, validate and test our solution to enhance the accessibility of all aspects of the program.

The DigiAcademy pilot platform, an accessible digital skills e-learning platform, was co-created and co-designed within Digi-ID PLUS and is part of an (EIT Health) EU innovation project. Over the course of monthly CAP meetings, the positive social impact of Panel team membership was highlighted.

The focus of this paper is to showcase the role of the CAP and demonstrate the impact membership had on them and the DigiAcademy app we co-created together.

2. Methods

In this section, we present the inclusive program design adopted via establishing our Citizen Advisory Panel. We outline the CAP preliminary engagement and recruitment strategy, their role in our co-creation and co-design process, and the method for analyzing their experiences.

2.1. Establishing our Citizen Advisory Panel (CAP): CAP Members

The first Digi-ID Citizen Advisory Panel was established in Ireland, comprising a group of seven individuals with intellectual disabilities. This paper presents the experiences of the members of this first Citizen Advisory Panel, in particular exploring their role in our program and the impact of working with the team for them. There are 3 who identified as women and 4 who identified as men on the Panel. The youngest of the group was 23 years old, and the eldest group member was 62 years old at the time of recruitment. The Panel members’ range of level of intellectual disability is mild to moderate. The CAP was intentionally established to be comprised of diverse ages, abilities, and digital literacy skills (Figure 1).

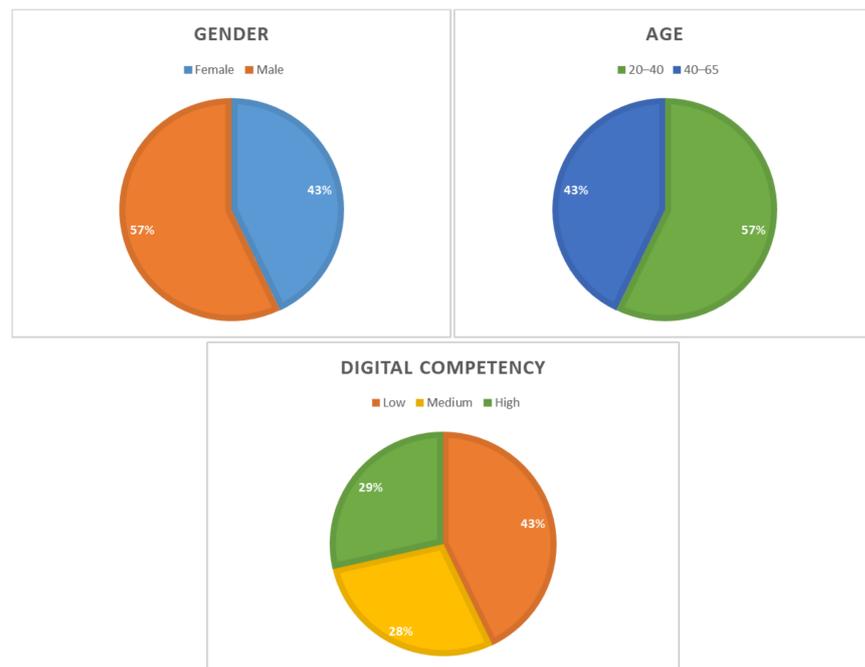


Figure 1. Our Citizen Advisory Panel’s (CAP’s) demographic information at time of recruitment.

Members of our first CAP in Ireland (Figure 2) are:



Figure 2. Our CAP members.

Brian Hogan (BH), who has been involved in Advocacy and Inclusive Research since 2006. Brian reflected on the importance of technology to enable social connection during COVID-19 and how he appreciated that he could follow the impact of his own contribution to our digital inclusion program as input was observed in the changes made in design:

“It is very important in COVID times that we keep in touch with friends and work but you need good equipment and good support. In research tracking the changes helps us track back and see what’s been done or not done from the ideas we put forward.”

Christina Burke (CB) has been involved in self-advocacy for many years and is a strong voice in the Irish disability community advocating for human rights for people with intellectual disabilities. She remarked:

“Advocacy is speaking out and having your voice heard wholeheartedly and to stop people having their rights taken away, people should not be discriminated against.”

Darren Heduan (DH), who expressed the urgency during COVID-19 for technology to be accessible for everyone to safeguard against loneliness:

“There is much work to be done in this area to provide everyone who needs it with access to digital technology. The pandemic has exposed people’s vulnerability and many people have been isolated and alone. This project is a great opportunity to open technology to all those who can access it with just a little bit of support.”

Denise Breslin (DB) has also been involved in self-advocacy groups for several years. During the pandemic, at her own service, she participated in making an educational video about COVID-19. Denise emphasized the significant role smart technology played in keeping her connected when in-person social interaction was restricted during the early stages of the pandemic.

“I use a smart phone and recently upgraded to a new one, and really this was my lifeline when we were in the first lockdown due to COVID-19 and unable to connect to people face to face in my usual day to day routine.”

Fionn Crombie Angus (FCA), who runs a social enterprise with his father called Fionnathan Productions, teaching children about nature and adults about inclusion, highlighted the opportunities technology offers him in his daily life and how he enjoys supporting others with their technology:

“It’s a great time to be someone living with a learning disability, and I am fortunate to have such a rich digital life. I like to help others use technology to reach their goals.”

James Delaney (JD) further developed his interest and skill in independent technology use and learning new digital skills during the pandemic to support his own social participation and connection with friends and his service.

“I currently use an iPad and a smart phone. I am familiar with WhatsApp and email. I use my iPad to do all my Zoom and Teams meetings.”

Mei Lin Yap (MLY) is employed in a national recruitment agency, and she is an advocate and a champion for the inclusion of people with intellectual disabilities in the community with a passion for technology:

“Through all of my education computers played an important role. I use computers in my work and in my leisure time I use technology. I use it every day for various things like communicating with family/friends over WhatsApp and Facebook. I love using social media”.

2.2. Recruitment

In our preliminary engagement or establishing our CAP, we consulted with a national umbrella advocacy organization and collaborating services to support the recruitment process. In consultation with collaborating disability services, we conducted accessible information sessions with the individual and supporter(s) to discuss and clarify their job

roles and responsibilities, code of conduct, and payment matters. Accessible information to provide a guide to the nature and scope of the role was developed, shared, and discussed with all individuals and supporters.

