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WFDB's 2ND GLOBAL REPORT: GOOD PRACTICES AND RECOMMENDATIONS FOR THE INCLUSION OF PERSONS WITH DEAFBLINDNESS

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>> SANJA TARCZAY: Good morning, good afternoon, all of you. I'm honored and have great satisfaction to greet you all in this great event, no matter where you are in the world today. I am especially honored that I can welcome you, all of you that are online to this special event that's going on right now within the 16th Conference of States Parties to the Convention on Rights of Persons with Disabilities.

Today, I want to say that this event is taking place in New York, currently in the U.N. building and we're broadcasting live. I hope that you will enjoy listening to information we're going to share today.

I want to use this opportunity to give a thank you to International Disability Alliance, IDA, it is an organization that is a cosponsor of this very important event inalso I very much thank you, a lot, because they are supporting us in every possible way. I would like to say that this part now, that follows, it will be technical details for people who are online, you have international interpretation, also you have voiced English and transcript, trasncript that is available during this seminar. I kindly ask you that you turn off your microphones when you're not speaking so that we don't have the noise and there will be time for comments and Q&As at the end of this webinar in the last 15 minutes. So that you can contribute yourself as well. Let me present myself, I am Sanja Tarczay, I'm from Croatia, and am a

deafblind woman. I am president of the World Federation of the Deafblind since October 2022. I would like to clarify some things regarding the second global report, the second global report, it is focused on good practices and recommendations as well as fostering inclusion of deafblind persons. That's also the goal of WFDB overall. We as a world federation, we are funded in 2001 and in 2007 we attained consul activity status at the United Nations Economic and Social Council, and also we are a member of the Board of International disability alliance, IDA, a very important role as well.

WFPD will in this event present our second global report on the inclusion of persons with deafblindness that was published last May. That means that this is not the first time we're talking about this, this is not the first public stance we have this this report, it is the second one. And it is very important that it shows the realistic situation of deafblind persons all over the world. We also want to present our project that is funded by E.U. horizons, 2020 programme, and that's focused on elderly, quality of life of elderly people. Also it is important to know that this second global report is actually building up on the first global report that was mostly focused on exclusion of deafblind persons and showing the examples where and how it did happen and occur, especially regarding the CRPD and SDGs conventions.

So this report, it is showing good practices and inclusion.

More about second global report, we will hear later on from my colleague, Christopher Woodfill, and our programme advisor for SHAPES project Lucia D'Arino will also add on to the HAPES project info.

Now I would like to greet our representative of IDA member Mr. Cato Lie, and he's representing the international Federation of

Spina Bifida and Hydrocephalus. .

I would give the floor to him now so he can say a couple of words to this event as well and some welcoming remarks too. You have the floor.

>> CATO LIE: Thank you, Sanja, for these kind words.

Good morning and good afternoon to all the attendees at this workshop. It is a pleasure for me to have the opportunity to share with you some introductory remarks as a Board member of the International Disability Alliance (IDA) and as president of International Federation for Spina Bifida and Hydrocephalus, abbreviated IF. The mission of IF is:

‑ to improve the quality of life of people with Spina Bifida and Hydrocephalus and their families without discrimination of any kind, the key activities is raising awareness, advocacy, community building, and Human Rights education. For the WFDB, this is an important component of awareness, especially since it coincides with the national deafblind awareness month. Congratulations to the World Federation of the Deafblind with the support of the international disability alliance and the association of the deafblind, with the financial support from the agency of development corporation, NORAD and the Norwegian association of global affairs for the report.

Your report provides an excellent resource to not only better understand the situation of persons with deafblindness, but also to learn about good practices and measures to increase and improve the inclusion of persons with deafblindness. It's case studies from different regions and specific recommendations to different stakeholders across thematic areas provides guidance and clear direction on how to achieve inclusion. Hope this will serve as an advocacy tool for deafblind community members and our allies to stimulate collaboration and partnerships to advance The Rights of persons with deafblindness but also to inform stakeholders on how to better foster inclusion of persons with deafblindness. This is similar to our journey at the international federation for Spina Bifida and Hydrocephalus, and it is a key Strategic Plan holder and representative organizations to persons with deafblindness and this project, it is important. In this way, you initiate and codesign key activities ensuring the perspectives and needs, importance to your community.

