Designing, Making, and Validating Accessible Products and Services: An Updated Account of Users' Perspectives

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Abstract

Participatory accessibility, i.e., the involvement of users in the design, making, and validation of accessible products and services, has been encouraged under the premise that it would ultimately prove beneficial both in terms of usability and user satisfaction. This article examines the role of users and Disabled People Organisations (DPOs) in the design and validation of access services by providing the results of four in-depth interviews with representatives of non-profit organisations active in Catalonia. The main topics covered in the interviews include users' views on design, production, and validation processes, the training and professionalisation of user consultants and validators, and users' input on standards. The results show that users are mainly involved in validation actions today. They are only rarely considered in early stages of the production chain. DPOs see the occasional exceptions to this trend as a positive indicator that processes may change in the near future. They demand the true integration of persons with disabilities in all the links in the production chain and, crucially, in management positions, as the only way to effectively cater for users' needs.

Key words: accessible design, participatory accessibility, accessibility validation, accessibility consultancy, Disabled People Organisations, persons with disabilities, users' professionalisation.

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1.   Introduction

Protagoras said that man is the measure of all things. We could transfer this statement to our field and assert that the user is, if not the only measure, an important measure of quality in accessibility. In their explanation of the shift from quantity to quality as a focus in media accessibility (MA) studies, Greco & Jankowska (2019, p. 4) underline the increase in user-centred approaches in research in the field in recent years. To establish the effectiveness of the resources and strategies we develop to make products and services more accessible, reception studies with users are typically conducted. Positive results in research involving users are generally considered results reflecting a high standard of quality of the product or service under examination. This paper places users at the centre of the discussion, focusing on their role in the design, production, and validation of accessible products, contents, and services by reporting on interviews with representatives from third sector organisations. The "third sector" is an umbrella term encompassing different types of organisations, such as charities, voluntary organisations, or social cooperatives. According to Northern Bridge (n.d., para 1.), there are three key elements defining third sector organisations:

> Non-governmental: although they often work with or alongside government agencies, and may receive government funding or commissions, third sector organisations are independent from the government.

> Non-profit: third sector organisations raise funds and generate financial surpluses in order to invest in social, environmental, or cultural objectives. They do not seek to make profits as an end in its own right.

> Values-driven: third sector organisations pursue specific goals which are often aligned with particular social and political perspectives. They may be associated with or work with political parties, but a political party is not a third sector organisation.

We aim to identify the actual role of the user in the validation process of accessibility services from the users' own point of view. For this purpose, in section 2 we first outline some important concepts such as universal design, usability and the function of users as consultants and validators. In section 3 we present the methodology followed to conduct the four interviews with representatives from two Disabled People Organisations (DPOs), namely Fundació Punt de Vista ["Point of View"] (PdV), and the Catalan Association for the Integration of the Blind (ACIC), and two third sector organisations working on accessibility: the Catalan Association for the Promotion of Accessibility (ACPA) and the Easy-to-Read Association in Catalonia (ALF).

The first association, ACPA, was founded in 2019 and works along three action lines, namely the defence of accessibility users' rights, the grouping of professionals working on accessibility, and the dissemination of accessibility research, with a focus on the outputs of Catalan universities. The second association, ALF, was founded in 2002 and focuses on making reading material accessible for people with reading difficulties and cognitive disabilities. ALF provides a stamp of approval to confirm the quality of texts that comply with the International Federation of Library Associations and

Institutions guidelines (IFLA, 2010). The third organisation, PdV, was founded in 2019 and aims to foster scientific research on injuries and diseases that cause sight impairment. Finally, the fourth Association, ACIC, was founded in 1992 and defines itself as a group of people who, being either blind or not, work to improve the integration of persons with a sight impairment into society.

Section 4 presents the discussion of the most prominent topics identified in the analysis, namely the users' practical definition of accessibility; the involvement of users in the design, production, and validation of products and services; the training and professionalisation of user consultants or validators; and insights into the connection between users and standards. Finally, section 5 sums up the most relevant points raised by the interviewees and proposes future action lines.

