

Methodological toolkit for identification and professionalisation of user expertise



This deliverable has been produced as part of the Erasmus + Key Action 2 Strategic

Partnership project: Users as Experts

Date of publication: 22 July 2021

Authors:

Irene Kamba-Maltezopoulou, Evi Demetriou – Synthesis Center for Research and Education

Helena Jonsson – Furuboda

Sara Kjellstrand – Funka

Simone Lerche - DIAS

The European Commission's support for the production of this publication does not constitute an endorsement of the contents, which reflect the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

2

# **Table of Contents**

1	Intro	ntroduction to the project and the toolkit content	
	1.1	Background	4
	1.2	Users as Experts project	5
	1.3	Methodological toolkit	6
	1.4	Partners	6
2	Wor	king definitions	9
3	User	expertise areas of interest	12
	3.1	Design	12
	3.2	Citizen science	17
	3.3	Raising awareness of the needs and experiences of persons with disabilities	18
	3.4	Persons providing advice in a professional capacity working as auditors on web	)
	accessibility		
	3.5	Incorporating user experts in accessibility testing	21
4	Iden	tifying user experts	23
	4.1	Who can be an expert?	23
	4.2	Testing by the user expert	25
	4.3	Collecting and processing user experiences	26
5	Trair	ning user experts (what learnable skills do user experts need?)	29
	5.1	Multifaceted training	29
	5.2	Learning methodologies	32
6	Met	hods for converting lived experiences into skills and further development	35
7	Forn	nalizing Users' Expertise	37
8	Cond	clusion: Shifting the narrative	39
9	Refe	rences and Advisory sources	43

# 1 Introduction to the project and the toolkit content

#### 1.1 Background

Information and communication technologies (ICTs) have significantly impacted the way we live, experience, and communicate, in both private and public sectors of everyday life (Bakardjieva 2005; Wellman & Haythornthwaite, 2008). They have transformed the ways we interact across divergent contexts, from the way we communicate and interact socially with family and friends, and find new romantic partners, to how we access information, buy groceries and get advice for monitoring our physical and mental health.

In the last decade, Europe's economic growth has been widely attributed to companies launching initiatives in the global e-market for their products, forging closer relationships with customers and suppliers outside the vicinity of their local branches, and offer their employees training from experts across the border. According to the European Commission, the proportion of individuals between the ages of 16 to 74 in Europe who ordered or bought goods or services over the internet for private use in 2022 was 66%, a significant increase of 15% from 2016. Indeed, the share of EU households with internet in 2021 stood at 92%, an increase of 20% from 2011 (Digital economy and society statistics - households and individuals - Statistics Explained, 2022). It is clear from these figures that the internet has become an integral element of the lives of Europeans.

The COVID-19 pandemic provided another -unintentional yet significant- boost to online and virtual services and experiences as a way to manage and mitigate the quarantine measures and other restrictions that prohibited and/or limited interaction in the physical space. Unsurprisingly, even after the lifting of the measures and restrictions, the impact of the pandemic seems to have permeated all aspects of daily life, leading to permanent shifts throughout EU countries. Nevertheless, the widespread integration of the online space with the physical also has its drawbacks. The concept of the "digital divide" refers to the "gaps in access to ICTs and particularly Internet access [...] yet the underlying access divide deepens and intensifies for some social groups, including some groups of disabled people" (Norris, 2001; Vincent & Lopez, 2010). Specifically, the developments of ICTs offer both opportunities for, and impediments to, the full participation in the economic and social potential of the Internet and equality of disabled people (Scholz, Yalcin & Priestley, 2017). If this had been the case, the Internet could enhance the quality of life for people with disabilities by significantly increasing their independence and the opportunity to partake in the workforce. Instead, people with disabilities face a "distinctive form of digital exclusion" (Scholz, Yalcin & Priestley, 2017, p.1), further isolating their presence, connection, access,

and representation in society. It is clear, therefore, that an intervention is long overdue. As mentioned above, the COVID-19 pandemic gave rise to a shift towards virtual and online tools and solutions, a shift that was forced rather than organic, and which was expedited and came out of extenuating circumstances that didn't really allow for a comprehensive inclusion strategy or tailoring to address the needs of people with disabilities, deepening the digital divide in ways that were difficult to foresee or anticipate.

#### 1.2 Users as Experts project

The Users as Experts project develops innovative solutions that enable VET (Vocational Education & Training) providers to convert personal experiences of disability into recognized areas of expertise. This idea, which we refer to as 'user expertise', promotes the increased inclusion of persons with disabilities in society.

User expertise can also improve outcomes in disability-relevant policy areas. To ensure that the digital transformation of society includes everyone, the EU has introduced new requirements for digital accessibility in the public sector. These requirements affect hundreds of thousands of websites and mobile applications, many of which need to be updated or tailored to ensure compliance. As such, demand for web accessibility expertise is likely to increase far beyond the current supply.

As a result, web accessibility experts, who understand the requirements and can identify compliance gaps, are needed. The project proposes to address this need by engaging those who are most likely to have experienced web inaccessibility: persons with disabilities. This has the added benefit of providing occupational opportunities to a target group that is excluded from the labour market across Europe and faces wide challenges in terms of employment and integration. In addition, it promotes inclusion in a deeply meaningful manner, recognizing the validity and value of their experiences and transforming it into actionable insights that can improve the experience for other users and allow businesses and organizations to meet the requirements of a truly accessible offering of services and products.

#### The project presents four interrelated Intellectual Outputs:

- A repository of best practices for making use of personal experiences of disability and inaccessibility (IO1)
- A methodological toolkit for the conversion of personal experiences into recognized areas of expertise (IO2)

- A typology of web accessibility competencies for persons with disabilities (IO3)
- A model curriculum for a course on web accessibility for persons with disabilities (IO4)

These outputs have been developed according to an iterative co-creation methodology. The project partners contribute to all activities and learn from each other in the process, and each activity is built on the results of previous activities. In addition, key target audiences – persons with disabilities, VET providers, and public sector bodies – are engaged in workshops, surveys, and interviews to ensure that the materials developed to meet existing needs and desires. All outputs are made available as open-source materials to VET providers, disabled persons' organizations (DPOs), and public sector bodies across Europe. In particular, the IO2 deliverable **Methodological Toolkit**, was also disseminated through a multiplier event, where participants from all intended target audiences has a chance to explore the content and discuss issues, communicating experiences, concerns, and also insights and ideas. The summary of these contributions can be found at the section, Final Thoughts.

#### 1.3 Methodological toolkit

The methodological toolkit for the creation of user expertise presented in this document highlights the following areas:

- how to identify lived experiences that are suitable for conversion into discrete areas of expertise
- how to carry out the process of conversion
- how to ensure that these areas of expertise are recognized as such by others

The insights provided in the toolkit have been formulated in cooperation with persons with disabilities, public sector bodies, and VET providers. The methodological toolkit draws upon the user expertise best practices identified in IO1. The eventual result is a set of hands-on guidelines that can be used by VET providers and other educational institutions engaging in both formal and non-formal adult learning.

#### 1.4 Partners

#### **SYNTHESIS Center for Research & Education**

SYNTHESIS is Cyprus' leader in social entrepreneurship and social innovation, creating and implementing research and educational projects of social impact (particularly in the fields

of social inclusion, employment, entrepreneurship, migrant integration, and sustainable development) and managing "Hub Nicosia," a pioneering social innovation hub which houses and supports organizations, entrepreneurs and enterprises with a social or environmental mission.