It is my understanding that one of your key activities is similar to the work within our federation, which is the representation and active participation of older person was deafblindness. In shored, complements to the World Federation of the Deafblind for your important work in doing such a fantastic job to advance The Rights of people with deafblindness worldwide reflected by both your recently published report and your active involvement in the SHAPES project. From the meetings this week, as part of the COSP16 we have work to do to also reach underserved communities within both of our organizations, representing persons and this is important for the further awareness and ensuring the recognition and respect of The Rights of this distinct disability group. I wish you an inspiring meeting and a successful event. Back to you, Sanja.

>> SANJA TARCZAY: Thank you, Cato for the wonderful presentation. WFDB is a very proud member of IDA Council and thanks to your support, WFDB can actually implement the nothing about deafblind without the deafblind.

We are trying to do everything that you already stated and we'll keep on trying as well.

Now I would like to give the floor to Christopher Woodfill, he is a deafblind man and also one of the Directors in the Helen Keller centre here in New York and also an executive ‑‑ a member of executive Council of IDA. I'm very certain that he will give a wonderful presentation of the second global report.

Chris, you have the floor.

>> CHRISTOPHER WOODFILL: I'm just getting the PowerPoint established, if you can give us a second, working out logistics.

Hello everyone, this is Christopher Woodfill signing. I'm very pleased to welcome you all to this presentation from the World Federation of the Deafblind, specifically on the 2nd Global Report.

Just last week, I was able to give a similar presentation at the European Parliament.

This is a much more reduced presentation given the timeframe that we're allowed. So I'll get to our significant points. Next slide, please.

Let's see. Is this on? Double‑checking.

First I would like to mention about the first global report that took place before I go more in depth in the second. The first global report, it was a partnership between the World Federation of the Deafblind, International Disability Alliance, international centre for evidence and disability, and Sense international. All four of those partners came together to create this first global report.

There was some very specific aims that were set out to achieve with a focus on the current situation of persons with deafblindness and specifically to call attention to the gaps that are specifically related to the Convention on The Rights of Persons with Disabilities, CRPD, because noticing that there was misalignment between representation of persons with deafblindness in those critical aspects. WFDB was able to move forward with the completion of this large report.

Thirdly, in 2018 when we were in Spain, the Helen Keller world conference took place. During that time, we were able to collect critical experiences from persons with deafblindness from around the globe.

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Once that was completed, and the information was gathered, a report was put together.

Firstly, what became very important, it is that this document became a key resource on persons with deafblindness. Also this was the largest population base analysis of persons with deafblindness which was based specifically on the Washington group questions.

The information yielded very specific data which was a 0.2% to 2% of representation of the global population. A very extensive, qualitative analysis was conducted across a wide range of policy areas. That included an extensive literature review.

Input from the World Federation of the Deafblind occurred for a ‑‑ through a variety of methods.

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The most urgent recommendations that came out of the first global report are as follows: Firstly, there is a significant lack of a universal definition of the recognition of deafblindness as its own distinct disability. That deafblindness is not just deafness and blindness alone, that deafblindness is its own standalone unique disability.

This is of grave concern with lack of universal recognition.

Secondly, the lack of the provision of support of deafblindness interpretation services, this includes interpreter guides and the lack of public funding to ensure most appropriate training and support and education to support individuals deafblindness to engage in work and community life with these supports.

Thirdly, there is a recognition of the need of additional research on issues concerning persons with deafblindness. There's a very rare amount of information that's available on the critical aspects related to persons with deafblindness. These are the top three urgent recommendations that came from the first global report.

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Moving on to the 2nd Global Report.