2. From Universal Design to Accessibility Consultancy and Validation

In the following paragraphs, we define and problematise some of the most relevant concepts later discussed by the participants of the study, starting with universal design. The European standard EN 17161:2019 "Design for all – Accessibility following a Design for All approach in products, goods and services" defines universal design as "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design". Yet a note immediately follows clarifying that "Universal Design shall not exclude assistive devices for particular groups or persons with disabilities where this is needed". It is therefore acknowledged that the default product or environment may sometimes need an adaptation or specialised design. In the case of audiovisual products, this usually takes the form of add-on services such as audio description (AD), sign language interpreting, or subtitles, among others. Such accessibility services – in their conventional, post-hoc manner – are defined as assistive technologies, because they are not incorporated in the design or the production stages of the product (Udo & Fels, 2010).[1] The concepts of specialised design and assistive devices are also related to another concept, that of reasonable accommodation, which is defined by Article 5(3) of the Convention on the Rights of Persons with Disabilities (United Nations, 2006) as follows:

> Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

A crucial difference between assistive technologies and the notion of reasonable accommodation lies in the fact that not providing the latter is a form of discrimination, according to Article 2 of the Convention on the Rights of Persons with Disabilities (CRPD) (Broderick, 2020). One question raised

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[1] Udo &Fels (2010) go as far as to argue that AD in its traditional form (created once the product is finished, without any input from the production team nor its users) goes against the principles of universal design.

in the present article deals with the stage of the design or production process at which accessibility services should be incorporated.

As argued by Greco (2018), Romero-Fresco (2019) and others, such "adaptations" should be part of the design phase, rather than the distribution stage and, ideally, should involve users. In this paper, we understand that such an involvement may take the form of consultancy or validation. However, to date, the functions of accessibility consultants and validators remain ill-defined within the field of MA. Likewise, the two are sometimes used interchangeably by DPOs. The DPO Plena Inclusión Madrid, for example, offers training in "consultancy" ("Consultor de Accesibilidad Universal") for persons with cognitive disabilities but uses the term "validator" in their ongoing project Train2Validate, which we discuss below, to refer to overlapping functions.

In many different contexts, consultancy is a broad term that refers to any form of feedback mostly, but not always, obtained from trained professionals and users to inform the design, production, and/or validation phases of a given product. Consultancy may or may not be paid by the individual or company developing the product or service either in an early stage or as a form of evaluation. For example, if a new exhibition is to be offered at a museum, a user consultant may be hired to offer their feedback on the exhibition's accessibility. This feedback may be holistic, not answering specific questions raised by the exhibition organisers. However, consultancy can also be targeted at specific services, as Romero-Fresco (2019, p. 35) exemplifies with the subtitles for the film *Nectar* (Crow, 2005) "produced in collaboration with a deaf consultant" who "helped to decide on the font, colour, speed and display mode of the subtitles on the basis of the visual identity, the *mise en scène* and the mood of the film". Benecke (2004) reports that the working practice for television AD in Germany involves a blind team member for the revision of the script. In the United States, trained users are often hired as voice talents for the recording of AD tracks.[2] Yet another example is cited by Hermosa-Ramírez (2022): in a recent survey conducted with companies that provide AD in Spain and the UK, one service provider stated that users were involved in the quality control of the script, the voice recording, and the final mix.

Validation, in contrast, necessarily entails specific items or a set of fixed guidelines that are put to the test with end users. For example, the usability of accessible services and devices, henceforth understood as "the extent to which a product [or website] can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" (ISO 9241), may be validated in accordance with the standard ISO 9241-11 (Ergonomics of human-system interaction – Part 11: Usability: Definitions and concepts). Bevan (2006) outlines three main usability measures: effectiveness in completing a given task, efficiency, and satisfaction. These measures can be evaluated based on the percentage of participants achieving the task they have been given, the mean time to complete the task, and user satisfaction, among others.

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[2] https://adp.acb.org/ [15.03.2022].

In the field of MA, a popular usability test has been the System Usability Scale (SUS) (Brooke, 1996; Sauro & Lewis, 2016). The SUS has been applied to explore subtitle customisation (subtitle position, size, and the use of a box) (Manchón & Orero, 2018), and to test a mobile application for AD (Walczak, 2018), among others. Indeed, as we indicated above, MA has seen a shift from maker and accessibility expert-centred approaches to a user-centred approach (Greco, 2018; Greco & Jankowska, 2019). Users have been increasingly involved in the production of accessible services in the scope of participatory accessibility (Di Giovanni, 2018) and accessible filmmaking (Romero-Fresco, 2019), although these approaches are not entirely new nor exclusive to academic contexts. Udo and Fels' early academic writings (2009, 2010) already promoted the involvement of both the creative teams and the users in theatrical productions on which they based their research. Another example is Kleege and Wallin's (2015), as well as Kleege's work (2016), written from the point of view of users, in which they advocate the participation of users as co-designers of accessibility services.