SYNTHESIS also provides non-formal education to youth and adults; beneficiaries include all people who are at the risk of social exclusion, including NEET youth, migrants, people with disabilities, or those with fewer opportunities. As an accredited Vocational Education & Training provider, SYNTHESIS focuses on the development of training programs that can empower small enterprises and their employees as well as enhance the employment of people who are at risk of exclusion and marginalization. For more information, you can visit: www.synthesis-center.org

#### **DIAS GmbH**

DIAS provides services in the field of inclusion and accessibility. DIAS tests the accessibility of websites and applications and trains and consults clients who want to implement workflows that ensure better accessibility of their products. To support the implementation and monitoring of web accessibility, DIAS has developed the BIK BITV-Test, which is based on the EN 301 549, the standard to which the German directive for the accessibility of public sector websites and applications points. The BITV-Test is the leading accessibility evaluation procedure in Germany and is carried out by a network of currently 19 organizations, the BIK BITV-Test-Prüfverbund. DIAS also has carried out several projects in the field of inclusion and accessibility, for example, BIK für Alle, COMPARE, INCOBS, or hörkomm.de. Currently, DIAS is carrying out the Team Usability project which is funded by the German Federal Ministry of Labour and Social Affairs (BMAS). The Team Usability project develops information and methodologies for people with disabilities who want to test the accessibility and usability of web content and apps.

For more information:

DIAS GmbH: https://dias.de/

Team Usability: <a href="https://team-usability.de">https://team-usability.de</a>
BITV-Test: <a href="https://www.bitvtest.de/start.html">https://team-usability.de</a>

#### **Furuboda Association**

Furuboda Association is a Swedish civil society association. The association operates Furuboda folkhögskola, an independent adult education college, which is Sweden's largest college for people with severe disabilities. Independent adult education has a unique and inclusive teaching method, where teaching focuses on the participant who is encouraged

and empowered to co-create their education. Furuboda's activities focus on general adult education as well as vocational orientation measures for unemployed adolescents, in which the organization pursues an interdisciplinary approach. Employment programs, as well as programs in cooperation with government agencies, is also a part of their work. The main purpose of these classes is to motivate and support adolescents to find employment or an appropriate vocational training position. Many of these adolescents are affected by disabilities and/or social challenges such as poverty, an existing criminal record, and migration.

More information can be found on: <a href="http://www.furuboda.org">http://www.furuboda.org</a>

#### **Funka Nu**

Funka is a market leader in digital accessibility, working with digital interfaces in terms of content, design, and technology. Funka provides analysis, education, support, user testing, and research to customers in the public and private sectors. The work and recommendations of Funka are grounded in research and 20% of the activities of the company are financed by research and innovation funding. The company is based in Sweden and has 30 employees. It has a dedicated research and innovation department with staff speaking 6 languages. With its background in the Scandinavian disabled people's movement, Funka has strong links to end-users and will be able to contribute with concepts and methods for user-centered development processes. The role of Funka in EU research projects has often been focused on research and definition around user needs, involving stakeholder consultations and involvement of end-users with and without disabilities.

More information can be found on: www.funka.com

# 2 Working definitions

Working definitions on user experience and design can assist to identify the user who is being served and guide the development of assistive approaches. They can be a model to show how to best serve individuals and create a user experience or product that is not only functional but can provide significant and event life-changing benefits for all users.

In the context of accessibility, these definitions can help in fabricating design that is user friendly, create a positive inclusive experience and fully incorporate users with disabilities to meet their needs in a holistic way that can vastly improve the way they live and work. As a part of this process, fostering lived experience by user experts is invaluable.

Acknowledging and utilizing their knowledge, transferable skills, and lived experience can lead the way to inclusive design that can create an accessible user experience. This, of course, is achieved in conjunction with consulting with decision-makers, leading to policy change to foster greater inclusivity for users with disabilities.

Working definitions can also assist in introducing the topic to audiences without previous engagement in the field, and/or organizations that are looking to explore the issue of accessibility and inclusion and are looking for a comprehensive foundation of understanding. Even within the project partnership, the varying awareness of the topics addressed, made it essential to provide a glossary of basic terms to ensure a fruitful collaboration and dissemination. Kindly note that the working definitions offered in the toolkit represent a basic understanding of the terms, rather than an exhaustive scientific overview.

Accessible Design: A design process that takes into account the needs of people with disabilities to create products, services, and facilities through accommodations that provide solutions for barriers such as physical, cognitive, or technical design as well as interaction with a product or service. (What Is the Difference between Accessible, Usable, and Universal Design, 2022). This process can be guided by governmental legislation and industry standards, as well as policy implementation. Despite the coordinated efforts in the EU, different countries still experience wildly varying standards for accessible design which creates obstacles and barriers for certain groups of users and poses a challenge for companies and organizations that are trying to reach transnational users.

**Accessibility**: A characteristic that focuses on ensuring there are no barriers to serving individuals when engaging with a product, service, space, or interaction experience.

**Adaptive Design**: The development of objects that foster ease of access for all people that could benefit from tailored modifications to products/services/spaces to make them more accessible and well fitted for any individual's unique needs at any given time in any given context.

**Assistive technology:** Programs, products, software, devices for people with disabilities that are assistive, adaptive, and rehabilitative and which have often included disabled people throughout the process of ideation, design, and implementation.

**Disability Expertise:** The lived experience and knowledge of disabled people developed within the interactions of their personal experience of disability and their relationships and interactions within society, cultural settings, employment settings, and the designed world (Council of Europe, n.d).

**Social Model of Disability:** Identifies systemic barriers, communication barriers, attitudes and biases, and social exclusion practices or stereotypes that make it challenging or impossible for individuals with disabilities to take part and function on an equal basis with the rest of society (Council of Europe, n.d). This model suggests that the physical, attitudinal, and social environment must change, and barriers must be removed to fully enable individuals with a disability to participate in all aspects of human life. User experts and their contributions and experiences can contribute significantly to that direction, particularly through inclusive methodologies and toolkits, contributing to a shift of attitudes that will be transformed into meaningful social change that transcends the political and economic context of that particular time.

**Universal Design:** A broad concept of design that considers products, services, environments, and experiences that are usable by all people without the need for adaptation or specialized design. This term is pivotal in discussions of inclusion as it represents the idea that users as of "equal value" without marginalizing certain groups by requiring "special adaptations or tailoring" for them.

**Usability**: A measurement of a product's, design's, or service's ability to be used effectively, efficiently, and satisfactorily by a particular group of users in a particular context to complete a certain set of tasks (*What Is the Difference between Accessible, Usable, and Universal Design*, 2022).

**User Experience:** The way a user interacts with a product, service, and the environment; encompassing all aspects of the design experience from branding, usability, and function to providing a meaningful and relevant experience to users. Human behaviours, needs, and

abilities are taken into account and the value of the experience may have psychological, cultural, physiological, and emotional components.

**User Experience Design:** A process that aims to create a user experience that considers every element that shapes the experience for products, services, and environments and considers how the experience feels, the usability, and how efficiently the products, services, and environments assist the user to accomplish their task (Stevens, 2022). This term represents a shift of focus from the mere functionality of a product / service towards the overall experience and the emotional components of it. Current audiences are not only looking for products and services that serve a purpose, but also for a positive and meaningful experience that is also aligned with their own principles and beliefs.

**User Expert:** A user/expert is a person who has developed expertise using their lived experience in dealing with the challenges of the environment due to a physical, sensory, or cognitive functional limitation.

**Web accessibility:** The process of ensuring that everyone has equal and inclusive access to the internet as well as creating and designing software, websites, and other technologies for everyone, especially those with various types of disabilities, socioeconomic restrictions, and other impairments unrelated to disabilities.

# 3 User expertise areas of interest

#### 3.1 Design

From design services and products to planning out spaces with accessibility for all, there are many components and variables that come into play to create a cohesive and user-friendly experience. Accessibility must be at the forefront for teams leading and managing design, when considering universal design, creating products, services, and experiences. The first step of the process is researching and understanding the accessibility issues that people face, and direct design efforts into an outcome that is inclusive, useful, functional, and pleasant. But how to research and explore the challenges users face?

User expertise can be the answer in this question and a significant component of the design process. Users should be consulted in every stage of design, even as early on as ideation. Identifying user personas during the beginning phases will ensure designers and other members of the process are fully aware of the range of the functional limitations of the individuals for which they are designing, but they are also aware of the unique insights and skills that these users may have developed as a response to the challenges they face in their daily lives. It is important to highlight that the engagement of User Experts is not only meant to identify weaknesses in design, but primarily to enrich the design process with the experience, expertise, and insights that the Users have, broadening the design horizon, thinking out of the box, ensuring diversity and often promoting ingenuity and innovation.