You may be curious as to why there was a need for a second report after those findings took place in the first. Well, it felt necessary to be able to build on successes of the first global report and those particular findings.

There was also a need to strengthen and consolidate the evidence that was discovered through the first report.

The second report then goes into much more depth and detail on the issues that were identified.

Sanja and Cato have already mentioned some particular points, particularly around the best practices and case studies that would address particular questions on these 17 different points that were identified and as well to provide some concrete guidance to governments, other organizations and agencies. Particularly for people that focus on individuals with disabilities there was a significant need to identify the supports necessary for individuals with deafblindness.

Lastly, the need to develop an advocacy tool, specifically on representation of persons with deafblindness for those championing the efforts of those individuals.

Also to make noted that this report was not specific only on persons with deafblindness but to see how the application could occur for other disability sectors in a more broad fashion.

Thinking about the process which the 2nd Global Report came to fruition.

There were several steps involved in that.

The world Federation of The deafblindness board members provided a strategic guidance, validation and oversight throughout the entire process. That was the role of WFDB.

Secondly, there was a World Federation of the Deafblind policy advisor, a staff individual, and that person acted as a coordinator to make sure that all of the pieces came together collaborating with projects and the various partners in order to compile this global report.

Thirdly, there was an advisory group established. Keep in mind that the WFDB representative was made available, myself, there was representatives from IDA, other, various entities that participated in the advisory group. They came together to provide technical assistance, strategic guidance, outreach to persons with deafblindness, and through other contacts and feedback all throughout the process.

It was a collaborative effort and everyone worked together to get to the aims identified.

There were various consultants involved that focused on both the qualitative and the quantitative research aspects of this process.

So bringing in various consultants were critical based on expertise to make this report a success.

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Briefly I will mention to you what is in the introductory chapters of the report.

The first is on the methodology that was used, I mentioned both the qualitative and the quantitative research methods that were used to compile this data. Both methods were critical and then were aggregated together to be able to share this information.

The qualitative aspects, we reviewed the literature, various studies that were available, surveys, narratives from individuals, et cetera, and then the quantitative measures were more on those Washington group points that I mentioned, and the NCIS which I will go into a little bit later.

It was a representative from UNICEF and the focus on children globally, we looked at those data points, and made sure that there was definitely representation in the MICS data that came from UNICEF. So we looked specifically on that aspect as well and were able ting a great all of the information together in a quantitative, qualitative fashion.

We also will talk about the report layout and the various points that were covered, but keep in mind, I only have time to elaborate on two out of the 17 today.

Also, in the introductory chapter is a focus on diversity of persons with deafblindness, and it talks about the onset of deafblindness, whether it was congenital in nature or acquired, it talks specifically on various ideologies that causes deafblindness and also the impact of the different degrees of sensory loss, individuals who may be hard of hearing, have low vision, et cetera. These introductory chapters also includes prevalence data.

I will expand again on two of the items that were noted, specifically on diversity and prevalence data.

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Of those 17 points that were highlighted, I can only go into two of those today.

Number one relates specifically to the legal recognition of deafblindness as indicated in the first global report, that there was no international recognition of the definition regarding deafblindness. WFDB did an extensive outreach and surveyed 30 different countries to gain information on this particular point. .

Specifically, on the definition of deafblindness as its own unique disability.

The survey was conducted, extensive outreach, across 30 different countries, and it was determined that the Nordic definition that's been in use is really the best in terms of representation. The reason it was chosen, it shows a social perspective as opposed to the medical model. It pulse away from the specific definition and degrees as it relates to sensory access points and focuses on a social aspect and a cultural connection.

That definition looks specifically on the impact of the experience of both of the sensory losses and the impact on the individual themselves. Again, it moved away from a specific medical approach of the degrees of the different sensory losses, so of all of those definitions surveyed, it was the Nordic definition that came to the top.

Second, focus specifically on the stigma and discrimination experienced by persons with deafblindness.

Individuals with disabilities globally experience discrimination, and that also includes persons with deafblindness. If you want more detail for it, please look to the report for expansion.