Finally, accessibility validation has also been linked to web accessibility and easy-to-understand materials, especially in recent research projects in MA. The European project EASIT (2018–2021)[3], devoted to easy-to-understand language in audiovisual products, defined professional profiles in easy-to-understand subtitling, AD, and audiovisual journalism (Perego, 2020, p. 73). The ongoing Erasmus+ project Train2Validate (2020–2023)[4] aims to compile materials for the training of easy-to-understand validators and ultimately to create a certified course for this profile. Both projects are relevant to and, in a way, synergic with our paper because of the emphasis they put on collaboration with third sector organisations as research partners.

3. Methodology

In order to examine the role of users and Disabled People Organisations (DPOs) in the design and validation of access services, this paper presents results from in-depth interviews with representatives of the organisations presented above, namely Joan Miquel Roig from the Catalan Association for the Promotion of Accessibility (ACPA), Elisabet Serra from the Catalan Association for Easy-to-Read (ALF), Josep Maria Llop from Punt de Vista (PdV), and Joan Heras from the Catalan Association for the Integration of the Blind (ACIC). Elisabet Serra is the co-director of ALF, an organisation that works with DPOs representing persons with reading difficulties and cognitive disabilities. The other three interviewees are board members of the organisations they represent, as well as accessibility users with different degrees of sight loss.

The interviews were held and recorded in October and November 2020. Because of the restrictions on contact and social mobility imposed in Catalonia at the time of the interviews due to the Covid-19 pandemic, which also restricted the interviewees' availability, the recording was done asynchronously, i.e., the authors sent the questions to the interviewees and the latter recorded and

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[3] http://pagines.uab.cat/easit/en [15.03.2022].
[4] https://plenainclusionmadrid.org/train2validate/ [15.03.2022].

transferred their answers with technical support from the authors. The questions were sent both in English and Catalan, and interviewees were free to decide in which language they wanted to record their responses. Each interview had an approximate duration of 30 minutes. Three of the interviews (except for that including ACPA's responses) were presented at the Media for All 9 conference, which was held online in January 2021 and organised by the Universitat Autònoma de Barcelona (Spain). The interviews are available in open access at the university's repository.[5]

The interviews complied with the applicable ethical procedures outlined by Orero et al. (2018). Before the interviews, the interviewees were informed about the objectives of the research. They gave their written consent to take part in the interviews and agreed to have the results of the interview published both in an open-access video and in printed format in a research article. In accordance with the consent given, the names of the interviewees as well as the organisations they represent are not anonymised in this paper.

The interviews were organised in four sections. The first section included warm-up questions. We were interested in getting to know the activities of each organisation in detail as well as in documenting first-hand definitions of the practical understanding that users have of accessibility, since such definitions are not frequent in academic literature. The second section contained the first set of main interview questions asking about the involvement of users in the design, production, and validation of accessible products and services. In the third section, interviewees were asked about the professionalisation of user consultants and validators as well as about avenues worth exploring for prospective training. Finally, the last section aimed to gain insight into the involvement of users in the development of standards. The list of questions for each section is presented as an Annex to this paper.

The interviews were transcribed by the authors, and the responses in Catalan were translated into English. The transcripts were manually annotated on a desktop application and classified following a thematic analysis methodology (Braun & Clarke, 2006; Saldanha & O'Brien, 2014), which has been effectively applied in recent qualitative research conducted on non-profit organisations (Jiménez-Andrés, 2021).

4. Results and Discussion

This section discusses the main topics raised in the interviews and identified in the thematic analysis. In each case, the discussion is accompanied by a selection of the interviewees' verbatim quotes. The answers in Catalan are shown in English for readability purposes. Each verbatim quote is coded with the abbreviation of the organisation represented by the interviewee (namely, ACIC, ACPA, ALF, or PdV) and a number that indicates the quote's order of appearance in this paper.

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[5] https://ddd.uab.cat/record/237450 [15.03.2022].