Users will often have different needs, at different times, and in different circumstances and contexts, so it is essential to strike a balance between the universal scope of the project/service and the most common contexts in which the product / service will be applied by the users.

More specifically, involving a wide range of potential users in the needs analysis / market research stage, ensures a holistic representation of the existing or upcoming needs, as well as a good chance to identify -previously missed- market gaps and tailor products and services to meet them. Further on, involving a diverse audience of potential / existing users in the testing / piloting phase as well, ensures real-life applicability and usability to meet the standards for accessible design. In that manner, this iterative and inclusive process creates a more complete product or service and limits the efforts directed at fixing issues that could have been avoided.

#### 3.1.1 Types of design and related project management methodologies

In order to facilitate the design process and to foster innovation, to develop new products and services, to iterate and process improvements with the final product several design and project management methodologies can be employed. Each organization / institution / business can choose the management methodology that better serves their needs and is most compatible with the working culture and the vision of the organization. Below you can find some indicative methodologies such as Human-Centered Design Thinking, Agile, Scrum, Lean, and Six Sigma.

Human-Centered Design Thinking: You can produce goods and services that resonate with and are created according to the needs of your audience by using the problem-solving method known as human-centered design, which places actual people at the center of the creation process. (Landry, 2020). The idea is to keep the needs, problems, and preferences of the users in mind. Because your clients have already tested the solution and are more invested in using it, you will subsequently design more user-friendly, accessible items that will probably generate a bigger profit (Landry, 2020).

Agile: The Agile technique essentially divides a project into many parts and uses these phases to manage it. Constant improvement at every phase and ongoing collaboration with stakeholders are required, while teams cycle through a process of planning, carrying out, and assessing once the job starts (*What is Agile Project Management*, n.d). Collaboration between team members and project stakeholders must always be ongoing. Agile project management is a word that can be used to refer to a variety of frameworks rather than a specific methodology. Some common frameworks include Scrum, Kanban, Extreme Programming, and DSDM (*What is Agile Project Management*, n.d).

Scrum: While Scrum is now the most widely used agile framework, not all agile is Scrum, and not all Scrum is agile. Scrum is a project management methodology created for small, cross-functional teams of five to nine individuals who divide their work into manageable tasks that can be finished in a fixed amount of time called a sprint (What is Agile Methodology, 2022). Team members, a Scrum master, and a product owner make up Scrum teams. Scrum is commonly used when a big project can be divided into 2-to-4-week sprints. Scrum emphasizes feedback loops via a ritual known as the "retrospective" (What is Agile Methodology, 2022).

Lean: According to Asana, lean project management is an Agile methodology that increases client value, by removing waste from each project phase. Less surplus is produced by lean project management, which can maintain your project in better shape (Asana, 2022). Lean

project management enables teams to execute more quickly by effectively managing their workflow and focuses on delivering value from the perspective of the client, in contrast to traditional project management, which is structured in phases that divide planning from execution (*What is Lean Management*?, n.d).

Six Sigma: The Six Sigma approach places a strong emphasis on improving customer requirements knowledge and removing waste and faults. These goals are accomplished by having a thorough understanding of engineering, project management, statistics, and the underlying systems and processes (Anbari, 2022). The goal of Six Sigma initiatives is to enhance the organization's goods, services, and operational procedures across a number of functional areas, such as manufacturing, marketing, finance, and administration. According to Anbari, these methods can contribute to creating and developing fully accessible products with the final user in mind and help people with disabilities thrive (Anbari, 2022).

#### 3.1.2 Areas of design

The following are examples of areas where user testing can be helpful for more inclusive design.

**Service Design** - Service design is related to the components of creating solutions for optimal experiences for users and service providers and improving the overall user experience involved in the service. It involves identifying the needs of the user along with coordinating the components of the experience in conjunction with their respective contexts. When creating a customer journey from the first interaction to the end of service, each aspect of the experience must be designed thoughtfully.

#### Components of Service Design:

- Actors those delivering the service
- Location the environment where the service will be provided e.g. online or inperson
- Props physical or digital artifacts
- Associates any other organizations involved with providing service
- User Experts people who create and use or are affected by the service and the processes and workflows involved to execute the service effectively

 Processes – workflows, and operations used to deliver the service and if technology is utilized for the service, then it includes user experience design

Holistic design of services will ensure that all user needs are being considered and user expertise will be ingrained in every part of the process to fully empathize with the relevant users. Customer journey maps, avatars and personas, as well as service blueprints can map out the dimensions of the users and enable the creation of an inclusive and accessible service that prompts a positive and meaningful customer / user experience.

**Product Design** - Product design is the procedure of finding a problem and subsequently developing a solution, certified with feedback from users. User experts are an essential part of this process and can be employed at every stage. Product design stages usually flow in this order:

- Identifying the problem
- Defining the problem
- Conducting user research, analysis, and journey mapping
- Ideation
- Product design
- Prototyping
- Testing

Design Thinking is an example of a design methodology that can be utilized to navigate the product creation process. It can assist to maintain the focus on the creation and improvement of products that resonate with the users, in order to ensure that products are accessible and inclusive, particularly for people with disabilities. Aspects and considerations of product design can include:

- Conceptual models, design, and navigation design
- Technical standards/aspects include considering
- Input, control, and mechanical functions
- Output, display, and control functions

Standards, guidelines, and regulatory and legal requirements must also be taken into account to ensure compliance of the product / service within the existing context or to initiate steps for policy changes that will change the context -if needed-.

The IoT (Internet of Things) in the format of smart devices and connected technology can also create new opportunities for people with disabilities. The development of accessible and adaptive products and services in this realm can improve the quality of life for users, resulting in the removal of social barriers, increased autonomy, improved social access and integration and provision of life-saving monitoring applications for some.

Nonetheless, access to the Internet and the possession of technology and equipment (even in the form of a smartphone) should not be taken for granted for all users with disabilities. As such, efforts should be made to ensure the existence of the basic equipment and provisions that would enable the full benefits of the IoT.

**Space / Experience Design** - This can encompass a user's UX/UI experience, or it can be a part of an interaction with a physical environment such as a space or a virtual - interactive experience. Both forms of experience design can employ the same processes and design methodologies.

Designing an accessible and inclusive experience involves considering all physical and non-physical components, as applicable. Indicatively, elements to be taken into account include:

- Building layout, form, scale, appearance, details, and materials
- Access, movement, mobility, and accessibility
- Environment landscape and visual impact, microclimate, noise
- Location views inwards and outwards
- Function and pattern of uses and activities, including community facilities and local services
- Social characteristics and demographics
- Economic factors
- Aspirations, concerns, and perceptions of individuals and local communities

- Access to technologies
- UX/UI experience

Along with user experts, many other professionals are a part of the design process. Governmental and regulatory decision-makers are contributors in this process as well. Amongst them are: policy development contributors, managers, researchers, product developers, UI/UX designers, software developers, writers, quality assurance personnel, accessibility training/consulting experts and other interested stakeholders.

#### 3.2 Citizen science

Citizen Science is the practice of the involvement and collaboration of the public in scientific research. It is a flexible approach that can be applied to very diverse situations and disciplines. Citizens can work directly with scientists and researchers, usually as unpaid volunteers, to share and contribute to data monitoring and collection programs. They can also act as contributors and collaborators and obtain leadership roles within a project. Citizen science projects produce a real scientific output and both the professionals and citizen scientists involved mutually benefit, while also positively affecting their respective communities.

Through citizen science, any member of the public can actively participate in many of the different stages of the scientific process, from defining the research questions to data collection, interpretation, and analysis to the publication and dissemination of results. This approach may be used as part of a broader scientific activity to capture a larger amount of data, without increasing the budget drastically of a research program. Community-based groups are often involved in these processes.

