**Report on WFDB’s 2nd Technical SHAPES Project Workshop**

**Geneva, Switzerland**

**11-12 July 2022**

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## **Introduction**

A two-day workshop titled “*WFDB’s 2nd Technical SHAPES Project Workshop*” was held on 11-13 July 2022 in Geneva, Switzerland, with the purpose of gathering feedback and information on the perspective of persons with deafblindness. The World Federation of the Deafblind (WFDB) organized the workshop in collaboration with the International Disability Alliance (IDA). The workshop was financially supported by the Norwegian Agency for Development Cooperation (NORAD) and the European Union, through its Horizon 2020 research and innovation programme (Grant agreement No 857159).

9 persons with deafblindness, from 4 different continents: South America, Europe, Asia and Africa participated in the workshop and contributed to significant discussions on key issues and challenges faced by persons with deafblindness in their regions. These discussions and key outcomes will feed into the WFDB’s 2nd Global Report on persons with Deafblindness, as well as the work carried out within the SHAPES Project.

From the WFDB Secretariat, the workshop was facilitated by Lucia D’Arino, WFDB Program Advisor, Rune Jensen, WFDB Policy Advisor, and Carina Olsen, WFDB Communications Officer. From the IDA Secretariat, programme support was also received from Priscille Geiser, IDA Program Director, Eleonora Guzzi, IDA’s Programme Coordination Officer and Jarrod Clyne, IDA’s Human Rights Advisor. María Eugenia Gil Díaz, Mercedes Ramiro and Dragana Jocic from the IDA Financial team or IDA’s Logistics Team, managed all logistical and financial matters of the workshop.

This report contains the key messages, observations and points discussed in the various sessions and group exercises.

## **Background**

*[This section is taken from the concept note for the workshop]*

The World Federation of the Deafblind (WFDB) is a global non-governmental advocacy organization by and for persons with deafblindness. WFDB is a consortium member of the SHAPES Project (Smart and Health Ageing through People Engaging in Supportive Systems), an Innovation Action funded by the European Union’s Horizon 2020 programme involving a total of 14 European countries. WFDB’s role in SHAPES is to bring the perspective of the deafblind community, coordinate and facilitate the participation of older persons with deafblindness across Europe into the project and contribute with the unique knowledge and understanding of deafblind people and their diverse needs, including through the production of more evidence and recommendations to improve inclusion of persons with deafblindness. [More information on WFDB’s role in the project can be found here.](https://wfdb.eu/shapes-project/)

The 1st Technical Workshop was held online due to COVID restrictions in December 2021 and included the same attendees as for the 2nd workshop, except an additional participant from North America, meaning there were 10 in total.

The 2nd Technical Workshop was held in person in Geneva and included the participation of the Executive Council (EC), which is the main governance organ of WFDB, elected by the WFDB General Assembly, supported by the Regional Representatives as an advisory group, as well as the President, Francisco Trigueros (Spain) and Vice President, Sanja Tarczay (Croatia), of the European Deafblind Union (EDBU).

This workshop provided with an opportunity to connect SHAPES stakeholders with persons with deafblindness, as well as gather feedback and engage in discussions with this particular sample group. SHAPES partners and representatives were invited to the meeting and encouraged to make use of this unique opportunity to collect information and views on research being conducted, technological solutions, accessibility considerations, etc.

## **Objectives of the workshop**

* Provide updates and information on the progress of the SHAPES project to the EC, Regional Representatives and EDBU as well as strengthen ties between WFDB and SHAPES consortium partners.
* Involve participants and interpreter-guides in the testing of two different digital solutions, in collaboration with SHAPES technical partners, as part of Pilot Theme 7: Cross-border Health Data Exchange Supporting Mobility and Accessibility for Older Individuals.
* Gather stories and good practices on older persons with deafblindness that could be relevant for WFDB 2nd Global Report, and also the SHAPES Project.
* Collect information from participants on the needs, barriers and priorities of older persons with deafblindness on different topics relevant for SHAPES such as physical and digital accessibility, technology and care systems.
* Create opportunities for future participation of persons with deafblindness in SHAPES activities, including dialogue workshops and WFDB’s 3rd technical workshop, which is planned to be held in 2023.