4.1. Towards a Practical Definition of Accessibility as Understood by Users

As explained by Astorga (2012), DPOs played an active role in the writing of the CRPD (United Nations, 2006). This means that their contribution was decisive in defining the notion of accessibility and how it has been used and disseminated ever since the CRPD publication. It is uncommon, however, to find more recent, updated user definitions of accessibility in current research articles. In fact, Tor-Carroggio et al. (2019, p. 63), for instance, explain that users appear to understand key notions connected to accessibility, such as usability, in different ways, without providing further clarifications as to how they might conceive them. To fill in this gap in our knowledge, interviewees were asked to provide a practical definition of accessibility in their own words. To begin with, ACIC01 replied:

> We understand accessibility on two levels: First, it is a key element in a policy project which understands society to be for everyone. It is based on the CRPD, legislation, and the premise that our society must be for everyone. Second, this project, this social commitment, must be materialised in regulations, legal measures, bringing together experiences, resources and discussions that make it possible to advance specific measures that should allow persons with disabilities to access contents or services of anything that is being made accessible. Ideally, this would be the case from the object's conception. But if it exists already, such measures should be included in its adaptation process to make it as accessible as possible. Ideally, completely accessible. [ACIC01]

Despite coming from a DPO fully devoted to blind and low vision persons, ACIC's definition clearly starts by highlighting the advantages of accessibility for the society as a whole. ACIC understands accessibility as a social, rather abstract commitment that needs to be concretised in a practical manner. Importantly, in their definition, they raise the idea that full accessibility may not be possible. When asked to provide examples of successful experiences in accessibility, they illustrated this idea by explaining that, in an accessible art exhibition, "accessibility must place emphasis (from the blind activism sector) on a blind person being able to grasp *as much as possible* of both narrative and aesthetic elements making up artistic discourse" [ACIC02, emphasis added].

ACPA representative briefly defined the notion by resorting to the term *usability* and, once again, underlining its benefits for the society as a whole: "I would describe accessibility as the set of techniques that allow making products and services usable for everybody" [ACPA01]. ALF's definition of accessibility, in contrast, placed emphasis on the advantages that accessibility has for the main users of easy-to-read materials. At the same time, ALF specified which formats effectively cater, in their opinion, for the needs of diverse users.

> Accessibility is a matter of rights and equal opportunities. Cognitive accessibility ensures people understand what they read and allows them to make free and responsible decisions. So, accessibility is about autonomy, confidence, trust and inclusion. [...] Very accessible content should include all accessible formats. That is, easy-to-read texts, Braille, audio, sign language, audio description and pictograms to be understood by people with hearing, visual and intellectual disabilities. [ALF01]

PdV's definition started by highlighting the importance of asking ourselves what the concept of accessibility has entailed historically in subsequent stages in time, since it is understood to be "complex" and "evolving". Technological advances need to be considered to define accessibility in each historical context. PdV went on to introduce the notion of effort in connection with accessibility: access services do not grant users content without effort, but such an effort must be a "reasonable" one. This idea resonates with principle six of Universal Design, where design "can be used efficiently and comfortably and with a minimum of fatigue" (Connell et al., 1997, p. 35). Another important aspect raised in the definition provided by the PdV's respondent is the fact that accessibility has a direct impact on all areas of life for a person with disabilities: the respondent explicitly mentioned a basic element belonging to the private sphere (a "washing machine") as well as elements of public life, such as contact with the "administration". In his view, equality should be sought in a transversal manner and accessibility is a means to achieve it.

> Accessibility is an evolving concept. Today I would say it is basically the ability to do things in a normal manner with a reasonable amount of effort. Let's put it the other way around: when someone has to do something with a high amount of effort, much above the average of the population, the task they are performing is inaccessible. So, when accessibility comes about because of very simple issues such as mobility, reading, writing, talking… we are talking about the basics of accessibility. When something is not accessible, like a washing machine or something related to the administration, there is a situation of inequalities. And the gap that exists between those who can perform a task with a reasonable amount of effort compared with those who cannot is a huge one. And the gap turns out to be a discriminating factor. [PdV01]

Finally, PdV raised the idea of "attitudinal" (in)accessibility. As defined by Schneidermann (2012, p. 5), this form of accessibility is "tightly connected to the cultural dimension, and more specifically to social relationships. It refers to circumstances in which our social behaviour is not driven by preconceptions, stigmas, stereotypes, or discrimination" (our translation). PdV drew attention to the fact that negative preconceptions sometimes come from persons with disabilities as well.