A citizen science project is open to all members of the public. However, some groups, such as people with disabilities, are traditionally under-represented. For a citizen science project to be successful and involve people with disabilities, the research process should be designed in an accessible and inclusive way, encouraging the participation of citizens with varying disabilities. This should go beyond the technical accessibility of research tools such as data collection apps and should take into account the way that people feel comfortable and like to engage and share information. Examples of how people with disabilities can be actively included in citizen science projects can be seen in EU-funded initiatives such as the "REINFORCE project".

Citizen science can be a powerful contributing force to the process of ideating, designing, creating, and implementing products / services / experiences that can activate and motivate community members to engage with processes that they traditionally viewed as "out of reach", allowing individual experiences to be transformed into meaningful contributions and insights, allowing a more diverse and inclusive pools of User Experts.



#### 3.3 Raising awareness of the needs and experiences of persons with disabilities

A disability ambassador or advocate is a person with their own lived experiences who engages in activities to raise awareness of how it is to have a disability, as well as to highlight issues of accessibility and usability.

Disability ambassadors can come from a range of different backgrounds, and they can work in several different environments and with various target groups.

#### 3.3.1 Advisors for the central government/local authorities

The disability ambassadors that work for the government play an active role in generating awareness of the opportunities created by employing people with disabilities. They also can help governments and other authorities to design, develop, implement and oversee policies concerning various topics that can help improve the lives of people with disabilities. (Human Resources and Skills Department Canada, 2013). They can also liaise between people with disabilities and public authorities and stakeholders, establishing and creating communication and rapport that can have long term impact in the lives of all community members.

In the UK, for example, there are Disability and Access Ambassadors who help to ensure that businesses are doing all they can do to support their disabled customers. They strive for improvement in the accessibility and quality of services and facilities in their sector for people with disabilities.

#### 3.3.2 At the workplace

Creating and maintaining a universally designed and usable workplace requires that one addresses the needs of a diverse group of employees, including people with disabilities. All employers recognize that each employee, or prospective employee, possesses a unique set of abilities and limitations.

The Principles of Universal Design can guide the design of environments, processes, policies, technologies, and tools to facilitate the integration of all employees in the workplace. Universal Design has the potential to optimize productivity, safety, collaboration, and communication for all employees.

Creating accessible work environments involves making workplace accommodations for employees with disabilities, including the employee workstation as well as the entire work facility or worksite. Areas of consideration for usability and accessibility in the workplace involve Environmental, Controls and Tools, Workstation and Storage, Computers, Communications, and Safety. Design of workplace policies and procedures, workplace wellbeing, accessible training technologies, and importantly, methods to complete work tasks are also essential components that should be included in the accommodation process. This provides a supportive environment that can increase productivity and job satisfaction and boost employee retention.

User expertise and in particular recognized/appointed User Experts are essential in the creation and promotion of more inclusive and diverse workplaces either as permanent employees or as visiting experts that can help open the discussion regarding accessibility, but also contribute with potential solutions or alternative options. In that role, they can address the needs of various employee groups and design policies and processes that promote equality and allow for personal and professional growth, while also providing insights into the user experience of becoming an employee, being an employee, and/or ceasing to be an employee.

When integrating accessibility across an organization, the role of disability champions or ambassadors is essential. It is important to first build on the champions' understanding of accessibility so that they can address accessibility issues within their departments and lead change across the organization. They should include people from key areas across the organization and become advocates for the adoption of accessibility plans by building and

engaging teams, generating awareness and skills, and promoting accessibility. An example of this can be seen in Barclays bank which, as of 2019, had 90 champions on board. These champions have gone through baseline accessibility training and additional in-depth training. Barclays also has Purple Champions, an allies program for people with disabilities across the organization, to continue to raise awareness around disability issues (*We are looking for disabled ambassadors or champions | Disability Rights UK*, 2022).

#### 3.3.3 For the general public

Many disability ambassadors serve as role models to the general public. These ambassadors are usually public figures, such as actors, musicians, athletes, models, etc. They either have a disability themselves, have a family member with a disability, or actively defend the rights of people with disabilities. They openly share their stories to serve as inspiration to others. Examples can be found in organizations such as Mencap, the UK charity for people with a learning disability. This is a crucial part of the ongoing efforts to remove stigma from people with disabilities, to prevent bias, prejudice, and dissemination and to normalize diversity in all aspects of human experience.

# 3.4 Persons providing advice in a professional capacity working as auditors on web accessibility

The W3C Web Accessibility Initiative (WAI) defines web accessibility as "websites, tools, and technologies [...] designed and developed so that people with disabilities can use them. More specifically, people can perceive, understand, navigate, and interact with the Web and can contribute to the Web" (WAI, 2022). Web accessibility does not only help individuals with disabilities but is also useful for people using mobile phones, smartwatches, smart TVs, and other devices with small screens, different input modes, etc. older people with changing abilities due to aging people with "temporary disabilities" such as a broken arm or lost glasses people with "situational limitations" such as in bright sunlight or in an environment where they cannot listen to audio people using a slow internet connection, or who have limited or expensive bandwidth (WAI, 2022).

For products, services, or interactive digital environments ensuring inclusive access for people with disabilities, web accessibility is paramount. A great accessible user experience design will enable people of all abilities, including those with disabilities, to navigate and interact with the web as well as the products, services, and experiences that are available.

The most common way to make sure that digital interfaces are accessible to as many people as possible is to implement the European and international standards on web accessibility. In the EU, the standard EN 301 549 "Accessibility requirements for ICT products and Services" is the baseline for all legal requirements regarding web accessibility. These are the requirements that the European web accessibility directive is pointing to. The EN standard itself incorporates the success criteria of the international standard Web Content Accessibility Guidelines (WCAG) version 2.1. These standards are technical, and in many cases, organizations need help from external experts to check if their websites are compliant with the requirements, and also to be able to implement the requirements where necessary. This is why in most countries in Europe there are at least one and, in many cases, several, specialist organizations working with auditing websites on accessibility ("Web Content Accessibility Guidelines (WCAG) 2.1", 2022).

Many of the specialist organizations employ persons with their own lived experience of barriers to accessibility as auditors. Some of the legal requirements in terms of accessibility relate to how websites are supporting assistive technology such as screen readers. Persons with visual impairments often have more experience and skills in using screen readers, and they are, therefore, often hired as auditors to test websites on requirements relating to accessing information without the use of vision and compatibility of the website with assistive technology. These positions can be both full-time, part-time, or on a contractually flexible basis. Although there are requirements of accessibility that concern persons with other impairments, such as motor impairments, hearing impairments, and cognition, research shows that it is more common that persons with visual impairments are hired as experts. Examples of organizations in Europe that employ persons with disabilities as auditors include Funka (Sweden), Braillenet (France), and Anysurfer (Belgium).

#### 3.5 Incorporating user experts in accessibility testing

During the later stages of testing prototypes of products, services, or spaces, user experts can be consulted to ensure the accessibility and usability of designs. User experts with disabilities are an integral part of the process. Involving them from conception to completion will ensure a thorough development of products and services, as well as lead to increased social accessibility, independence, community integration, and involvement.

Some ways to incorporate user experts in disability testing are:

- Utilizing assistive technology in testing for participants who may require assistance.
- Ensure testing for those with different disabilities visual, auditory, physical, and cognitive.

- Connect with various local disability organizations to find testers.
- If testing is in person, ensure accessibility of the location.
- Time may be a concern for those with certain disabilities so this must be kept in mind when testing.

A great user experience meets a particular user's needs in the specific context where they use the product. Working with user expertise brings vital information and knowledge from their experience that can inform every stage of design. Engaging users as experts fosters the growth and employability of individuals with disabilities. User expertise and their lived experience not only guide the design process from conception to completion but involve them in the very products and services that they may require themselves while increasing social integration and contribution which will have life-enriching effects.

It should also be kept in mind, that accessible products and services have benefits for all users, as they are often simpler and more intuitive to use. Therefore, testing the products and services with persons of different abilities also makes it easier to spot and correct design issues that may affect all users.