Accessible email communications were developed to engage with our CAP to schedule meetings, share project work for review and create an interactive space and rapport amongst members to share views and update the group on community and advocacy activities and news. Each member was asked whether they would like to include a support person if they wish to in our project communication emails and meeting attendance. All members were encouraged to participate actively in each meeting, with turn taking guidelines in place to ensure each member had opportunity to voice views, experiences, and ideas. One-to-one meetings were also scheduled with individual members to carry out a specific piece of project work and, if sought, to provide tailored support to any task clarification needs.

Some CAP members have represented the project at national, EU, and international conferences where they voiced their views on digital inclusion and have explained their specific input into the design and co-creation process of our education program.

The study has received full ethical approval from Trinity College Dublin's Faculty of Health Sciences Ethics Committee and from all the collaborating services Ethics committees and following translation of the project accessible materials, the same process has been replicated in all EU partner countries in respective languages and similar engagement with their collaborating services.

2.3. 'Does This Ring True to You?': The CAP's Role in Our Co-Creation and Co-Design Process

As an ongoing European project, Digi-ID PLUS aims to create and extend inclusion in the digital space for people with intellectual disabilities. The project builds on the participatory action research method by adopting a user-centered design methodology and iterative co-creation and co-design process (Figure 3) to inform, shape, and determine the program and solutions to the challenge of digital literacy to improve inclusion for people with intellectual disabilities.

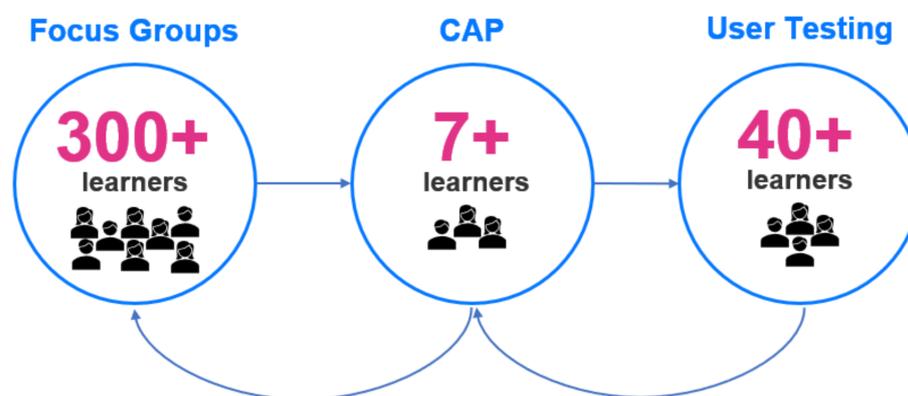


Figure 3. The Digi-ID PLUS Iterative Co-Creation and Co-Design Process.

As demonstrated in the research and validated within the Digi-ID PLUS project [17], user-centered design enables an optimal result with an iterative co-design process that focuses on user experience and user needs together as a whole. In this way, user involvement is essential to create usable and accessible systems [18,19]. A user is defined as involved when they are informed and actively engaged, their views are considered, and the exchange of knowledge and experience takes place between users and providers during the full co-design process [20–22].

Bearing this in mind, the CAP has a central role in our co-creation and co-design process: all project materials, research questions, and findings are reviewed, co-created, and validated with them iteratively. To collect and structure data within the Digi-ID PLUS work program, accessible monthly CAP meetings online (Figure 4) to engage with all members in meaningful ways, co-create project materials, provide expert-by-experience

prototype review work, and to ensure their voices, insights, and experiences are heard, included, and shape every critical project decision. Data collection was completed during CAP meetings, where members had the opportunity to voice their personal experiences of inclusion and be recognized for their work and their expertise. Discussing their experiences in a collaborative peer support setting facilitated the opportunity to share and learn from the experiences of others in the group.



Figure 4. Example of our CAP meeting on the left and example of CAP member presenting user design feedback at European Patients' Forum congress 2021 on the right.

The co-design and development of our DigiAcademy app is a core goal of the Digi-ID Plus program. The current pilot version of DigiAcademy (Figure 5) has been co-created and co-designed with our community. Our CAP had a core role in this process by reviewing and validating the design feedback and testing the app in an iterative process as described above. As a team, we pushed our co-creation process to an optimum level through support and one-to-one and team coaching to enable and empower CAP members to become our 'digital educators', demonstrating the power and potential of people with intellectual disabilities to be the 'face' and 'voice' of our accessible education program.

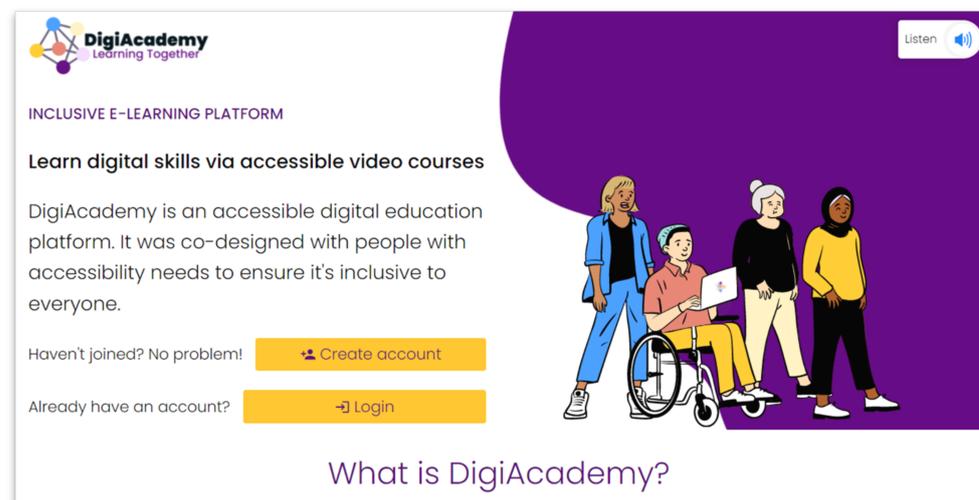


Figure 5. DigiAcademy landing page.