> There is a worse kind of accessibility: attitudinal inaccessibility, i.e., when you want to get into a company, to be recruited, access a job position, etc., and your company thinks you're not valid because you have a disability, the mental shutdown basically creates a strong inaccessible barrier. And that is a cultural stigma we need to overcome. Last but not least, there is also some degree of attitudinal inaccessibility when we, persons with disabilities, think we aren't valid enough to participate in what is understood as normal life and refuse the challenge to fight for our rights and endeavours. So, accessibility is an evolving concept. While some years ago for a blind person accessibility meant walking with a cane, today it means that electrical cars can detect that there are people with special needs so that drivers are alerted because the car is warning them of what's going on and of the pedestrians walking in the area where the car is driving. Accessibility is a complex concept. We have to work on the mental barriers and the technological barriers. [PdV02]

4.2. DPO's Perspectives on User Involvement in Design, Production, and Validation Processes

Again, according to the poietic design proposal (Greco, 2019), the overall monitoring of the product needs to take place in the design phase and not after the service or product is already available for the public. Nevertheless, the interviewed participants agreed that, today, users are still seldom involved in the design process of products or services. Only ACPA and ACIC mentioned that there are exceptions to this trend, although they are rare. According to the interviewees, such an involvement is desirable to achieve better solutions for users, because today, accessibility solutions are "like a patch" [PdV03] unsuccessfully trying to provide "magical solutions" to cater for users' needs, which hinders "a true involvement of users leading to an effective result" [ACIC03]. Indeed, as put by Lawton Henry (2007, p. 17), "involving users at an early stage of the project and asking them to validate prototypes allows 'any necessary fixes before you get too far along the development process'". "Patches" or "fixes", as noted by the interviewees, may also have a negative impact on production costs. In the area of easy-to-read, organisations that cater for the needs of people with disabilities are "pushing for users to be considered in the process of creating accessible documents" [ALF02]. PdV indicated the need of having persons with disabilities in management positions in companies as a means to ensure that the "touch and sensitivity" of persons with disabilities is considered from the starting point of the design of a product or service [PdV04].

> Accessibility comes last. Products and services are designed and then people wonder whether they're accessible or not. [...] If we have people with disabilities in high management positions, the design of products and services will encompass the sensitivity that disabled people need to have. [...] In other words, could you design policies for women without women? The answer is no. So, you cannot design accessible products without the cooperation of those who truly need accessibility. [PdV05]

PdV and ACPA also mentioned a few examples of products or services which took accessibility and the needs of users into account from scratch and proved successful on the market, as well as handy for different user profiles, such as Apple's mobile phones or the AppleTV streaming platform, which integrates AD and subtitling for the d/Deaf and hard of hearing in different languages in its audiovisual content[6].

The literature has reported that users are typically involved at later stages of the production chain (Lawton Henry, 2020). This was in line with the interviewees' experience. According to the respondents, the involvement of users in validation "is key, needed, and indispensable" [ACIC04]. ALF systematically checks the texts they adapt to easy-to-read language with the target audience. ALF's representative explained that she had coordinated this kind of action often. PdV and ACIC interviewees reported having been part of accessibility validation procedures for the public

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[6] At the time of the interviews, AppleTV did include AD and subtitling for all its products, as noted by the interviewees. However, Arias-Badia (2022) reports changes in the accessibility measures on this platform.

transportation network or for private companies providing accessible media content, among others. ACPA's interviewee had been involved in several studies carried out by university researchers to validate the accessibility of emerging audiovisual services.

The respondents provided insights, based on their experience, into the most suitable methods to gather users' feedback. From their perspective as users, all interviewees suggested focus groups as an effective means both for considering accessibility in design and production phases and for accessibility validation. It is worth noting that focus groups are also considered an important technique in research involving persons with disabilities because, apart from allowing interaction, they offer "flexibility of implementation" (Kroll et al. 2007, p. 690) and can "foster the empowerment of people with disabilities" by stimulating the participants' interventions (Pretto, 2017, para. 12). In recent years, this type of research activity has been effectively implemented and has yielded crucial results in international projects working on accessibility, such as TRACTION or ImAc (Matamala, 2021). In their DPOs, the interviewees are used to exchanging and sharing knowledge and experience with peers, as is promoted in focus groups. ACPA underlined the need for the chosen participants of focus groups to be as heterogeneous as possible. The difficulty entailed in envisaging services or products that are 100% accessible was raised again at this point in the interviews.