Thirdly, the focus on disability specific services, again, through the lens of the life experience of people with deafblindness.

There may be services available to people with disabilities but it may not be satisfactory for the needs of the person with deafblindness. As a sub bullet, you need to look around the identification, assessment and referral process for individuals with deafblindness. We need to look at successful strategies in each one of these components, identification, assessment, referral.

And the next bullet, focuses on rap takings and focus on training and communication access points. Again, please look into the report for more details on this.

The third is up bullet related to accessibility, assistive devices and technology.

Persons with deafblindness rely very heavily on technology, various devices that are made available to them because otherwise they would not have the capacity to be able to reach out and communicate as needed.

It is important to look at how those devices can be made accessible for individuals with deafblindness worldwide. Lastly, on this sub bullet, interpreter guides and live assistance. Again, it shows the critical need for interpreter guides and assistance in a variety of capacities.

That is impactful in all areas of our lives.

Specifically, we need to look at government support funding options supporting the efforts in moving them forward.

Next bullet. It relates to participation.

Looking at how persons about deafblindness can participate more wholly in their social community as opposed to staying in an isolated experience.

That is more detailed in the report as well.

Lastly on this slide, it is data collection research.

I have to say, without data and collecting this information, don't know where we are and it is such a critical aspect that will help us to move forward.

It is very critical to be able to have the proof to be able to support the statements that we make.

This is why we have combined the findings from the first report and a more detailed second report. That is just the beginning, there is more research and data collection that is necessary in going forward.

Next slide, please.

Taking a look at the time, I know we're short.

So this is the last list of points I want to share with you.

Specifically related to the focus on laws, policies and services.

One critical point relates to inclusive education. The report has shown that access to the general education curriculum for students with deafblindness is extremely underserved. We have to take a specific look at how to even the playing field to make education accessible to students.

Secondly, relating to health. Taking a look at healthcare services, the general population, it is much more accessible, much more advanced for individuals with deafblindness.

Whether limited or no access to healthcare was found. Those results were much lower and much more of a representation of the general population. Thirdly, related to work and vocational training, it is noted that the employment rate for individuals with deafblindness was significantly lower than those of the general population. Again, how do we raise the bar in those standards to allow access to more ‑‑ to raise the access points for work and training. Fourth, social protection. This is often absence in the life experience of people with deafblindness as they often have a more vulnerable experience.

It is proposed that we take a specific look at the benefits for social protection for those individuals with deafblindness.

Fifth, participation in public and for political life. Such as the election process, getting involved in activism. The representation of the community.

Typically speaking, persons with deafblindness have been excluded from those opportunities. There are many individuals with disabilities that are advocates and are engaged in activism, however, even those efforts may not have included persons with deafblindness to date.

To those efforts need to be looked at. The report goes into further depth on that. The next point relates to recreation and social life, of course all individuals, must enjoy the recreation time to be involved in hobbies, various activities and that includes people with deafblindness.

Oftentimes these experiences of individuals with deafblindness are much more limited, which also relates to the access to interpreter guides and various sports that would support the individual to get out into the community and engage in different social experiences.

One individual, carry Thomson, a friend of mine, who lives in Boston Massachusetts, in the United States, established a dance studio, it was a concept they came up with, the idea was to teach dance lessons and it was open to all individuals.

It wasn't focused only on persons with deafblindness, it was just an idea of total inclusion.

Hearing people signed up for the dance class and when they got there, they realized there were people with deafblindness also in the class and as they moved ahead, saw the successes in that.

They were able to provide free access to deafblindness individuals and also provided interpreter guides and supports to make the class a success. This allowed persons with deafblindness to participate in the dance class just as equally as those of the general population.

Individuals of the general population paid for the coursework, the funds were collected and then those funds were the revenue profits of the person who established the business. Again, this is a great opportunity, one example, to show inclusion of persons with deafblindness in a social experience. This again is detailed as well in the global report.