DigiAcademy is comprised of short video tutorials on priority topics identified by users during the focus groups and validated with our CAP, delivered by our digital educators. Preliminary findings analysis from our inclusive co-creation focus groups identified priority digital skills topics to address key digital literacy issues. Repeatedly our community discussed the need for introductory onboarding digital skills, from getting started with video conferencing calls, internet, and social media to guidance on password management with a particular focus on independent use and awareness of accessibility features.

In reviewing our research findings with our CAP, we validated this need for introductory digital skills, identifying main digital skills education topics, and we selected the most

commonly known software: getting started with email—Gmail, getting started with social media—Facebook, getting started with video calls—Zoom and getting started with phone messages—WhatsApp. CAP members' growing competency in independently using these mainstream software was identified. Following a series of CAP meetings, two members demonstrated key digital skills that covered priority topics identified in our focus groups, e.g., virtual video calls and social media. Subsequently, a third member received initial peer support from another CAP member and his support worker, and our team for getting started with email. This process led to our first three digital educators' recruitment. Each member was supported to assume the role of a digital educator in these topics. Together we co-created easy-read education materials and video tutorial scripts and coordinated individual practice and coaching sessions with the individual and their supporter (where there was a preference for this key worker or family member) and 1–2 project team members. These individualized sessions enabled us to test and validate the education materials and video tutorial scripts together and significantly invest time to target and tailor our sessions to each individual's unique learning and presentation style to build the individual's confidence in communication and presentation skills via mock practice runs to prepare for professional video tutorial production.

As described, focus group findings reviewed and validated with our CAP guided both the content and the format of content delivery. Repeatedly during our focus groups and CAP meetings, the topic of independent use of mainstream technology arose. In terms of accessing training, engaging with educational videos to learn new things emerged as the most popular and accessible option. Significantly for our community ensuring video content was accessibly delivered and providing easy-read accessible versions to accompany learning. Accessibility as the most crucial component of our education tutorial format was unanimously reported by all our CAP members as fundamental and video format viewed as the most effective means to achieve this:

“Using videos is really good as you can watch them over and over again colourful and not boring.”; “It could give us a step by step guide how to use different technology.”; “Our videos will help more people easier access to technology in the future.”

Video modeling, an instructional teaching method in which someone (typically a supporting professional) shows the learner with an intellectual disability from start to end in video format to use electronic devices, has been demonstrated as an effective method from the research as well [23–27] and also confirmed with our community.

For example, a collaborator Intellectual Disability Day Service Manager highlighted the benefit of accessible videos to encourage individuals' independent training, in contrast to supporters who, with good intentions, can rather than support use, do the digital activity for the individual:

“Having videos on hand, accessible, I think for our services users and for all service users is going to be a great benefit to them because it is very easy for any of us maybe step in and doing something for somebody, supporters and family members, but having that there they can stop start rewind and go back, it is something that can be built on, you can do it for anything, it can be broadened out into independent living skills”.

2.4. Analysing Experiences Shared by Our CAP

During our first monthly CAP meetings frequently our CAP members discussed their role and their work within the Digi-ID PLUS project and the positive impact membership was having on their social and digital skills. Based on that, the first author formulated research questions [11,28] that supported the collection of more qualitative data for our analysis. The first step was the transcript of our CAP and their supporter's contributions video recordings during our meetings from 2021 until June 2022. On the data gathered with the transcripts, we conducted a thematic analysis [29] to focus on the data rather than on pre-defined categories and take our panelists' perspectives into account when coding and identifying our themes/sub-themes.

The last author read and familiarized themselves with the transcript and identified the codes. The first author, the principal investigator of our project, reviewed and validated the coded transcript. All discrepancies were resolved through discussions between the first and last author until a final set of codes was agreed on. Following this, both authors conducted a classification and definition of the categories by grouping codes in terms of differences and similarities and by underlying quotes [29–31]) This process led to the definition of key themes in relation to the codes: add the list of themes here. The final key themes and sub-themes identified by the first and last authors were reviewed and validated with our CAP members (from the third to the second-last authors), a selection of them were also checked with their peers within our community [32], and lastly, themes and sub-themes were also reviewed by the second author.

3. Results

Direct benefits for our Citizen Advisory Panel members were rooted in providing opportunities for people with intellectual disabilities to voice their personal experiences of inclusion and being recognized for their work and their expertise, and that their voiced lived experiences were listened to and informed all our project’s critical decisions. Discussing their experiences in a collaborative peer support setting facilitated the opportunity to share and learn from the experiences of others in the group, and we have heard from members and their supporters how their team membership has enhanced their confidence and their communication skills. Team membership presents them with new strategies and ideas for themselves, new digital skills, and fostering new friendships.

Moreover, the inclusion and acknowledgment of their expert by experience input via direct payment into their own bank account were beneficial in multiple ways; for their own career development, the enhancement of the study’s inclusive method and becoming an inspiration for their peers and facilitating peer support opportunities. For more than half the group, this was the first occasion to be engaged in paid work; for a smaller number, this was the first occasion to have their own bank account opened and to learn how to access their account online.

In the next sections, we present our CAP’s voices and experiences categorized in themes identified during our meetings (Table 1).

Table 1. Summary of our Citizen Advisory Panel’s experiences.

Theme	Sub-Theme 1	Sub-Theme 2	Sub-Theme 3
Theme 1: CAP meetings as an inclusive social activity	Working with peers in the group ¹ (DB)	Learning new digital & social skills	Making new friends ¹ (DB)
Theme 2: Co-creating our digital skills education app	Having people with intellectual disabilities at the core ¹ (MLY)	Helping people with disabilities use technology ¹ (CB)	Having the recognition of being included in the app creation ¹ (MLY)
Theme 3: CAP peer-to-peer support	Supporting each other ¹ (DH’s supporter)	Teaching & learning with peers	Improving their confidence ¹ (DB’s supporter)
Theme 4: CAP work and payment	Feeling of being included and getting paid ¹ (MLY)	Being included in the research ¹ (FCA)	Voices being valued ¹ (MLY)
Theme 5: DigiAcademy Digital educators	Helping others get started and be more Independent ¹ (FCA)	Feeling empowered and respected ¹ (MLY)	Sharing experience with new digital educators

¹ This sub-theme content is created from our CAPs or their supporters’ quotes.