> I understand that it is better to have a heterogeneous group, since there are many different degrees [of sight loss] and many different, and even opposing, needs with the same type of disability. [...] I think it is necessary to ensure that, within the same type of disability, users are heterogeneous. [ACPA02]

> It's true that every person is different in terms of their blindness, their low vision situation, and also their abilities and skills to interpret and understand reality. That's true. But we need to find some average point. Here you know you won't have a 100% accessible product for everyone, but you may have a very good degree of accessibility in most products. [PdV06]

The respondents did not specify how heterogeneity should be achieved. Different inclusion criteria are used in the industry and in academia to plan the recruitment of participants for focus groups. As explained by Kroll et al. (2007, p. 692), in the case of focus groups involving persons with disabilities in health research, the recruitment may be based on the type of disease or impairment of the participants, or

> [r]esearchers might […] decide that the disability type or disease classification does not matter but that a certain disability-related characteristic, such as using a mobility device (e.g., cane, wheelchair, scooter) or location (e.g., nursing home) are more important.

Both approaches are also found in accessibility research. Thus, the Royal National Institute of the Blind in the UK bases the selection of participants in focus groups on medical criteria, i.e., they gather feedback from persons who have been diagnosed with each of the most frequent vision disorders and eye diseases in the UK (Rai, 2021). Research conducted within the framework of the ImAc project, in contrast, ensured a balanced participation of blind and low vision participants in their experiments,

but did not assess specific health conditions as a variable for the selection of user validators (Fidyka et al., 2021).

The interviewees recommended involving active members of DPOs when it comes to discussing or validating accessibility, rather than any individual with disabilities, since these organisations "represent the shared experience of users, their preferences... after analysing them together" [ACIC05].

> We think, though, it would be good to involve user organisations. Why? Because even if they sometimes are small and don't group lots of people, that's true, the opinions of the persons in these organisations are discussed together. So, their views go beyond strictly personal views. That offers an added value, it opens up perspectives. [ACIC06]

In line with this piece of advice, ALF reported on a recent experience in collaboration with the Catalan Intellectual Disability Federation (DINCAT) for which ALF adapted the list of contents for a Public Service exam[7]. The working group involved in this collaboration included easy-to-read adapters, DINCAT, technicians, an illustrator, a layout designer, and a team of users. According to them, "from the start, users contributed their point of view, and it was taken into account throughout the project. Finally, the same working group verified that the level of the adaptation was appropriate for people with intellectual disabilities" [ALF03].

4.3. Training Opportunities and the Professionalisation of User Consultancy

The interviewees did not appear to be familiar with the training opportunities available for users to become (trained) accessibility consultants or validators. For blind and low vision users, PdV mentioned occasional training offered by the National Organisation of Spanish Blind Persons (ONCE). Likewise, ALF explained that "in the field of cognitive accessibility, there are entities that train their users so that they can assess the main communication barriers to understanding environments and services". According to this DPO, "this could be a route to professionalise people with intellectual disabilities" [ALF04].

To the best of our knowledge, there are only a few courses focusing on accessibility which have considered accessibility from the outset in material design. Some of these courses are targeted at persons with disabilities as students, while others adopt a more general approach and consider different student profiles, including those with disabilities. A recent example is the European strategic partnership project DA4you, which provides educational materials for institutions, individuals, etc., to ensure accessibility for digital learning tools. Other cases were mentioned in section 2: The EASIT project, funded by the European Union, has recently published a platform with accessible learning

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[7] https://repositori.lecturafacil.net/ca/node/818 [15.03.2022].

materials[8] for persons interested in becoming an expert in the creation, adaptation, or translation of digital content in easy-to-understand language. Among the courses intended for persons with disabilities, the above-mentioned Erasmus+ project Train2Validate is worth highlighting. It is led by the non-profit organisation Plena Inclusión Madrid, and its aim is to create materials and a comprehensive course specifically intended for users to become certified experts in easy-to-read content validation. The project researchers advocate certification as a key step towards better employment opportunities for persons with cognitive disabilities (Dejica et al., 2021, p. 9), a group that faces major obstacles in access to employment. According to Inclusion Europe (2020a, p. 6), persons with cognitive disabilities "are more likely to be unemployed [when compared to the general population as well as to persons with other kinds of disabilities], have lower rates of employment, and are often in sheltered settings", which "do not promote independent living" nor grant "a minimum wage" (Inclusion Europe, 2020a , p. 7). This situation has become worse since the pandemic (Inclusion Europe, 2020a, 2020b).