Lastly, excuse me, second to last relates to preventing violence. As mentioned before, persons with deafblindness are actually one of the most vulnerable populations globally. As you may imagine, it is quite easy to take advantage of someone who has limited access to information, resources and we need to take a look at ways that we can prevent that violence from occurring.

Lastly on this slide, it is response to emergencies.

Oftentimes emergency preparedness there are many efforts that may take place in the general population, this may sometimes include Persons with Disabilities, but generally speaking, if that person with a disability is involved in emergency preparedness strategies, that does not mean that a person with deafblindness has been considered, we have to think more extensively on how we can broaden the representation and make sure that persons with deafblindness are included in all of these efforts.

So again, these are just two highlights from the list of 17 points that are more detailed in the report, and now I would like to move on to the next slide that talks about some of the conclusions that were found.

Prior to moving on to that. I do want to mention prevalence. This is such a critical point, I just want to be able to share some of this with you.

Yes. Let me move on to those specific numbers.

So, for quantitative findings, that I had mentioned earlier, in the first global report, the numbers that were found were 0.2 to 2.1% of the global population has what's called severe deafblindness. Estimating that 0.1% of the population of under the age of 40 years has deafblindness and then could be potentially up to 6% of the general population of individuals aged 75 and older were identified as having deafblindness.

In the second global report, there was a stronger focus on children between ages of 2 to 17 years old. This report indicated that .05% of children within that age range were identified as having severe deafblindness. Which might mean that an individual has no access to vision and no access to hearing. This number could be translated into essentially 5% if we look at what's considered moderate deafblindness, someone that has both a fairly moderate level of both hearing and vision loss. That number represented essentially 14 out of 10,000 students for .14%.

Then representing individuals with mild deafblindness, perhaps a milder impact on both vision and hearing, and was represented of 70 out of 10,000 individuals or .7%, all of these numbers together totaled just over 1.8 million children in a total of 36 countries that was collected through extensive surveys.

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I would like to close focusing on some over arranging conclusions.

The first being, that there is a more increased awareness of the situation of persons with deafblindness. That was a very positive outcome of these efforts.

However, governments, NGOs, OPDs, et cetera, must establish a clear understanding of ways in which to support and identify persons with deafblindness.

The second, identify key barriers which included stigma that was mentioned, misperceptions about capabilities, lack of access to interpreter guides, limited or lack of access to information, the low incident rates in terms of identification, the high support needs of individuals with deafblindness, the complexity of the different interventions that are necessary, lack of understanding and resources and isolation. Those are a list of items that are identified as key barriers for persons with deafblindness.

The 2nd Global Report, it aims to improve the position of persons with deafblindness within the broader mainstream services.

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These are the last two points on overarching conclusions. It also was a call for a global mechanism to be established that addresses systematic gaps in live assistance, which includes interpreter guides, also being in alignment with other groups of Persons with Disabilities which in doing so could champion the efforts forward for persons with deafblindness.

Lastly, of course, it was the recognition of that there is a long way to go to make these aims, however we're starting to see that there are different pilot programmes that are being established that are addressing many of these components that we have listed today.

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So for a very quick review before we close, are the urgent priorities that came out of, again, the first global report. Remember, again, it was the lack of universal, national recognition of a definition on deafblindness. The second, it is the lack of the required support, specifically on deafblind interpretation services, and thirdly, the grave need for additional research on data collection.

Those are the top three urgent priorities identified in the first global report.

Here are those urgent priorities identified from the 2nd Global Report.

The first report had three urgent priorities, the second has four identified. The first being to establish an international, national and sub national or regional recognition of deafblindness as its own disability. That remains a top priority across both of these reports.

Secondly, to establish a system for informational resources and continuous training on it deafblindness specifically for essential frontline workers. So that could mean anyone involved in the life of person with deafblindness, healthcare, education, rehabilitation, et cetera. All of the aspects that impact the life of a person with deafblindness. Those individuals who come in contact with persons would be considered those essential frontline workers. Thirdly, to establish public funding for live assistance for persons with deafblindness, which may include teaching assistance, interpreter guides, et cetera.