In a recent EU study on inclusive web access for persons with cognitive disabilities, several sources confirmed that accessibility issues experienced by users with disabilities in user testing were also issues that persons without disabilities struggle with. The only difference is that persons without disabilities try to overcome the issues themselves, whereas persons with disabilities get stuck. The implication is that the unique knowledge and experience of persons with disabilities can lead to insights that are not only beneficial for persons with disabilities but everyone.

# 4 Identifying user experts

#### 4.1 Who can be an expert?

Any person with any type of disability, whether visible or not, has the potential to become a User Expert and use their experience to inform decisions, policies, products, and services in a variety of fields, including web accessibility. This includes persons with:

- Physical disabilities
- Complex or divergent communication needs
- Sensory impairments, and
- Learning, cognitive, and mental difficulties

Areas that are not fully represented or catered for in the mainstream design of products and services and people who experience them are often not able to either fully use or fully benefit from products or services, or they have negative and challenging experiences as users, leading to feelings of frustration, exclusion, marginalization, disappointment, and demotivation.

Although it is difficult to define the exact process of identification of User Experts due to the diversity of the people that could qualify for such a role, and the varying contexts in which such a role could exist, some characteristics could highlight the prospects of becoming a User Expert:

- Being part of a user group that faces challenges or disabilities (as mentioned above). This can be due to a permanent or a temporary situation and it can be present from birth of developed later in life. It is often eye-opening how the experience of individuals changes once they experience a disability through an illness or an accident. For example, a visitor in the hospital may see nothing wrong with the design and functionality of the entrance until he/she visits the premises as a patient with a broken leg that is unable to walk and needs to use a wheelchair.
- Being able to spend time in the process of acquiring the User Experience by accessing/using /experiencing the product/service. Although the experience may happen even involuntarily, it is essential that the user expert dedicate time to assess it, experience it in a timely or repeated pattern and spend time trying out different options / situations.

- Being able to work analytically and document that experience: these are elements
  that are crucial for the documentation and transferability of the experience in order
  to benefit as many users as possible and to inform decisions in varying departments
  and levels of hierarchy within an organization / institution / business.
- Being able to commit to the process and meet any requirement such as reporting, notes, etc. It is essential that the user expert is committed to the tasks at hand and able to persevere with consistency and accuracy when the demands of life may interfere with the capacity and availability of the user expert.
- Being able to maintain both a personal perspective and a general perspective meaningful for the group represented. Striking a balance between seeing the leaves on trees but remaining aware of the whole project is an essential element in the User Expert journey; the ability to shift between the small and big picture leads to more insightful and meaningful contributions that can inform decisions that affect all the users.
- Being aware of the broad compliance framework or being willing to be informed and educated about it. It may not be possible for every User Expert to be fully proficient in the regulatory or legal framework or the compliance efforts in each sector; but it is essential that the User Expert is willing to dedicate time and efforts in order to increase their awareness and skills in these topics.
- Being willing to share the experience even though it might not have been optimal or positive. It is important for the User Expert to feel comfortable and confident in conveying their user experience, highlight their contribution in it, and identify areas of improvement or iteration.
- Being able to offer ideas or solutions that could make the product/service/ experience more inclusive and better suited for people with disabilities. Providing insights, ideas, suggestions, and opinions can help inform corrective actions and also help shape better products / services / experiences.
- Being willing to communicate and cooperate with other stakeholders and assume a
  guiding or consulting role. Being a User Expert often includes stepping out of one's
  comfort zone and assuming a more active role and more responsibility, as well as
  higher moral or emotional awards. Nonetheless, it may also require good
  communication and negotiation skills, good teamwork skills, active listening, and a
  common vision founded on shared principles.

Special consideration should be given to efforts to bring higher visibility to traditionally overlooked users or users from marginalized or challenging backgrounds or users from minority groups, that are often reluctant to share their experiences or are often not even acknowledged as users of certain products/services/websites etc. As discussed in the following sections, all users have the potential to become user experts if they wish to do so and if they receive appropriate and tailored support.

#### 4.2 Testing by the user expert

Depending on the area or field of interest, the User Experts might have to focus and deal with a variety of aspects of a product/service/experience, however, some key elements always need to be addressed as part of the assessment process, such as:

#### i) Technical/practical aspects

- Was the user able to access the product/service?
- Was the user able to make full use of the product/service?
- Was the user able to make partial use of the product/service?
- Were there operability or access barriers in the process?

#### ii) Knowledge or skills aspects

- Did the use or access of the product/service require knowledge not easily accessible to the user group?
- Did it require skills that certain user groups might be lacking or unable to acquire?
- Were there alternative knowledge/skill paths available to the user so that they could make full use of the product/service?

#### iii) Emotional aspects of the experience

- How did the experience of using or attempting to use the product/service make the user feel?
- Are there differences in the emotional response of users with disabilities when compared to users without disabilities?
- What types of feelings did the experience invoke?
- Was there a way to communicate those feelings (feedback form, review, comment form, etc)?
- What type of emotional impact did the experience of the product/service have on the user?

How will the user communicate this experience and to whom?

#### 4.3 Collecting and processing user experiences

Depending on the context of the research for user expertise, several tools can be of value in collecting the user experience, such as:

- Questionnaires addressing all the aspects mentioned in Section 3c. The question-naires should be designed and applied taking into account the characteristics of the User group and be intuitive, accurate, short and easy to navigate and complete. Although the choice and phrasing of questions cannot be discussed in detail, it is essential that both closed ended questions and open-ended questions are included to allow participants to voice any other input or comment that is not directly addressed in the included questions. The language used should be inclusive and non-discriminatory, and relevant to the cultural and social context of the country / group. As in all other processes, it is essential to include user experts or plain users in the process of designing, framing, and disseminating the questionnaires.
- Focus groups (either uniform with users from specific backgrounds or diverse focus groups, involving various users with different types of disabilities or difficulties). Focus groups give the opportunity to users to discuss and offer more detailed, varied, and comprehensive answers / insights to the issues raised / questions asked. They can also serve to forge working relationships that may prove valuable in later stages as well. When planning a focus group, special attention should be given to the selection of participants, the venue and its accessibility, the duration of the meetings, the facilitation of the focus group and the ways in which the proceedings will be documented. As always, the results of focus groups and any conclusions drawn from them, should be made available and communicated to all participants as part of a debriefing / follow-up process.
- Personal interviews that can address the qualitative aspects of the user experience and explore the individual experiences in depth. Personal interviews can enrich the contributions, offer unique insights and allow for a more iterative process that permits many aspects to be explored, not only as activities, but also as experiences. As in all other means of collection, it is essential to inform participants of the scope and content of the meeting, ensure GDPR compliance, maintain an open and honest communication and remain mindful and respectful of individual limitations, opinions, or viewpoints.

All the above tools would need to be designed and co-created with the insights of the users themselves or with insights from existing user experts; otherwise, there is a risk of the questions/issues raised not relating to the experience users with disabilities had. It would also require several rounds of testing the tools to ensure that there is a balance between the individual experiences of users (that are heavily dependent on their circumstances as well) and the representative experience that is relatable also to other users with similar or even different disabilities.

Even experiences that are not common or representative of more common issues can offer valuable information about the design and use of products and services and can help inform decisions in all aspects of creating, promoting, distributing, advertising, and selling products and services. They can also help bring awareness to issues that are often overlooked or underrepresented due to cultural, social, political, or other biases and prejudice.

For the processing of user experiences, statistical tools may prove useful in identifying trends or common themes and highlighting broader issues relating to each group; nonetheless, to access the full depth of insights, further qualitative analysis will be needed to complement the quantitative aspects.

The points to be considered in the processing are, among others:

- Are the user experiences representative of the collective of users?
- To what extent and under which circumstances can they be considered representative?
- Are there conclusions or correlations that can be drawn upon?
- Are these conclusions or correlations applicable in other similar contexts / situations?
- Are there common themes or trends that can inform the design of products/services?
- Are there issues severely affecting or prohibiting the user experience?
- Are there points of interest relating to gender, age, or other demographic characteristics?