We asked respondents to share their own views on how training targeted at users should be planned in the future. It is worth noting that they welcomed the question and underlined the fact that they had never been asked that as users: "It's the first time that someone has asked me what kind of content I think should be included in validation training" [PdV07]. While this aspect is beyond the scope of this paper, we believe that the input of users on the educational requirements of a prospective accessibility expert should be further explored in future research. Most of the current courses offering training in accessibility do not seem to consider the main accessibility users, i.e., persons with disabilities, as eligible for this kind of training. Instead, they are aimed at persons without disabilities.

In answering this question, ALF focused on the demand for materials catering for the needs of potential students with reading difficulties and stated that prospective courses should incorporate the following: "Easy reading, signage like paths, pictograms, and photographs, comprehensible explanations, the use of audiovisuals and visual aids, and a structured environment, avoiding overstimulation" [ALF05]. ACIC, in turn, suggested the analysis and discussion of best practices as the most relevant type of activity in prospective training:

> In our view, the training of such a validator – in today's non-professionalised scenario – is essentially shaped by experience, by the experiences of others and by our previous experiences, and by discussion. So, the best training, in our view, would be to enrich personal experience by learning from further experiences. For example, if we talk about theatre or museum accessibility, we will analyse specific samples and resources to reflect on them as a group. [ACIC07]

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[8] https://transmediacatalonia.uab.cat/easit/ [15.03.2022].

In their answer, ACPA focused on expectations regarding content:

> It would be very useful to teach how to systematise the different types of needs in relation to the products or services under study. Likewise, a broad knowledge of the different tools or accessibility alternatives would be needed, as users do not necessarily know them all. [ACPA03]

Finally, the question of experiential authority was brought forward in the form of user professionalisation. Experiential authority (as opposed to traditional authority) is increasingly being discussed in the context of mental health service provision (Noorani, 2013) and research (Voronka, 2016), for instance. In this context, users are sometimes asked to "essentialise" their experience to "represent and speak for an essentialised group of others whose interests are wide and varied" (Voronka, 2016, p. 198).

Both ACPA and PdV respondents stated that they personally (i.e., not speaking on behalf of their organisations) would not favour user professionalisation:

> On the one hand I think that, in essence, validation is an activity aimed at a product that has a value on the market, and accessibility is part of the price of this product. However, professionalising validation could generate an increase in costs that may distance small productions from accessibility and, perhaps, generate a kind of professional "caste" that would act as an intermediary for end users and disregard specific, more individual needs or sensibilities of users. [ACPA04]

PdV's respondent added that as a DPO they were inclined to believe that technology makes professionalisation necessary today: "what we need to tackle today is much more complex than what we needed to address before" [PdV08]. The interviewee focused on the need for prospective professionals to be aware of current accessibility needs in all areas of life, and for them to be knowledgeable of the accessibility area on which they would be working. In his opinion, "consultancy is specific to the area where people would be working or performing certain activities" [PdV09]. He further emphasised that consultants needed to be familiar with the way in which users perceive reality and suggested that a minimum of 2–3 years' experience with users should be required in professional consultancy.

4.4. Users' Input on Standards

Matamala and Orero (2018, p. 150) have emphasised the idea that "end users should have a voice in standardisation agencies". According to these authors, standardisation committees should not only be comprised of representatives from the industry and academia – end users should also be directly involved in prospective standards on MA. This is in line with PdV's position that users should hold managerial positions.