In school, also in life outside of school that public funding must be established.

The fourth, is to provide further funding through more research, again, to collect the necessary data to support these needs.

While there may be 17 points identified, there maws be fudge funding to go more in depth to find more details on these points.

You can see this more expanded upon course in the 2nd Global Report.

We want to make available to you all critical resources, it is, of course, the first global report, it is available through the reading as well as the second.

The links are provided here. Remember again, the first global report provides sort of an introduction, a foundation to the needs, and the second goes much more in depth to identify these barriers and identifying various strategies.

Thank you so much for your attention during this presentation.

>> SANJA TARCZAY: Thank you very much, Christopher. You really had a wonderful presentation and you were able to summarize it very well and sharing key points of this report. I'm very grateful for your contribution to this.

Now I would like to give the floor to our colleague Lucia D'Arino, the project manager for SHAPES project and is also working for WFDB, she's an important person that makes our disability and progress happen and now I would like to ask her, kindly ask her, to tell us more details about SHAPES project. I hope that we will have enough time for your presentation and Q&As. You have the floor.

>> LUCIA D'ARINO: Thank you, Sanja, for the kind words.

I will now proceed to present WFDB involvement in the SHAPES project and I will talk about the inclusion of older persons with deafblindness in this project.

So just to share some information in numbers, the SHAPES project is a 48 month project, it started in November, 2019, and it will end in October, 2023.

So we only have a couple of months left.

There is more than 300 staff members being ‑‑ that have been employed either directly or indirectly by the SHAPES project, and it is composed of a consortium of 36 organizations, which includes WFDB. It involves 14 European countries, it engaged with more than 2,000 older adults, which include older people with deafblindness in 15 pilot sites. There are also 10 work packages in the project and the project has secured 21 million in E.U. funding.

As we see, the SHAPES is a large‑scale project, and it has two main visions, which is on one side to build an open platform that will include digital technologies to improve the lives of older people, and these technologies include, for example, assisted robots, wearables, so that they can be smart watches, for example, mobile applications, et cetera. So the aim of the SHAPES project is to facilitate long‑term healthy and active aging, and maintaining a high quality of life of older people in the community.

So WFDB's role in the project, it is interesting and impacting. As I mentioned, WFDB is a consortium member and we bring to shape the perspective of the deafblind community. So when we talk about the deafblind community, we not only means persons with deafblindness, we also mean deafblind interpreters or guide interpreters and we mean family members, so we're talking about the whole ecosystem of persons with deafblindness. We also try to showcase the diversity. We try to show that persons with deafblindness are very different and have different needs, communication systems, accessibility requirements, et cetera.

We also contribute with our understanding on our members in the understanding of the situation of persons with deafblindness and their diverse needs. More specifically on topics related to health, so access to health, ensuring that persons with deafblindness have a healthy aging technology, so this means access to technology, making sure that assistive devices are there, available, and are shared and also accessibility. So really ensuring that accessibility measures and standards are respected and that can be both physical and environmental accessibility but also overcoming attitudinal barriers. So really avoiding the stigma and the stereotype that often are associated with persons with deafblindness.

We also advocate for the inclusion and The Rights of persons with deafblindness in the project and more specifically older persons with deafblindness. Within the project, which is focusing on the E.U., Europe in this case, when we talk about older people, we refer to people that are 65 years or older and then we use the CRPD as our basis. So really, this is what we use as the framework when we try to advocate for The Rights of older persons with deafblindness.

We also coordinate with WFDB members, the involvement of older people with deafblindness and make sure that people with deafblindness are involved throughout the project, throughout the work packages, and throughout the different activities.

What are the general objectives.

So WFDP involves to be involved in all key processes of the project and we also see this as an excellent opportunity to collect data in the situation of older people with deafblindness. Again, raise awareness on deafblindness as a disability, also in line with the 2nd Global Report which Chris just presented. We also try to ensure that the platform and the digital solutions that are developed as part of the project are inclusive of persons with deafblindness and we're studying ways in which technology can prevent exclusion and isolation of older people with deafblindness which we know is a very big issue of this specific group.