- Can the experiences that are unique or non-representative be used to inform decisions?
- Can the non-representative experiences provide insights into potential problems or solutions of accessibility and/or user experience?
- Are the conclusions produced able to apply to other sectors, issues, products, or services?
- What conclusions can be drawn to identify gaps in inviting and sustaining user experts?
- What motivates or demotivates user experts?
- Do user experts perceive the experience of being a User Expert as positive and to what extent? Why or why not?
- What could improve the experience of being a User Expert?
- How are User Experts perceived by other groups / people?
- How do organizations / institutions / businesses view User Experts?
- What actions can be taken to increase the perceived value and recognition for user experts?

# 5 Training user experts (what learnable skills do user experts need?)

#### 5.1 Multifaceted training

The training participants need to have previous personal experiences of exclusion from the specific context where user expertise is supposed to be applied. Based on previous experiences, the training should aim at developing relevant knowledge and skills needed for different aspects of the User expert role. As such, the training should be multifaceted, and it should include Knowledge, Skills, and Attitudes.

#### 5.1.1 Knowledge

Knowledge of the context where the User expert role is needed, for example:

- Target groups / existing or potential audiences (it is essential that the User Experts in training are made aware of the target groups that they are addressing, even if they might not be a direct member of these groups).
- Different types of disabilities and the needs associated with them (User Experts should have a basic understanding of the various types of disabilities that exist and to be able to draw some rudimentary conclusions about similarities and differences of the experience).
- Adaptive strategies for excluded groups (when becoming a User Expert, an individual is expected to overcome several limitations either on a personal or on a social level; to ensure the success of this process, individuals should be equipped with a range of adaptive strategies).
- Laws, regulations and policies applicable (different countries may have different frameworks and applicable regulations, it is important that the User Expert is taught about these and is able to explore the effects these may have on the individual or collective user experience).
- Technical knowledge & technical language (although not always necessary, User Experts should be offered training content on the basics of technical knowledge and language, especially in relation to web accessibility and the IoT.

Procedures and guidelines for testing (since each testing process might be different,
User Experts should be trained both in the general concept and steps of testing and
in the particular testing process thy will be asked to employ).

#### **5.1.2** Skills

 Awareness (User Experts should make efforts and be informed and trained towards remaining aware of the context and situation affecting their own group but also other groups of people with disabilities.

In addition, they should also be able to:

- understand the causes and consequences of exclusion and how it affects individuals, groups, communities, and societies in general.
- identify and explore their own needs and experiences of exclusion and draw parallels to other people's experiences and situations.
- identify other's needs and experiences of exclusion and relate to them
- reflect on and analyze previous experiences and adaptive strategies

What is more, they should develop and further enhance skills relating to:

- Representation
- Effective Communication and Active Listening
- Describing and explaining the needs of the group represented making the information relatable to other users, stakeholders, or members of the public
- Providing and Receiving feedback throughout the process
- Addressing and engaging stakeholders at all levels
- Implementing the acquired knowledge to evaluate and test the usability of existing products or activities or to assist in the design of future products / services / experiences

#### 5.1.3 Attitudes

A significant component of the work or focus of a User Expert is to contribute towards a more inclusive process that will lead to the development of products, services and experiences that do not reinforce marginalization for people with disabilities and do not perpetuate stereotypes and bias. Several aspects of that process relate to the skills and knowledge that a User Expert needs to acquire and demonstrate. But the list wouldn't be complete without a mention of some of the attitudinal aspects that a User Expert should cultivate and promote. Despite the blurry line between what can be considered a personality trait and is therefore innate, and what can actually be nurtured and enhanced, below there is a brief list of attitudes that can support the role and scope of a User Expert.

- Being Open-Minded and able to explore and experience products and services that are outside the comfort zone of the User Expert.
- Empathetic: in order to enhance the scope of the User Expert's contributions, it is essential that the User Expert is able to "walk in the shoes" of other potential or existing Users that may have different disabilities or are facing different challenges.
- Honesty and reliability: It is essential that the User Expert is truthful and honest in their review / account of the product / service / experience and are able to complete their tasks in a reliable and structured manner.
- Objectivity: it is important that the User Expert maintains a balance between their individual experience and personal perspective and the overall perspective that encompasses the needs and wants of other categories of Users as well. User Experts should be objective in their contributions and able to shift their perspectives to explore different angles.
- Collaboration: although the work of a User Expert might appear solitary, it is essential that the User Expert is able to communicate and collaborate effectively with all the other people involved in the process of designing and delivering a product, service, experience and is also able to collaborate and address other stakeholders and audiences as well.
- Self-awareness, confidence, motivation and perseverance: the User Expert may face various challenges in the process of contributing towards products / services / experiences, they can be more easily overcome if the User Expert is aware of their own

strengths and weaknesses, they are able to maintain their motivation without external intervention and are able to persevere even in the face of adversity.

Training can contribute towards all the necessary elements (knowledge, skills, attitudes) and while the theory, methodology and the delivery of the training is dependent on the needs and circumstances of each case; it is important that inclusive and interactive methodologies and theories such as Experiential Learning, Immersive Learning, Transformational Learning and Situated Learning Theory are used to prepare Users to become User Experts, and to advance existing User Experts.

#### 5.2 Learning methodologies

#### 5.2.1 Experiential Learning

As the name suggests, Experiential Learning can be described as "Learning by Doing". It is a theory coined and defined by David Kolb, as the process whereby knowledge is created through the transformation of experience. By engaging learners in hands-on experiences and reflection, they are better able to understand both theoretical and practical knowledge, and transfer their experience into the other contexts.

The Experiential learning process is based on 4 distinct components<sup>1</sup>:

- Experiencing
- Reflecting
- Thinking
- Acting

The above elements form a cycle of learning that allows for the acquisition of new skills, new knowledge and also a shift of attitudes towards empowerment and motivation.



<sup>&</sup>lt;sup>1</sup> https://online.norwich.edu/academic-programs/resources/4-components-experiential-learning-cycle

#### 5.2.2 Immersive Learning

Immersive learning is a facet of experiential learning methodology. It uses virtual reality (VR) to bring Users into immersive simulated or artificial environments , mimicking real life situations. Using VR for immersive learning takes the User on a complete sensory experience using sounds, images and sensations while they explore or navigate the virtual world through a training program. A complete immersive educational experience engages all learning styles from visual, auditory, reading, writing and kinaesthetic. This form of learning can have self-directed learning applications as well as collaborative group-based learning applications and it can help User Experts becomes better prepared for their scope of work, without exposing them to unnecessary risks. It is also a learning methodology that can be used to explore products / services / experiences in a virtual environment while minimizing the costs associated with the real-life experience.

#### 5.2.3 Transformational Learning

Transformational learning, developed by Jack Mezirow<sup>2</sup>, refers to deep, useful and constructive learning that prompts Users to make sense of their lives and assign meaning to their work or other activities. This type of learning adds a layer to the mere acquisition of skills and knowledge, allowing the Users to become components of the living experience and contribute towards meaning assigned to activities and life in general.

Closely linked to experiential learning, transformational learning works towards developing core attitudes such as perseverance, resiliency, satisfaction, self-worth, self-actualization, motivation, and empowerment that are crucial for existing and aspiring User Experts.

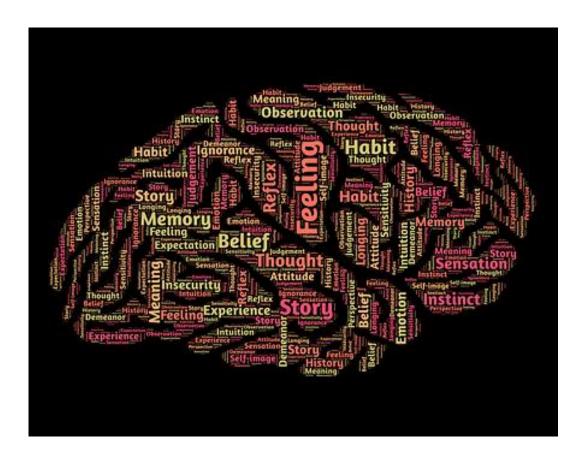
#### **5.2.4** Situated Learning Theory

Situated Learning Theory is based on the notion that learning occurs through the active engagement within contextual experience (Kurt, 2021). The core concept in SLT is learning as an unintentional process taking place along with the experience (Herrera, 2022). Overall, the User's experience merges with their conceptual and intellectual adaptation to the situational context. Therefore, the User can potentially learn from the people, place, and objects in the environment (whether physical or virtual) in addition to learning from the trainer who is formally assigned to the training program.