Some accessibility standards explicitly mention users as a part of design, production, or validation processes. For example, in the case of the Spanish standards UNE 153020 for audio description and 153010 for subtitling for d/Deaf and hard of hearing audiences, "users" are the first kind of stakeholder mentioned in a list of relevant agents in the creation of the norms (AENOR, 2005, p. 3; AENOR, 2012, p. 4.). AENOR (2005, p. 3) emphasises the role of users in the decisions made: "The opinions, preferences and experiences of blind and low-vision persons have been taken into special consideration" (our translation), together with the input of AD professionals. Users are considered in standards to the extent that standards are adapted to cater for user needs, as is the case of the Spanish UNE Norm for easy-to-read materials, which has a version written in easy-to-read language specifically aimed at validators (AENOR, 2018). ALF respondent explained that the Spanish UNE Standard for easy-to-read materials "includes the validation process by end users, so those of us who adapt content always consider the end users and their reading comprehension needs. Users are always the focus of our work" [ALF06]. It must be noted, however, that previous research on easy-to-read language professional practices in Europe has shown that professionals are not always in regular contact with users and/or do not always incorporate the feedback from users into their written outputs (Arias-Badia & Matamala, 2020; Arias-Badia & Fernández-Torné, 2020).

The current interviewees emphasised the idea that the involvement of users in the process of making services or products accessible is especially necessary for processes "with no clear-cut standards" [ACIC08]. ACPA also raised the issue that the average user is not familiar with standards. In our view, further communication should be fostered to make not only users aware of accessibility expectations, but also to advise public administrations and the private sector. Following Bestard-Bou (2019, p. 162):

> Accessibility conditions will be adequate only if they are valid for the user. Standards or regulations are necessary to guide how these measures are implemented. It is not only the users who benefit from the clarity in the implementation of accessibility, but also the administrations or the agents of the private sector active in this field, since they will be confident that they are intervening effectively and not wasting resources (our translation).

5. Conclusions

This paper has put third sector organisations, and crucially DPOs, at the centre of the discussion to answer yet underexplored questions regarding the role of users in the design, production, and validation of accessible products and services. From the received responses – admittedly, limited in scope to four Catalan organisations – it is clear that users are taken into account in validation today, but are only rarely considered in the early stages of product/service design. The DPOs we consulted see some exceptions to this trend as a positive sign, indicating that practice may change in the near future. They demand true integration of persons with disabilities in all links of the production chain, but crucially in management positions, as the only way to effectively address users' needs. Similar logic could be applied not only to the industry, but also to research on MA. Following the principles of community-based participatory research, users could also become co-investigators, initiating, and

actively contributing to research projects that seek to solve accessibility issues that users (or organisations) themselves have identified (Hermosa-Ramírez, forthcoming).

It is worth noting that one of the main points raised in the interviews is the central role of user organisations in conveying views previously voiced in user groups in the context of associative activities. DPOs perceive themselves as relevant stakeholders when it comes to making products and services accessible. In one of the interviews reported in this paper, ACIC respondent stated the following:

> We do not give advice on specific audio description strategies or on a device for tactile reproduction, because there are experts for these things, but we do promote such activities and validate their application and viability. It is our role, so we've done it often. [ACIC09]

This paper has argued that the input from users actively involved in activities promoting accessibility is relevant to better understand not only users' needs, but also their enriching views on design and validation processes, on the training and professionalisation of user validators, and on their basic understanding of what accessibility entails. In this sense, we would respond to ACIC's quote above by saying that DPOs' representatives who delve into accessibility matters from a practical, life-experience point of view and who know about the needs of users and the access solutions they apply daily, should be regarded as key accessibility experts. The voice of users representing not only themselves as individual recipients of access services, but the whole groups of persons with similar needs is an essential resource in any validation process. Inclusion Europe (2020, p. 12) explicitly notes: "People with intellectual disabilities *and their representative organisations* have to be consulted" (emphasis added). Likewise, efforts should be made to improve communication and dissemination of standards and research advances to DPOs, since users raised the need to be better informed in the interviews. Article 29 of the Universal Declaration of Human Rights establishes everyone's right to "participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits" (United Nations, 1948). Greco & Jankowska (2019, p. 8) draw attention to outreach in MA and argue that dissemination must be not only systematic but also "understandable by the different stakeholders, especially users". Let us, then, close the paper by quoting ACIC again, in support of DPOs being an inextricable agent of any dialogue aiming at advances in accessibility:

> So, the most important thing is to have a constant feedback process among legislators, public policy makers, activists promoting accessibility, professionals who develop specific resources, in all areas, and users who are supposed to enjoy them. If we consolidate open, joint work processes, I am convinced that we will be heading towards a more accessible society. [ACIC10]

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