## **Participants’ detail**

The workshop was attended by 9 participants with deafblindness, including 44,4% women and 55,6% men.

Two of the participants were aged 65 years old or older, and living independently.

The statistics from participants are found below.

Table 1. Disaggregated data of participants.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| *Number of participants & characteristics* | | | | | | |
| **Total** | Men | Women | Age: 65+ | Indigenous | Deafblindness | From remote areas |
| **9** | 5 | 4 | 2 | 2 | 9 | 2 |
| **55,6%** | **44,4%** | **22,2%** | **22,2%** | **100%** | **22,2%** |

## **Accessibility and Reasonable accommodation for the participants**

All 9 participants were supported by their interpreter-guides to ensure their effective and full participation.

English-Spanish interpretation was foreseen, for Spanish speaking participants.

The workshop was structured in sessions of 45 minutes with 15 minutes breaks, to give participants and interpreters enough time to rest.

All presenters and speakers were asked to present themselves every time before taking the floor and were reminded to speak slowly and take small breaks in between sentences to allow for enough time for interpretation. Two different coloured and shaped cards were given out which indicated the speaker when to speak slower or stop speaking.

Documents such as the concept note, agenda, practical details and technical information about the meetings were shared in advance via email.

However, in some cases, there was a failure to provide certain resources during the sessions in accessible format (i.e.: large print or in braille), such as the signature list and presentation notes. This was well noted and taken into consideration for future meetings.

## **Day 1: 11th of July 2022**

WFDB President Geir Jensen opened the workshop with welcome remarks followed by the introduction from participants, which included 9 persons with deafblindness and their interpreter-guides from the following countries: Colombia, Ecuador, Nepal, Norway, Finland, Croatia, Spain and Uganda.

There was a round of presentations from the participants themselves and their interpreter-guides, as well as WFDB and IDA Secretariat members.

### **SHAPES Project (2019-2023)**

Lucia D’Arino, WFDB Program Advisor and focal point of the SHAPES project, gave a [presentation on SHAPES](file:///C:\Users\lucia\OneDrive\Documentos\Documents\WORK%202020-2023\WFDB\SHAPES-MAYNOOTH%202020-2023\13.%202nd%20Technical%20Workshop%20July%202022\Presentation\SHAPES%202nd%20Workshop_Lucia's%20presentation.pptx) and provided information on WFDB’s role as a consortium member of the SHAPES Project. The project is targeted at persons above the age of 65, living in the community, independently, connected with to other members of community, in contrast to living in institutions or isolated from the community.

The session was dedicated to consult and gather feedback from the representatives with deafblindness, who provided their perspective and an overview of the situation in their country or region on the following topics:

* Current situation, challenges and barriers faced by older persons with deafblindness
* Good practices and recommendations
* Physical accessibility of public areas and services
* Digital accessibility and the use of technology to improve quality of life

Discussions:

Discussions on the SHAPES Project amongst the participants focused on the following topics:

* Selection process of participants involved in the SHAPES project: all older persons with deafblindness involved in the project (through interviews, focus groups, workshops, etc) have been selected through national or local organisations of persons with deafblindness
* [SHAPES official website](https://shapes2020.eu/): Access Earth is the technical partner responsible for the website, and it has been developed to be made accessible for all as it adheres to the WCAG 2.0 guidelines
* How to ensure removal of barriers: Continuous collection of feedback from end-users through feedback mechanisms such as this Technical Workshop in question are helpful in understanding the barriers faced by the deafblind community. The SHAPES project should be viewed as a starting point in which barriers are documented and shared. There is still further information that needs to be gathered.
* Rune Jensen provided some background information as to how WFDB became involved in the SHAPES project, explaining that without the perspective of persons with deafblindness, SHAPES would not be able to create an ecosystem of new technology that could provide a better, safer, and more inclusive society for older persons to live independently in their own home. Indeed, the SHAPES is an EU project, yet it is also a project for the global population.
* On the issue of the SHAPES project targeting only persons in Europe who are 65+ in Europe, it was clarified that WFDB is also interested in feedback from persons outside this region and considers other perspectives relevant. Lucia D’Arino highlighted the workshop in Kenya in November 2021, as an example of how feedback from outside Europe feeds into the general feedback on the project.
* Poverty was flagged as a main barrier: Participants mentioned the case of both individuals with deafblindness living in poverty and with a lack of financial means to acquire assistive technology, as well as challenges for persons with deafblindness living in poor regions and low-income countries. One of these challenges being that deafblindness is often not recognised as a distinct disability in low-income countries. This leads to different understandings of deafblindness, i.e., completely deaf and blind, or one of the two, as well as issues in collecting disaggregated data.
* Questions were raised on which ‘classification’ or ‘category’ of deafblindness is being represented in the project. It was clarified that the different participants involved in the research represented multiple realities of deafblindness, which means they had different accessibility needs and communication systems, etc.
* There were also questions on the level of access to health of the older persons with deafblindness that were interviewed by Lucia D’Arino in 2021. Lucia D’Arino explained that the interviewees have access to free health care services in various European countries however, the quality is not necessarily good or 100% inclusive and accessible to persons with deafblindness.
* Attention was also brought to the topic of decreased activity levels and attention span amongst older persons with deafblindness, as well as conditions such as dementia. Concerns were raised regarding society’s expectation of a continued high activity level amongst this specific age group, as experiences and research suggest that activity levels, along with interest in for example technology, decreases with age. This must be respected and understood. We must also bear in mind that we are experiencing a transition in which everything can be accessed online, however, most older persons with deafblindness are not yet digitally literate, increasing inequality.
* Experiences from an African context were shared; In Africa, older persons with deafblindness often live with family members, such as their children, and are therefore more integrated in the local community. In Europe, the living situation varies across contexts and regions. In some parts of the world, it is common to live with family members and stay integrated in community, whilst in others, it might be rare meaning older persons with deafblindness end up living in institutions, for example.
* Participants are looking forward to the final WFDB SHAPES report, to be published in 2023, which will focus solely on the situation of older persons with deafblindness and can be used as an advocacy tool to advance the rights of this particular group around the world. Suggestions for a strategic use of the final SHAPES report was put forth. Some participants suggested that the data should be brought to the political discussion on UN level. Lucia D’Arino explained that the report is still in development, and that target audience, etc., is still to be decided.
* There were questions on what will happen once the SHAPES project is over in 2023. Lucia D’Arino confirmed the project will not be extended and there are no planned activities after October 2023 associated to it.
* Participants inquired about the amount of data on persons with deafblindness gathered so far within the SHAPES project. Lucia D’Arino explained that there is a decent amount of qualitative data however, quantitative data are lacking. There is data on health, technology, barriers, interpreter-guides, etc but there is a lack of examples of good practices.
* Questions regarding who will benefit from the SHAPES project were raised: academia, current older persons with deafblindness, future generations of older persons with deafblindness, or everyone else? Lucia D’Arino responded by explaining that since the lead organisation is a university, the data will be used in academia, for instance, information on older persons with deafblindness has and will be published in academic papers and is thus useful for academia. The SHAPES project aims to improve independence and quality of life, and it was estimated that 2,000 individuals would be involved in testing solutions, including older persons with deafblindness. Indeed, project can be relevant for the future.