3.1. Theme 1: Citizen Advisory Panel (CAP) Meetings as an Inclusive Social Activity

The nature of our Digi CAP meetings was intentionally designed in the context of the outbreak of the COVID-19 pandemic as a community engagement social activity to meet the needs of people with intellectual disabilities to enable social interaction, discuss technology tips and connect with other peers with potential to make new friends and have fun together (Figure 6). As we discuss in the subsequent section, the format of our CAP meetings

was strategically designed to test out the method of online co-creation focus group, and subsequently lessons learned during our initial meetings informed and shaped the structure and design of our focus group activities with our collaborating services community.



Figure 6. Citizen Advisory Panel Christmas Social.

Our CAP members reflected on the benefits of these meetings as a cooperative space to engage with their peers and work together and feel part of our team:

- *“I have really enjoyed working with my peers in the group. It has been a brilliant experience and I’m making new friends!”* (DB);
- *“I feel nervous when I started first in the group, and just talking with the people in the group helped me. I liked sharing the things I’m interested in within the group.”* (BH);
- *“We are doing a great work, we are doing team work and it is also fun”* (JD).

We also designed these meetings to give the opportunity, the time, and the space to our members to learn and share new digital skills with their peers, and we heard how this benefited members’ confidence in using technology.

- *“I now feel more confident using my smartphone and Zoom, to stay connected with my family and friends, this helped to keep me healthy and happy.”* (CB);
- *“I have known more about Zoom, with new apps, download attachments, and then working on this. Also the work that goes in to designing our new app.”* (JD);
- *“I learnt how to setting up for meetings and work on a new iPad.”* (DB).

Our meetings were also designed to support our members to feel more relaxed and overcome any anxiety about using technology and to support each other to have more confidence and improve their social skills:

- *“I was happy that I was put up to it, and here with the meeting with all ye and see how the whole program was going. Thanks to give me the confidence to do this.”* (DH);
- *“I felt nervous when I started first in the group, and just talking with the people in the group helped me. Now I like sharing the things I’m interested in within the group and learn new things.”* (BH);
- *“In the first meeting I was nervous to get out to this group. What helped me was: Just give it a go and get used to talk to the group and confidence will come up and see how you will enjoy it!”* (DH).

In establishing our Citizen Advisory Panel and supporting our members’ active participation, we designed and coordinated inclusive and flexible meetings to meet the members’ needs as a group and also as individuals. Initial liaison with the Irish umbrella organization National Federation of Voluntary Bodies to support linking with interested groups and individuals was instrumental support. Cooperation and support from keyworkers, speech

and language therapists, and other health professionals and families were vital, especially at the initial phase of onboarding our new members and processing banking information and sharing contact details and other personal information.

Our CAP's supporters also validated and appreciated the effectiveness, accessibility, and inclusivity of the design and the implementation of these meetings, also emphasizing how the 'relaxed pace' can facilitate 'more meaningful work' and that they are being 'upskilled' as well during this "journey":

- *"The importance of slowing down and creating space is something I need to be reminded of again and again, these meetings are wonderfully inclusive in that way and surprisingly I often have the sense that more meaningful work gets done when a group takes a more relaxed time on the journey."* (FCA's supporter);
- *"I think James is getting really interested and it is great for me as well because I'm learning a lot, so that's great for me because I'm going to be upskilled as well"* (JD's supporter);
- *"It is being a fantastic experience to support Denise in this really exciting program. It's great to know that her input into the group has been so valued. Denise's confidence level improved a lot, she is using different range of tech and she is sharing that knowledge with her peers and staff members, wonderful that ripple effect."* (DB's supporter).

3.2. Theme 2: Co-Creating Our Digital Skills Education App (User-Centered Design)

We have adopted a user-centered design methodology and iterative co-creation and co-design process to inform, shape, and determine our solution. We are engaging people with intellectual disabilities from six intellectual disability services across Ireland, with the same process replicated by our EU partners in their countries. As mentioned in the method, the key sounding board and beating heart within our process is our CAP; our CAP members' voices, insights, and experiences are heard and included in every critical decision of our project, and we validate with them all the materials and findings. The CAP's input into the DigiAcademyapp's design was therefore integral to the process. An example of the app's course page, co-created with the CAP, can be seen in Figure 7.

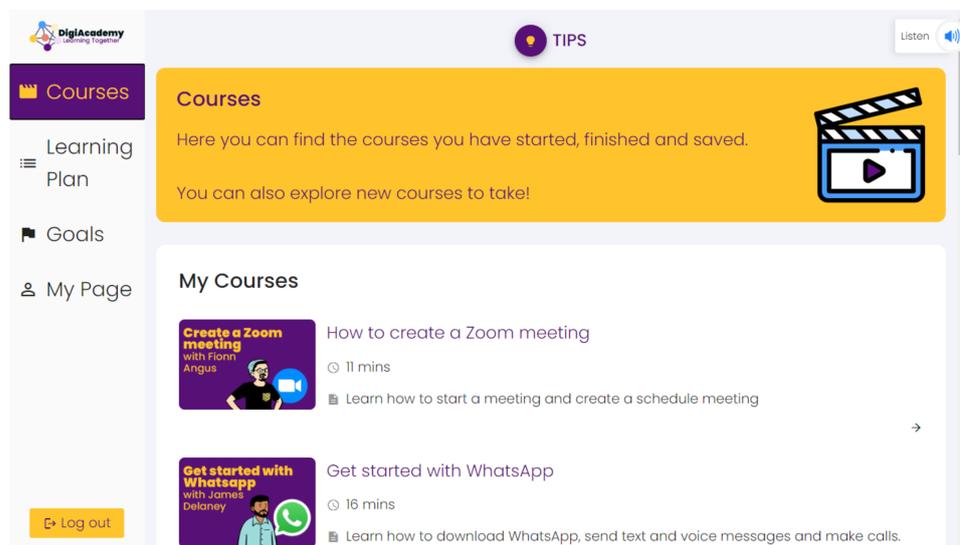


Figure 7. DigiAcademy 'My Courses' page.