We also disseminate the resolves both internally within SHAPES project and externally through the reports, Articles, journals, our website, social media, et cetera.

To share some of the examples of our work, we have had older people with deafblindness testing digital solutions, providing feedback, and we have also had our board representatives testing some of the digital solutions and sharing their views, and we have also conducted interviews and focus groups with older people with deafblindness on different topics such as barriers to access to technology, barriers to access to health, et cetera.

We have also produced reports that document the challenges and provide recommendations.

In the 2nd Global Report presented by Chris we also included a section on the SHAPES project and we shared the case study of an older women with deafblindness from Spain and her ex experience with assistive devices and technology.

Also we're proud to say that three workshops have been held where we have been involving WFDB representatives and where we have been able to update and involve our board members.

We have also public indicated internal reports on how to improve the accessibility of the project and shared that about different consortium partners and we continue making assessments on SHAPES project, the resources, promotional materials, so this is a continuous effort to make sure that the project is as inclusive as possible.

So we have been involved in several publications, and I'm not going to go over all of them. This is to shed light on different topics such as the red and white cane, interpreters, deafblind interpreters, the ecosystem of people with deafblindness and we're happy to have been involved in different presentations and coauthored different Articles.

I come to my next slide, which is why is chap an example of ‑‑ why is SHAPES project an example of a good practice? Why are we talking about this? We consider this project is an excellent example of how to include persons with deafblind persons and we're very proud to be involved in the project because it is not so common that people with deafblind persons and their representative organizations are involved in large scale programmes.

To give reasons as to why we consider this a good practice, two disability, they are consortium partners, this includes the European Union of the deaf and WFDB, our organization was involved from early planning stages, and this is really important, we have a seat at the table from the beginning, which means that we're able to plan our involvement. Reasonable accommodations are reflected in the budget, so this includes sign language interpreters, travel expenses covered for interpreters, et cetera, and also accessibility meetings are often held to continuously evaluate the accessibility of the project and in inclusion and accessibility has been adopted as a crosscutting requirement. This is not just the responsibility of one organization, one specific task, but there are efforts to make sure that inclusion and accessibility is included throughout the project.

Also WFDB has been able to maintain the ownership of the project and the decision making power and that's been very important. The board members have been able to decide the direction of the project to some extent and what activities we want to be involved in. Also the project has connected the disability community with hundreds of stakeholders around the E.U. There have been a direct involvement and participation of end users with different types of disabilities, not only deafblindness but also other groups and I would said there is an increased awareness on disability inclusion, accessibility, both internally within the project, with our 36 partners, but also externally, and we have been able to collect data, and information on older people with disabilities and specifically older persons with deafblindness. We're very proud to say that we are working on a global report for older persons with deafblindness where we will include the findings of the shape project and also include information on people with deafblindness outside of Europe. We want to broaden our scope and use this report to continue advocating about the importance of including persons with deafblindness and representations in mainstream projects. It has happened, this is an example, it works. The collaboration, it is excellent, it is important to emphasize that the funds and the resources, they must be there and must be there from the beginning.

But we're very proud to say that if collaboration and the financial resources are there, it is possible to include persons with deafblindness and we have been able to do it so fruitfully so this is a quick summary, I share my email address on the slide which is projects@WFDB.EU. Feel free to reach out if you like information or if you would like to share any other information on older persons with deafblindness since we're putting together this global report, and I share the official website of the project which is chap and I remain available for any questions, I'm aware of the time, so I will now pass the floor back to our moderator.

>> SANJA TARCZAY: Thank you very much, Lucia, for this wonderful presentation involving SHAPES project. Your contributions cannot be measured.

Listening to you, to Chris, to Cato, all of the speakers today, I have a feeling that the dream of deafblind persons is becoming a reality, step by step.