This allows for both the User and the instructor / trainer / facilitator to become co-creators of the learning experience and form better rapport and a more engaged learning

<sup>&</sup>lt;sup>2</sup> Fleming, Ted. (2018). Mezirow and the Theory of Transformative Learning. 10.4018/978-1-5225-6086-9.

experience that -as mentioned in transformative learning- goes beyond the mere acquisition of skills and knowledge. In a sector where often the circumstances or work realities can be harsh, establishing and nurturing this type of learning environment can have a profound effect on job satisfaction, motivation, and resiliency for existing and aspiring User Experts.



# 6 Methods for converting lived experiences into skills and further development

Although it is not possible to provide an exhaustive description of all the methods available for converting lived experiences into skills and exploring further development options, the following key points should be considered:

Harnessing lived experiences will take different forms in different contexts. At the core, transforming experiences into skills is about highlighting, formalizing, and celebrating the knowledge and expertise that has been gained through the lived experiences. This can, for example, be done by:

- Helping the person with the lived experience to learn about the theoretical background to their experience, thus providing a methodological and knowledge-based framework in which to formulate and express their experience. This is in particular important in the context of training persons to become experts, such as auditors or citizen science researchers.
- Providing positive feedback and motivational guidance to ensure that persons with their own lived experience of disabilities are confident that their opinion and feedback are valuable. Research shows that there is still a stigma around disabilities, which may hinder persons with experiences of barriers to step forward as test persons, for fear of doing something wrong.
- Observing how persons with their own lived experiences of disabilities tackle barriers to accessibility and document the skills used in the navigation of barriers. This documentation can be used to formalize skills and knowledge learned in informal settings.
- The degree to which the person with the lived experience becomes an expert will also vary according to the setting. It is preferable that users participating in user tests are not experts, since the user tests are meant to capture the experience of ordinary users who can respond naturally to the tasks and have not learned specific skills to deal with the barriers, they discover in the user testing.

By contrast, auditors need a more formal background to be able to act in a professional environment and present their findings using the language of the professional clients they will be working with.

Overall, the process converting lived experiences into skills, knowledge and attitudes can be broadly described as follows:

- Collect the lived experiences. Collection could be done through the documentation
  of the testing process or the experience process (if it wasn't part of organized testing), questionnaires, interviews, focus groups.
- Contextualize the lived experiences: what were the circumstances, conditions, situations present at the time of the experience? What did they affect the process and the experience?
- Analyze the lived experience: what components existed within the experience?
   How many and which were internal to the User and how many and which were external? What were the positive / negative elements? How were they experienced, mitigated, and managed?
- Process the analysis of the experience to create a framework of knowledge, skills and attitudes that contributed to the experience.
- Explore transferability of the experience: how common or uncommon is that experience? What is the common ground for users and what are the main differentiating factors?
- Provide conclusions / suggestions: summarize and document suggestions and insights directed towards the team managing the process relating to the product / service / experience.
- Follow up: make sure to maintain communication and debrief User Experts with updates relating to their contributions and how they were integrated or implemented.

# 7 Formalizing Users' Expertise

To formalize User Expertise, in addition to the section above, the below points can serve as a broad checklist:

#### **User background:**

- In which category/type of disability does the user belong?
- In which category does the user wish to have their experience formalized?
- How many years of experience does the user have in that field/category?

#### User knowledge:

- Is the user aware/informed about the regulatory framework (if any) relating to the issues they are wishing to become user experts in?
- Is the user able to assess compliance of the product/service/experience to the regulatory framework?
- Is the user familiar with basic principles as described in section 2 (definitions and terminology)?
- Is the user comfortable in using the above definitions and terminology in addition to other relevant knowledge in the field?
- Is the user able to offer guidance or advice relating to the issues identified?
- Is the user able to make assumptions/generalizations relating to the prevalence of the issue in users with similar or even different disabilities?

#### User training and experience:

- Does the User have a track record of contributions as a User Expert?
- Has the user received any type of support/training/guidance relating to user expertise?
- Has the User Expert undergone training at any point during his/her efforts as a User Expert?

#### **Country situation:**

- Does the country / sector have a structured, regulated process for recognizing User Expertise?
- Is the sector / country / community able and willing to support the process of developing a formal recognition process through Vocational Education & Training, Non-Formal Learning or other paths?
- Are there active citizenship organizations that can initiate and advocate for the implementation of a formalization process for User Expertise?

# 8 Conclusion: Shifting the narrative

Most European countries have introduced website accessibility laws, amended online communication, and taken initiatives toward adapting audio-visual media products to cater to accessibility needs (ITU News, 2021). Nevertheless, the production and distribution of accessible ICTs remain lacking, especially the development of the universal design principle and providing the necessary means for the targeted group to use said systems. (ITU News, 2021). However, what is less common is the inclusion of persons with disabilities in the discussion and validation process of accessible design. To achieve ITU's Connect 2030 Agenda, there is a need for countries to provide "enabling environments ensuring accessible telecommunications/ICTs for persons with disabilities" (ITU News, 2021). As soon as 2023, significant effort need to be made across sectors to ensure meaningful and sustainable change towards inclusion and integration.

By shifting the focus towards the people whose needs are being targeted and establishing their authority as the expertise for developing the accessibility structures of ICTs, European countries are closer to reaching this target. The Users as Experts project aims to close the "digital divide" by deconstructing the design of accessibility by not only recognizing the expertise of the person whose ICTs accessibility is affected but promoting their authority in the restructuring and adaptation process.

In that manner, persons with disability are active co-creators of their own futures; they themselves become the proponents of their own visibility and active participation both in the online space and beyond. Additionally, their contribution is paramount to the initiation and development of a sustainable dialogue on accessibility across sectors, and economic, social, political, and environmental contexts.

There is a lot of work to be done still in order to restructure our current local and global societies and communities, and the work must start with listening to the voices that have previously been silenced and excluded. One voice at a time, one User Expert at a time, communities can start to be transformed in ways that make human experiences recognized, accepted, communicated, and celebrated.



In the process of reviewing and updating the Methodological Toolkit (IO2) the document was presented and discussed as part of a Multiplier Event that took place in Cyprus in two different dates in May. The audience of the events consisted of volunteers working with people with disabilities, professional coaches and trainers, researchers, ICT practitioners and IT start-ups; although the number of participants and their demographics cannot be considered as a representative sample for the whole population or other European audiences, we thought it would be important to share some of their insights as part of this section.

The audience was very interested in the concept of User Experts and shared a common vision towards more inclusive communities and societies, lifting of barriers related to disability, elimination of prejudice and bias, and ultimately mitigation of marginalization for all people with disabilities: physical, mental and cognitive. In addition, there was extensive consensus regarding the principles that should underline the process with the highlights being respect, honesty, communication, inclusivity, diversity and tolerance.

Nonetheless, they also raised a lot of issues that can hinder the process of introducing the concept of User Experts, such as:

- limited awareness about the types of disability (especially invisible disabilities),
- limited monitoring of the exact numbers and demographics of people with disabilities within communities and/or countries,
- lack of specialized provisions in the regulatory and legal frameworks that would officially recognize and -in a sense- regulate the role of a User Expert,

- lack of awareness in special interest groups and associations of people with disabilities regarding the opportunities represented in the role of User Experts for improving products / services / experiences,
- lack of related content in materials used to guide people with disabilities in the efforts to become employed or more integrated within society,
- lack of specialized training that would enable coaches, trainers, volunteers to guide people with disabilities to become User Experts,
- confusion and vagueness in definitions and terms related to User Expertise,
- misconceptions about the value of User Expertise,
- reluctance and avoidance on behalf of companies and organizations / institutions to explore the role of User Experts and to include them in their processes,
- downplaying or misrepresentation of the added value that User Experts bring into a business / organization,
- misguided beliefs that people with disabilities should be accommodated rather than included as equal contributors,
- bias and prejudice regarding people with disabilities,
- limited time and financial resources that could enable and support the process of introducing User Experts in more aspects of everyday life and everyday products and services.