In reviewing our program, our CAP highlighted the positive impact and significance for them and the wider community that their voices, those of people with an intellectual disability, are the driving force of our program:

- *"I am delighted to see that people with disabilities are at the core of the co creation of developing this digital education program"* (MLY);
- *"It's important that our voices are listened and included."* (CB);

- *“I feel very proud that with this app we can help other people with intellectual disabilities.” (DB).*

All members also expressed that knowing that their contribution to ensure our app is accessible is rewarding and how they are enjoying working to support and help their peers through giving their expert-by-experience insights, as they are co-creating and co-designing with the team:

- *“I feel our work will help so many people with disabilities use technology.” (CB);*
- *“It’s great making this app and making it accessible for people with all disabilities, we will grow with confidence with using this app. I feel that with this app that we are creating, this is gonna make a huge impact on people’s lives. That recognition of being included in something great, resonates volumes to me. That’s why I love what I do.” (MLY);*
- *“With our work in Digi-ID we could help people with intellectual disability making things easier to read and feel included, and we could help each other.” (BH).*

3.3. Theme 3: Citizen Advisory Panel (CAP) Embodies Peer-to-Peer Support

Our CAP discussed their positive peer-to-peer experiences, in which they were able to support each other in learning new digital skills and developing existing ones. For example,

- *“I have learnt a lot from my peers in the group and it was great to help them on how to use the screen reader.” (DH);*
- *“I remember influencing Darren in how to use Zoom, and then Darren talked me about the screen reader and that was very helpful! I liked that Denise talked about her Fitbit.” (FCA);*
- *“I discovered with my peers in Digi-ID how to use the headphones, it blocks out the background noises. You can hear more clearly and you can understand the questions more clearly.” (BH).*

Additionally, they also spoke of their enthusiasm for their roles as peer mentors in supporting each other. This can be seen in excerpts from FCA’s and MLY’s dialogue. The CAP’s supporters also commented on this.

- *“I think that the mentoring role is so exciting and important.” (FCA);*
- *“I feel excited to be a mentor, I feel excited to share the learning with other people and help them with the work” (MLY);*
- *“I just noticed how great was that Darren and Fionn supported each other, recommend things to each other and helped each other, it showed the importance of the peers to peers’ support and stay connected with each other, it was great for them to have the opportunity to help each other out and in this way improve also their confidence.” (DH’s supporter);*
- *“Denise’s confidence level improved a lot, she is using different range of tech and she is sharing that knowledge with her peers and staff members, wonderful that ripple effect.” (DB’s supporter).*

3.4. Theme 4: Citizen Advisory Panel (CAP) Work and Payment

Embedded within the Digi-ID Plus program is a strong commitment to addressing the issue of poor access to employment opportunities for people with intellectual disabilities. In establishing our first Citizen Advisory Panel, it was essential to ensure all members received payment for their expert-by-experience role both in the Panel and that all digital educators also received payment for their work with the team both in preparing and delivering video educational courses for our platform.

Members spoke that receiving payment for their work contributed to feelings of pride and sense of being valued for their work.

- *“I felt very important as I got paid to be an advisor and it’s great to continue working all together! It is a great group. I’m proud.” (CB);*
- *“It is important that people like me are included in the research. When we help each other we all learn much more.” (FCA);*
- *“It is so important that feeling of being included and getting paid for the work that I’m doing, it is so nice to feel valued, and it is also important to put money in the pocket to do the things*

that I love to do [...] Working on Digi-ID it is absolutely fantastic! It is a great initiative, it is a great project to work on, and just it is great that people with disabilities, or my voice as well, is making an impact on the work that we are doing.” (MLY).

The importance of valuing people’s lived expert-by-experience insights as uniquely positioned to work as our expert user consultants and fully recognize this via payment for their specialized work is also emphasized and valued by our intellectual disability service collaborators. For example, one of our key collaborating services’ Head of Business Development and Service Design, when asked to describe the collaboration within the Digi-ID PLUS program, said:

“Esther always had the vision that Digi-ID and DigiAcademy would provide employment in the future, and I think that is one of the things that is so special about our involvement in this. We know Ireland is one of the lowest unemployment rate for people with disabilities, the fact that some of our users have now become part of the paid Citizen Advisory Panel has been so special. It’s really a landmark moment that we really can see coproduction in place and people’s inputs really being valued.”

3.5. Theme 5: DigiAcademy Digital Educators

Training as a Digi Academy digital educator has been an important and valuable experience for our CAP members. To date, three members from our original CAP have trained with us, actively engaging with our education content choice based on their own areas of interest and expertise, script co-creation, practice sessions, the course co-design, and the recordings with a professional video production company. Learning together is a motto within the Digi-ID team. Adopting a flexible approach to working with each digital educator by adapting to the learning and communication style of each individual drove all aspects of the co-creation process, e.g., tailoring coaching and preparation sessions and recording to each individual’s preferences to ensure everyone had an enjoyable work experience and showcased the best of their abilities.

We designed the script co-creation and the recordings activities as fun and flexible activities, where our digital educators can improve their skills, showcase the best of their abilities and learn new things in a fun, creative environment to inspire other people to have the confidence to give technology a go to enhance their own lives.

About this experience, MLY felt empowered and respected:

“I loved the experience and really felt empowered and respected as the teacher.”

JD was delighted to recognize his own progress in learning new digital skills and the opportunity to share with peers what he has learned:

“I had great fun it was so new to me and I loved everything. Before I couldn’t use email, now I can’t believe I am the teacher for others to learn.”

While FCA also emphasized the value of working together as a team to help others:

“I really enjoyed working together to produce the tutorials. I love knowing my videos can help others get started and be more independent”

When asked about their experiences and feeling after the recording days in the video production studio (Figure 8), each educator expressed positive emotions:



Figure 8. Digital educators video tutorial recording experiences.