It's the perfect time for a global deafblindness, and I really hope that all of us together will be able to do that with joint efforts.

We have a little more time remaining, 10 minutes. So we're open for commentary and for questions by all the participants.

Anything that we don't have the time to cover today you can send by email in our official mail addresses, so if there are any comments, questions, I'm giving the floor to participants.

>> Hi, everybody. I'm looking at the questions, and I see that there has been a question on Botswana, and challenges in the education of children with deafblindness, so we want to say that we have included information on children with deafblindness, and the recommendations, they're more general about persons with deafblindness in general, please refer to the specific chapter on education so you will there find more specific details on what is the situation like, and what are the recommendations.

I would like to give the floor to Chris in case he would like to intervene and so the question is more specifically what are the key measures that can be adopted to the support of the inclusion of children with deafblindness in education.

So Chris, feel free to enter fine if you have anything else to add.

>> CHRISTOPHER WOODFILL: Yes. I can make a few key recommendations that came out of the global report, specifically as it relates to education for children with deafblindness.

One very critical aspect, it is the need for live assistance.

That relates to teaching assistance in the classrooms, and the term that we use for that, it is interveners.

I know there is different terminologies that identify this role in the classroom.

Here in the states, when we talk about live assistance, that is the rule that's referred to.

Secondly, you will see in the global report, it is the idea of main steaming education.

Now, that is in and of itself a controversial issue from within the deafblind adult community because there is different ideas of what segregated settings might be and we have to think where we are working from if it is from the alignment of the SDGs and the CRPD, but specifically that language talks about the mainstreaming of education of children with deafblindness.

Also we need to look at the establishment of a curriculum that allows for the full inclusion of children with deafblindness into the education system and very specifically to establish teacher education programmes to be able to educate students with deafblindness, not only the live assistance that we're referring to in the classroom, but preservice programmes that would educate teaches. Again, live assistants, establishing curriculum, and also educational training programmes.

Does that address the question.

>> LUCIA D'ARINO: Thank you for that. The report is divided into different chapters as Chris presented and we have one specific on education, please refer to the chapter for more specific information on that. So I see there is a question on elderly population for deafblindness and what kind of intervention or support is being considered in addition to technology, if you're referring specifically about the SHAPES project, this is an innovative action project focused specifically on technology and the integration of assistive devices as well. But in the future, we'll have other topics, including isolation, mental health, deafblindness when it is acquired as aging, so we really want to include, you know, a more broader perspective, and not just technology although we'll include the findings of the chap, but we're doing research, trying to do research on other topics and if you have any resources, suggestions, please feel free to drop us an email, we're going to reach out soon to our members to collect more data, and any data that you have, any good practices, examples, case studies, on older people with deafblindness, we would love to hear from them, as I said, this is a global report, so we're including, you know, pretty much all of the regions in the world, so please feel free to reach out, we would love to hear from you. I see there is another question on the plan for a third global report, currently we have no plans. We are not conducting any research for the third global report, however, we would love for this to become a reality, we're open to looking for new means of collaboration, obtaining funds for it, as I mentioned, the project ends in October of this year, so we're open to looking for ‑‑ to collaborating, finding new sources of funding for sure.

Yes, fingers crossed R that the third global report can be a reality in a few years time.

I will pass the floor back to Sanja Tarczay in case you have anything else to add and I believe we have a couple of minutes left.

First I want to use this opportunity to say thank you to all of our speakers that we had today.

And all of the interpreters that gave us support to make this happen.

Most important of all, what I want to say, is that for all participants, that are included today, in this event, that you can keep on looking for new information and updates on our official pages, took, other social media.

Important things to remember, alone, we can only do so little, together we can do so much. So supports from all of the participants is very valuable and we can do much more with your support. Remember and respecting the Helen Keller week, where we can see that there are a lot of events and happenings to remember her and in regard to that week, and I hope that you can also follow that on social media and enjoy the deafblindness awareness raising month.

Thank you very much for being here and I hope to see you soon in some other opportunity.

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