In addition, the audience also contributed with some brainstorming ideas that could broaden the prospects for introducing and framing the role of User Experts; a brief overview is offered below:

- Public awareness campaigns on Social Media
- Inclusion of the concept of User Experts in Vocational Education & Training programs
- Inclusion of the concept of User Experts in trainings / inductions offered to people with all types of disabilities

- Tailored efforts to engage people with acquired short-term or long-term disabilities who can act as ambassadors, bridging the gap between the experiences of people without disabilities and the experiences of people with disabilities
- Interventions offered in a municipal / governmental level to give incentives to companies and organizations to engage User Experts
- Internship or sponsorship programs for User Experts in a variety of sectors (For Cyprus, the hospitality sector was offered as a prime example)
- Tailored campaigning and lobbying addressed to companies and businesses that design, create, manufacture and promote products / services / experiences
- Increased visibility for the terms related to User Expertise, User Experts, etc.
- A formal qualification process that could make the role of a User Expert transferable and recognizable across EU countries
- An addition of a requirement for User Experts in ISOs relating to products and services
- Further research to highlight the benefits of the role of User Experts and how it can lead to better product and service design, stronger brand identity, brand loyalty, and higher revenue.

There can be no doubt that User Expertise can be a powerful tool for shaping our everyday lives and the experiences we share and a powerful motivator towards more inclusive societies and communities that cherish diversity, promote integration, and flourish on respect and equality. Further efforts are, of course, required in that direction since the EU countries vary differently in their state of affairs relating to people with disabilities.

It is our hope and wish that the Users as Experts project and the partnership as a whole, have contributed to these efforts in an efficient and meaningful manner that can be replicated, transferred and further enhanced in the years to come.

# 9 References and Advisory sources

- Asana. (2022, June 26). What Is Lean Project Management? Kanban Software for Agile Project Management. Retrieved August 25, 2022, from <a href="https://kanbanize.com/lean-project-management">https://kanbanize.com/lean-project-management</a>
- Bakardjieva, M. (2005). *Internet Society: The Internet in everyday life*. London, Thousand Oaks, New Delphi: Sage.
- Council of Europe. (n.d.). Disability and Disabilism. Manual for Human Rights
   Education with Young People. Retrieved August 24, 2022, from
   https://www.coe.int/en/web/compass/disability-and-disablism
- Digital economy and society statistics households and individuals Statistics
   Explained. Ec.europa.eu. (2022). Retrieved 11 May 2022, from
   https://ec.europa.eu/eurostat/statistics explained/index.php?title=Digital economy and society statistics households and individuals
- Herrera, S. (2022). Situated Learning Theory Theoretical Models for Teaching and Research. Press Books.
   <a href="https://opentext.wsu.edu/theoreticalmodelsforteachingandresearch/chapter/situated-learning-theory/">https://opentext.wsu.edu/theoreticalmodelsforteachingandresearch/chapter/situated-learning-theory/</a>
- Human Resources and Skills Department Canada. (2013). Federal Disability
  Reference Guide Canada.ca. Government of Canada.

   https://www.canada.ca/en/employment-social-development/programs/disability/arc/reference-guide.html
- Inclusive Design Research Centre. Legacy.idrc.ocadu.ca. (2022). Retrieved 12 May 2022, from <a href="https://legacy.idrc.ocadu.ca/about-the-idrc/49-resources/online-resources/articles-and-papers/443-whatisinclusivedesign">https://legacy.idrc.ocadu.ca/about-the-idrc/49-resources/online-resources/articles-and-papers/443-whatisinclusivedesign</a>
- ITU News. (2021, December 1). Persons with disabilities: Nine steps for Europe to
  ensure digital accessibility. ITU Hub. Retrieved August 25, 2022, from
  <a href="https://www.itu.int/hub/2021/03/persons-with-disabilities-nine-steps-for-europe-to-ensure-digital-accessibility/">https://www.itu.int/hub/2021/03/persons-with-disabilities-nine-steps-for-europe-to-ensure-digital-accessibility/</a>

- Kurt, S. (2021, February 21). Constructivist Learning Theory. Educational Technology. Retrieved August 25, 2022, from <a href="https://educationaltechnology.net/constructivist-learning-theory/">https://educationaltechnology.net/constructivist-learning-theory/</a>
- Landry, L. (2020, December 15). What Is Human-Centered Design? | HBS Online.
   Business Insights Blog. Retrieved August 24, 2022, from
   <a href="https://online.hbs.edu/blog/post/what-is-human-centered-design">https://online.hbs.edu/blog/post/what-is-human-centered-design</a>
- Norris, P. (2001). *Digital divide: Civic engagement, information poverty, and the Internet worldwide*. Cambridge University Press.
- Scholz, F., Yalcin, B., & Priestley, M. (2017). Internet access for disabled people: Understanding socio-relational factors in Europe. Cyberpsychology: Journal of Psychosocial Research on Cyberspace, 11(1), Article 4. <a href="https://doi.org/10.5817/CP2017-1-4">https://doi.org/10.5817/CP2017-1-4</a>
- Stevens, E. (2022, June 22). What Is User Experience (UX) Design? Everything You
   Need to Know. CareerFoundry. Retrieved August 24, 2022, from
   https://careerfoundry.com/en/blog/ux-design/what-is-user-experience-ux-design-everything-you-need-to-know-to-get-started/
- Vincente, M. R., & Lopez, A. J. (2010). A multidimensional analysis of the disability digital divide: Some evidence for Internet use. *The Information Society*, 26, 48-64.
- (WAI), W. (2022). *Accessibility Fundamentals Overview*. Web Accessibility Initiative (WAI). Retrieved 12 May 2022, from <a href="https://www.w3.org/WAI/fundamentals/">https://www.w3.org/WAI/fundamentals/</a>
- (WAI), W. (2022). Making the Web Accessible. Web Accessibility Initiative (WAI).
   Retrieved 12 May 2022, from <a href="https://www.w3.org/WAI/">https://www.w3.org/WAI/</a>
- We are looking for disabled ambassadors or champions | Disability Rights UK.
   Disabilityrightsuk.org. (2022). Retrieved 12 May 2022, from
   <a href="https://www.disabilityrightsuk.org/news/2016/june/we-are-looking-disabled-ambassadors-or-champions">https://www.disabilityrightsuk.org/news/2016/june/we-are-looking-disabled-ambassadors-or-champions</a>
- Web Content Accessibility Guidelines (WCAG) 2.1. W3.org. (2022). Retrieved 12 May 2022, from https://www.w3.org/TR/WCAG21/
- Wellman, B., & Haythornthwaite, C. (Eds.). (2008). The Internet in everyday life. John Wiley & Sons.

- What is agile methodology? (2022, July 19). Red Hat. Retrieved August 25, 2022, from <a href="https://www.redhat.com/en/topics/devops/what-is-agile-methodology">https://www.redhat.com/en/topics/devops/what-is-agile-methodology</a>
- What Is Lean Project Management? (n.d.). Kanban Software for Agile Project
  Management. Retrieved August 25, 2022, from <a href="https://kanbanize.com/lean-project-management">https://kanbanize.com/lean-project-management</a>
- What is the difference between accessible, usable, and universal design? | DO-IT. (2022, May 24). DOIT. Retrieved August 24, 2022, from <a href="https://www.washington.edu/doit/what-difference-between-accessible-usable-and-universal-design">https://www.washington.edu/doit/what-difference-between-accessible-usable-and-universal-design</a>