- *“I loved this, it was a great experience, I’m so happy I will inspire other people and thank you so much for having me a part of this project.” (FCA);*
- *“I’m so happy, it has been a great experience to record this about technology for people with disabilities. The best thing of the day has been . . . Everything!” (JD);*
- *“It was an amazing opportunity to be in a professional recording studio. I felt like an actress, I really gave my best and I learnt a lot. I loved also to work on the script with the Digi-ID team to keep improving and adapting them to myself on the day.” (MLY).*

We also asked them what they would like to share with their peers in our new Citizen Advisory Panel who may like to become our new DigiAcademy digital educators. They pinpointed five key factors that especially helped them: (1) ‘the right support in place’, (2) ‘do some practice together’ with the team, (3) taking breaks, (4) ‘have fun’, and (5) ‘believe in yourself’:

- *“I’m very excited to support new panel to become our new digital educators. Some tips for them is having the right support in place to do a good job and don’t be afraid to ask questions, because it’s okay to make mistakes but what really matters is keep going . . . have fun and believe in yourself!” (MLY)*
- *“I liked being able to work, break, work and break again. I loved working hard for the tutorials, work is important but break are important as well, and it is great to have some support as well.” (FCA)*
- *“Just learn and practice and then you will know what you are doing after that. You ask people (ed: the Digi-ID team) how to do it and do some practice together with them and after that you will find to have more confidence.” (JD)*

We hope that our digital educators will keep inspiring others to join us on our mission as we continue to grow our community and develop our solution to ensure people with accessibility needs can live the digital lives of their choice.

3.6. Sharing Two CAP Members' Experiences: Darren Heduan and James Delaney

In this section, we showcase two CAP members' experiences: Darren Heduan and James Delaney.

Darren Heduan. At the outset, Darren found it difficult to actively engage in our first two meetings; he was also relying heavily on his speech and language therapist to express his views and communicate with the group. One of the main issues he expressed at the start is the social exclusion and impact on him feeling at ease with the group was his experience living in a rural location:

"Living in a rural location makes it hard to have a social life. The only time I can talk to anyone is on WhatsApp or Messenger"

During the CAP meetings, intentionally designed as a fun, creative environment to enable social interaction and exchange of learning, Darren became more and more confident, active, and participatory, communicating mostly independently from his therapist. Darren spoke with great self-awareness and recognition of the progress he had been making and now encouraging other peers to participate more fully too:

"In the first meeting I was nervous to get out to this group. What helped me was: Just give it a go and get used to talk to the group and confidence will come up and see how you will enjoy it!"

After five CAP meetings, he was also inspired by his peers in the group to share digital skills knowledge with our community; therefore, the team supported him in recording a short video where he explained to our community how to use the screen reader on the phone and where he offered his support to all the people who would like to know more:

"I have learnt a lot from my peers in the group and it was great to help them on how to use of the screen reader."

When asked about his overall experience being a CAP team member, he expressed positive emotions emphasizing the confidence he had developed owing to the CAP meetings:

"I was happy that I was put up to it, here with the meeting with all ye and see how the whole programme is going. Thanks to give me the confidence to do this."

Darren's speech and language therapist validated and appreciated the effectiveness and inclusivity of these meetings, also enhancing how, thanks to our CAP meetings, he 'got confident and his speech is clearer', how they 'empowered him to feel part of something' and how she is learning 'a lot' as well from this experience:

"Darren has changed as a person because of these Zoom calls, he is now got confident and his speech is clearer, thanks so much to give him this opportunity because it's really empowered him to feel part of something. It has been a brilliant experience and I have learned a lot as well."

James Delaney. Initially when CAP member, James joined the team, he was very shy and not active during the meeting. In terms of digital engagement and independence, James did not have his own email address. Our CAP meetings are intentionally designed as a community engagement social activity to meet the needs of people with intellectual disabilities to enable social interaction, discuss technology tips and connect with other peers with the potential to make new friends and have fun together, create the chance for his peers in the group to support and inspire him to feel part of the group, work as a team member and increase his confidence. Recently James said:

"We are doing a great work, we are doing team work and it is also fun".

As mentioned before, our meetings are purposively creating the potential for all our CAP members to learn new digital skills and share tips with their peers. This was the case for James. Another CAP member shared with him some tips on how to create an email address, and now James has his own email address to communicate with the other team members. With the support from the group, he also learned how to receive email and open

attachments, how to write emails, and receive pictures and documents. James continues to develop new skills within the group and contribute to app development work as he recently remarked: *“I have known more about Zoom, with new apps, download attachments, and then working on this. Also the work that goes in to designing our new app.”*

As illustrated above, our goal was to push our co-creation process to an optimum level through support and one-to-one and team coaching to enable James to become our internet and email ‘digital educator’ and share with the community the lessons learned during his experience as a CAP member, demonstrating the power and potential of James and the other digital educators to be the ‘face’ and ‘voice’ of our accessible education program. Training and assuming the role as one of our digital educators, James has noticed his confidence and social skills developing, and he reports how enjoyable he finds the work, as illustrated in the section above (3.5 Theme 5: DigiAcademy digital educators).

James’ key worker emphasized how James is now feeling part of the team and learning new digital skills and the ripple effect of inspiring his peers in his own intellectual disability service:

“James can inspire people, having more knowledge, being part of a team that talks about a lot of technologies all the time, so he has been inspired as well and he is sharing this project and his experiences with his peers.”

James’ key worker also added how ‘important for him’ it is to send and receive emails within the day centre and have the opportunity to deliver DigiAcademy presentations in person for his peers in their own service:

“James has shared his email about his Digi-ID experience the centre and then he has a talk in the advocacy meeting. That was so important for him.”

James and our Principal Investigator (EM) were also interviewed by the Irish national broadcaster RTÉ.

James, reflecting on his experience, shared with the journalist that he is happy to now use email to stay socially connected and for his video tutorials to help others.

“Using email helps me stay in contact with my friends, family and colleagues. I really enjoyed making the video tutorials. Now I can show you how to access the internet.”

Following the RTÉ interview, James discussed how much he enjoyed this new experience and how it boosted his confidence:

“I’m so happy with that, it was very exciting and it gives me confidence!”

4. Discussion

Key findings from our CAP members’ experiences are collated and presented below, connected to the identified themes.

4.1. Digi Co-Creation Process: Citizen Advisory Panel Meeting and Digi Focus Group Designed as an Inclusive Social Activity

With our Digi CAP meetings, we strategically informed, shaped, and tested the method of online co-creation and co-design focus group. Subsequently, lessons learned during our initial CAP meetings shaped the structure and design of our focus group as social activities with our collaborating services community. Based on that, the co-creation focus group was intentionally designed in the context at the outbreak of the COVID-19 pandemic as a community engagement social activity to align with our frontline collaborators in Intellectual Disability services to meet the needs of people with intellectual disabilities to enable social interaction, discuss technology tips and connect with other peers with potential to reconnect and or make new friends and have fun together.