On the topic of technology, the following points were mentioned:

* Participants discussed devices and apps that allows users to measure blood pressure and read results in accessible formats, e.g., braille. It was commented that there are many good devices for persons who are blind, but not for persons with deafblindness. The Orbit Reader (refreshable braille display) was mentioned as a good example for accessibility, as it can be connected to several devices by either Bluetooth or USB.
* There were discussions on the different operative systems, such as iOS and Android. Some participants explained that iOS/Apple has many accessibility features that are lacking in the Android systems. It was highlighted that iPhones are well adapted for persons with deafblindness, as it can be used by those with residual sight to magnify text, or by those with residual hearing through use of Bluetooth. The disadvantage being that technology (and Apple products in particular) are expensive. The participant from Asia disagreed with the comments on iPhones, stating that in his experience, iPhones are difficult and time-consuming to use, compared to Android.
* The topic of robotics was brought up. Prior to the SHAPES project there had been much talk of robotics, but now, it has no longer been discussed. Lucia D’Arino responded to questions regarding robotics by explaining that SHAPES are indeed developing robotics however, these are currently underdeveloped and inaccessible. WFDB is not involved in this specific component of the SHAPES project.
* The importance of recreational life, including walks and outdoor activities, was highlighted. Participants agreed that technology can only do so much if one fails to maintain one’s health by exercise and maintaining a healthy lifestyle. Persons with deafblindness should be encouraged and supported in maintaining their health.
* Participants commented on the diversity of persons with deafblindness and their different needs. Some are able to use glasses or hearing loops and some use screen reader software. Many can use computers, whilst others do not, for example, due to poverty or age. Data and statistics must be gathered, and also, before stating that a certain assistive device is useful or accessible, it must be tested by persons with deafblindness.
* Participants suggested developing an app that can translate sign language to speech. This would be useful and transferrable to the African region.
* Experiences in accessing news and information through personal and professional network was shared amongst participants.
* The topic of emergency response was brought up. Persons with deafblindness are diverse, but the need for safety and security is constant, nevertheless. This must be at the forefront of discussions when discussing disaster risk reduction and emergency response.

On the topic of accessibility in private and public areas, the following points were discussed:

* It was brought to attention that even though many persons with deafblindness slow down their activity level as they get older, deafblind age-specific services still need to be in place in order to ensure that those who wishes to stay involved have the opportunity to do so.
* Examples of accessible living and recreational environments in Bulgaria, Denmark and Slovenia was shared. Amongst other, there are railings and traces along the pavement, originally intended for the blind but which persons with deafblindness also benefit, leading to, for example, parks or grocery stores. At parks, there are information signs  
  with braille inscriptions proving information on the surrounding area. This enables persons with deafblindness to live more independent lives. It was suggested that this might be more common in low-income countries, where interpreter-guide services are not available at large.
* The topic of guide dogs was discussed in depth amongst participants. In some regions, the use of guide dogs has increased exponentially in the past decade. It was pointed out that it can be difficult for a person with deafblindness to take care of a guide dog, if living alone, as a guide dog needs much care and attention. A guide dog that is not trained properly, or is otherwise unhappy, can be dangerous as it may lead to collisions with lamp posts, cars, or even brick walls. Experiences on training both guide dog and guide dog-user in Spain was shared. Requesting a guide dog trained for persons with deafblindness is a lengthy process but 90% of the Spanish cases are successful. It was pointed out that there is limited, if any, cases of guide dogs in the African region.

## **Day 2: 12th of July 2022**

The morning sessions on second day of the workshop focused on gathering personal feedback on specific digital solutions. Participants and interpreter-guides who owned personal devices were able to download these apps and provide information on its usefulness, accessibility, usability, etc.