As demonstrated in the research [19–22] and validated with our research, the user-centered design enhances the overall experience of product interaction for the user and improves user experience, accessibility, and the viability of the solution developed. This approach facilitates the full team focus on the specific requirements, positioning users’

needs and preferences at the core via their continuous active involvement. Coleman et al. (2016) illustrate how users are involved when they are informed and actively engaged, their views are considered, and exchange of knowledge and experience takes place between users and providers during the full co-design process.

Our CAP experiences (Theme 1 and 3) also demonstrate the positive impact of purposely designing our CAP meetings as social inclusion activities rooted in a user centered design methodology.

The pandemic has accelerated research into the effectiveness of conducting online focus groups with very positive preliminary findings [33,34]. In particular, in Santhosh et al. [34], the researchers collected success strategies also validated with our program, such as good advertising and incentives, electronic calendar invitation and limited duration, and how to manage technical difficulties, low participant engagement, and suboptimal data collection. The authors suggested a limit duration of 1 h or less, but, within our program, we have found that also 2 h meeting can be very effective, especially if arranged in the late morning and with a comfort break at the hour point and regular check-ins and on each half hour; adopting a flexible approach to shorten the meeting if energies/interest wain and naturally responding to our members' preferences. We also invite and support our CAP members to record bite-size videos of themselves to describe or share thoughts with the group, with the researchers, or with the community about using their own devices and technology. This led to an effective method, especially for more reserved or more vocal members and/or those who had more significant communication needs.

Flexibility and having support needs met have been identified as critical when engaging with people with intellectual disabilities online [10,22,35]. Applying a flexible approach drives all of our interactions with our CAP. Each individual member has his/her own preferences and needs, and all activities and materials are tailored to everyone.

One of the main challenges encountered during our co-creation and co-design activities meeting people with intellectual disabilities online, and also demonstrated by the research [14,35], is surrounding the increased reliance on skilled staff and staff availability to facilitate the meetings and the reaching of the participants. Lack of staff, exacerbated by the pandemic, created more issues reaching people with intellectual disabilities who, even if interested and willing to participate, often rely on staff support. Many intellectual disability service providers reported supporting research participation was challenging due to the natural prioritization of health and safety concerns during the pandemic; therefore, the design strategy of our focus groups as flexible, adaptable, and inclusive social activities, with the aim of co-creating a digital skills education solution, contributed to be easily integrated into the intellectual disability service providers' daily program.

4.2. Peer-to-Peer Support Proven to Enhance Learning among Citizen Advisory Panel Members

Establishing our CAP bringing peers together offered opportunities to engage in peer-to-peer support. Peer support has been defined by Mead [3] as '... a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful.' Burke and Hodgson [4] explored the concept of peer support within the context of Mental Health, and it was suggested that this can have multiple benefits both for those providing and receiving peer support. These benefits are suggested to include increases in self-esteem and self-efficacy [4,5]. Conversely, networks that hold meaning to their participants have also been shown to decrease adverse effects, such as loneliness [2].

Peer-to-peer support is recognised to be most effective when it is co-produced, meaning that it has input from those who would use it (adopting the ethos of 'Nothing about me without me'), and when the existing knowledge and skills within the community are acknowledged, harnessed, and rewarded [4,5]. As outlined previously, our CAP was intentionally established to include diverse voices, each of whom represents diverse ages, gender, and digital competency. By discussing their views in a supportive, collaborative setting, the CAP facilitated the learning of new skills and the improvement of existing

ones within this group. While other studies have examined the effectiveness and value of peer support in other contexts, such as within Mental Health [4,36], most studies focus on neuro-typical peers tutoring neuro-diverse peers [37–40]. In this way, while other studies have focused on the imparting of knowledge between neuro-typical and neuro-diverse peers, this focus group allowed peers to support each other with their skills through their lived experiences.

As can be seen from the results of this study, the CAP has spoken positively about the support they received from their peers. For example, FCA and BH mentioned learning from their peers how to use different technologies and features on social media. The CAP also reported on the positive social roles they experienced as part of the CAP, detailing their enthusiasm about their roles acting as mentors to each other and acknowledging the importance of supporting each other too. With this evidence in mind, our Citizen Advisory Panel's experiences presented here support this positive view of peer-to-peer support.

4.3. Work and Payment: Advocating for People with Disabilities to Have an Equal Right to Work

With our project, we are promoting, supporting, and advocating that people with disabilities who want to work are supported and enabled to identify opportunities. Embedding the CAP to address the inequity of employment opportunities and enhance the technology development via an iterative process with them and our community. With this, we are also promoting the guiding principles of the UNCRPD, which says that people with disabilities have an equal right to work. This includes the right to have the same conditions of work as others, including opportunities, pay, health and safety conditions, and a work environment that is open, inclusive, and accessible. It is important for people with intellectual disabilities to have a job, receive payment for their work, bring economic independence, social inclusion, personal fulfilment, and many other positive outcomes described within this discussion.

From the results of the Irish Census 2011 [7], the unemployment rate amongst disabled people in Ireland was 30.8 percent, compared with 19 percent for the overall population. Of the total of 542,277 people aged 15 and over with a disability, 112,502 or 20.7 percent, were at work. This compares with 50.1 percent for the overall population aged 15 and over who were at work. The unemployment rate amongst disabled people was 30.8 percent, compared with 19 percent for the overall population. The unemployment rate amongst people with learning disability was 43.9 percent, with 25,895 people with learning disabilities who were in the workforce.

The census 2016 [8] results demonstrated that the unemployment rate for people with a disability in Ireland is 26.6 percent compared to 11.5 percent for people who do not have a disability. The group with the lowest employment is people with intellectual disabilities, with an employment rate of only 17.3 percent.

For Ireland, people with disability are paid less; the wage gap for people with disabilities, as a percentage of non-disabled's wage, was 21.3 percent in 2017. While in Sweden is 37.3 percent. In the Netherlands, it is 22.3, and in France, it is 18 percent, all high by EU standards, where the wage gap is 11 percent [9].