Before the testing of the digital solutions took place, a short poll through hand raising was conducted amongst the participants to gather basic information on their access to technology and usability. The results were the following:

* 7 out of 9 participants use a smartphone
* 2 out of 9 participants use a tablet
* 7 out of 9 participants use a computer or laptop
* 6 out of 7 participants who own a smartphone/tablet use an iOs operating systems
* 1 out of 7 participants who own a smartphone/tablet use an Android operating systems

1. **‘I Can See’ app by SciFY**

SHAPES Technical partner SciFY (Science for you) from Greece, represented by Antigoni Poulou, presented remotely the ‘I Can See’ App. It was originally aimed at persons with a visual impairment and allows to see print or images such as menus and signs in different formats or sizes. It allows the user with residual vision to access information by enhancing contrast, change background colours, etc., when using the phone camera as a magnifier. One may use the app to access information found in, for example, restaurant menus, street signs, or photos.

Discussions:

Feedback on the ‘I Can See’ app focused on the following points:

* The need of having residual sight: Only those with residual visual can currently use the app and it is therefore not accessible for those who are totally blind. An app which lets users take a photo of the information and is then described by volunteers was highlighted as an example of the reverse, namely an app accessible for the blind with   
  residual hearing. However, there is a need for apps which are accessible for individuals who cannot see or hear at all.
* Accessible formats: It is important to ensure that the app is compatible with braille lines, and screen reader software or includes a voice over in order to access the text, for it to be useful to the participants and considered fully accessible.
* Availability: Participants were surprised to learn that the ‘I Can See’ app is currently not available for iOS/Apple devices. It was also pointed out that Apple devices already have many of these accessibility features integrated in the iOS system, without the need to download any external apps.
* Examples of useful Apps: The ‘Seeing AI’ app, by Microsoft, was highlighted as a useful and accessible app by participants. This app lets the user scan objects to get a description of the object, for example, when shopping groceries or to find out whether lights are turned on in a room. The ‘Seeing AI’ can be connected to a braille line and is available for both iOS and Android operating systems. Other apps, such as ‘Lookout’, ‘InstaReader’ and ‘InVision’, all available for Android, were mentioned as examples of accessible, high-quality apps that persons with deafblindness may use to better access information.
* Digital divide: It was commented that some of the participants had an impressive amount knowledge on and access to technology, compared to others. These were asked to share how they had acquired this information. To this, it was replied that by staying active and curious, searching for information independently as well as asking others. With simple trial and error, one can learn much about technology. Participants also explained that they were part of WhatsApp groups where information and experiences on technology are shared.
* Diversity: It was brought to attention that due to the diversity of persons with deafblindness, there is a need for several apps for the same purpose to be available, rather than just one. And that these apps are given a trial period in order to establish the best possible way to make it accessible to the entire deafblind community. It was suggested that a list of app recommendations could be shared, for example on WFDB website, so that persons with deafblindness can more easily find information about which apps are available and accessible.

1. **‘Access Earth’ app by Access Earth**

Matt McCann, representative from Access Earth in Ireland, presented the ‘Access Earth’ app which provides a mapping and review database for persons with disabilities as it shares information on the accessibility of areas and businesses. The app works similarly to Google Maps, but includes accessibility information for places such as restaurants, museums, theatres, etc. For example, the user may verify beforehand if a restaurant has menus in accessible formats or if a shop’s entrance can is accessible to wheelchair users.

Discussions:

Feedback on the ‘Access Earth’ app focused on the following points:

* Concept: The participants generally expressed satisfaction with the concept of the app and believed it could be very useful for them. It was tested by them and confirmed it was compatible with braille lines and screen reader software.
* Information: As the app relies on the users to enter data on their area or region, information and data of places and businesses is lacking or very limited. Unless more information is added onto the app, it will not be very helpful for everybody.
* Language: It was suggested that the possibility of having several languages to choose from would improve the usability of the app.

Additional feedback was gathered from this sample group of persons with deafblindness on technology and recommendations. The main comment was to encourage all stakeholders involve and consult different persons in the deafblind community and their representative organisations on developments and improvements related to technology, assistive device and artificial intelligence, in line with the motto “nothing about us without us”.