As demonstrated here and described in a recent international review [10], people with intellectual disabilities still appear to be considered implicitly within society to have lower social value, and they are facing huge challenges to find and maintain employment opportunities, challenges exacerbated during the pandemic. For example, in Spain, during the pandemic, 11.3 percent of the people with intellectual disabilities had to adapt to working remotely with others, but they also had to face work disruption (67.5 percent), restricted working (11.9 percent) and lay-off (4.2 percent) [10,41].

In Bialik et al. [42], the authors demonstrated how people with intellectual disabilities remain underrepresented in both the literature and in employment programming in low- and middle-income countries. The authors underlined how when the barriers to inclusive employment for people with intellectual disabilities are reflected in the literature; they are commonly reported through the perspectives of employers or through the perspectives of

academics, disability service providers, and professionals. Supporting our CAP members to be more independent via employment and digital skills education and facilitating space of self-advocacy where they can be listened to and respected, we would like to promote how their voices and experiences can contribute to a more inclusive employment promotion and provide guidance for practitioners aiming to design similar inclusive program hiring people with intellectual disabilities.

4.4. People with Intellectual Disabilities trained and Supported to Be Our DigiAcademy Digital Educators Are Teaching Digital Skills and Inspiring Their Peers

The platform and its content have been specifically co-created and co-designed to meet the digital skills learning outcomes to enhance health, well being and social inclusion. No video-based e-learning platform currently offers an accessible, personalized learning experience for people with intellectual disabilities with low levels of digital skills. The platform will allow the user to tailor their learning path to their needs, with the help of a supporter (social worker, caregiver), and by utilizing AI to identify the best learning strategies for each user based on their profile and learning behavior.

As previously described, we pushed our co-creation process to an optimum level, enabling CAP members to become our 'digital educators' and guiding and inspiring others to follow the same journey, demonstrating the power and potential of people with intellectual disabilities to be the 'face' and the 'voice' of our accessible education program and the effectiveness of the peer-to-peer support.

Therefore, the course content is presented by people with intellectual disabilities themselves, who act both as ideal tutors as well as motivational role models. The digital educators expanded their own digital skills knowledge in particularly related to accessibility and confidence during their work with the team, enabling them to showcase their own digital experiences to support their peers' digital engagement.

As examined by different studies and demonstrated with our program, peer-based on-line education and initiatives are associated with better outcomes [43,44], such as increased self-esteem, self-efficacy, and collaborative learning, especially the effectiveness of peer-led programs for people with intellectual disabilities [36,44–46].

During recent DigiAcademy user testing with collaborating intellectual disability services, our tutorials are receiving positive feedback from participants and intellectual disability services, reporting that the tutorials' content and design are accessible and enjoyable, the structure of the step-by-step guide and our digital educators' presentation is clear and accessible to engage with. Peer-to-peer learning has been recognized as an enabling factor in the acquisition of new skills, echoed by a recent user:

"I find so empowering to see that people are learning, growing, realizing their potential and what they are capable of doing. I love to see that the people with disabilities are our teachers."

Our digital educators' work is also inspiring other people with intellectual disabilities in our community to be our next digital educators. For our community, it is essential to see their potential and how they can learn new digital skills and share them with their peers.

Some study participants we met during the recent focus group activities expressed warm appreciation for our digital educators. For example, a 22-year-old girl with Down Syndrome said: *"Mei Lin is really amazing, she seems like an actress and having great fun! I love drama and I would like to be the next Mei Lin."* A young man with intellectual disability also felt inspired by our digital educator James: *"It is so inspiring how James has learnt how to use Gmail and now he is teaching other people doing the same. I love technology and I learnt a lot of digital skills, I would love to become a digital educator as well."*

Our community value being directly involved in the co-creation and co-design of our solution and to explore the opportunity to be one of our new digital educators, this also leads them to be inspired to participate more "in the decisions of the society", to improve their digital skills both independently and via the solution created, and to share their knowledge and experiences with their peers.

4.5. Digi-ID PLUS: Next Phase

Since the inception of the program, given the positive results and feedback reported in this article from the Citizen Advisory Panel recruited in 2021, we have grown our collaborating network to include four more intellectual disability services, and we have now recruited a new Citizen Advisory Panel in Ireland who along with our original group will be working with us during the program. As with the original group, the new CAP is intentionally established to include diverse voices with diverse age, gender, and digital competency and, this time, also include a member who uses digital device for communication. Each new member also represents one of our intellectual disability service collaborators (excluding the ones already represented within the original group). This will also bring together different views and stronger connections with our community. Within this group, new digital educators will be selected and trained to co-create and co-design new content for our app. With the new CAP we are establishing, the intention is to test an online peer system of support for digital and social skills acquisition together with the original group.

Our EU partners are also creating their local Citizen Advisory Panels with support from lead partner country Ireland and new opportunities to engage with European partners' new panels and advocacy groups as well, with a new development of online intercultural meetings and the possibility to engage in mobility exchanges between partner countries to be explored.

5. Conclusions

The challenge we are facing within our project, also demonstrated in recent international review, is that the right of people with intellectual disabilities to be digitally included and listened has not always been heard during the pandemic. They would like to be listened, to advocate for themselves and their peers, and to become more independent in the digital life of their choice. It is essential that the research and the development of solutions enable their deep involvement and inclusion as hired team members in the full process: all the findings review, the decisions of the materials, the solution creation and design, and all the project activities and milestones. It is important that they feel directly involved and that the solution and the research are following their suggestions and their point of view; this can impact feelings of ease and comfort to participate and contribute and the work itself and to be inspired to participate more "in the decisions of the society" and to improve their digital skills both independently and via the solution co-created together.

The nature of our Digi CAP meetings was intentionally designed in the context of the outbreak of the COVID-19 pandemic as a community engagement social activity to meet the needs of people with intellectual disabilities to enable social interaction, discuss technology tips and connect with other peers with potential to make new friends and have fun together. This format was strategically designed to test out the method of online co-creation focus group, and, subsequently, lessons learned during our initial meetings informed and shaped the structure and design of our focus group activities with our collaborating services community to involve and engage our participants effectively and actively.

Ultimately, the co-creation process and the peer-to-peer support led to an implementation of a solution that is listening and accommodating all aspects of its delivery to the accessibility needs and wishes of the community of users it is co-created for.

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