

THE WORLD FEDERATION OF THE DEAFBLIND (WFDB)

Speech manuscript, Geneva, February 4th, 2019.
IDA SDG-CRPD Workshop

Geir Jensen, President.



Before I elaborate on the strategic and political aspects of our work on the global report, I want to give a brief summary on it. I will not go into details as you will hear more from one of the researchers developing the report on the technical level later during this workshop.

The title of the report is:

At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness.

Through an academic review, internal surveys and a global participatory process among persons with deafblindness, we managed to produce a report that proves that persons with deafblindness still is left behind as a marginalized group, not only in society at large, but also within the broader disability movement.

The report concludes with around 20 recommendations covering preconditions for inclusion, social protection, education, health, work and employment, political participation and social participation.

All recommendations can only be fully resolved if the three most urgent steps are taken, our call to action, and we are given:

- Universal acknowledgement and recognition of deafblindness as a unique and distinct disability, with its own specific challenges, barriers, support and inclusion requirements.
- Publicly funded deafblind interpretation services, in particular interpreter-guides.
- Funding for further research and strengthening of the advocacy work, including funding of the tools and technical support needed.

Introduction

From the onset of our work, turning political support into action was a challenge.

Action dictated the need for funding, and funding was connected to specific activities to resolve specific issues.

With lack of documentation, evidence, of our status and situation, we saw the need for a global mapping of persons with deafblindness.

A mapping covering the internal situation of DPOs by and for persons with deafblindness, covering the daily lives of persons with deafblindness and finally covering the academic research and literature published on Persons with deafblindness.

The outcome of such a mapping would be a report providing evidence and recommendations.

With the help of IDA we developed at project proposal and managed to acquire funding to develop and publish such a report.

Our primary objective with the report, at the start of our work, was to identify the issues we needed funding to resolve. Funding that previously had been rejected because we could not document the needs we were talking about.

THE WORLD FEDERATION OF THE DEAFBLIND (WFDB)

Speech manuscript, Geneva, February 4th, 2019.
IDA SDG-CRPD Workshop

Geir Jensen, President.



Strategic considerations

Starting on our report, we needed to find the proper measure to compare with. The apparent and natural measures was the CRPD and the SDGs.

They are the foundation for most of us in our ongoing advocacy, our main instruments.

Internally we then faced some challenging discussions.

A primary question was: Who are we developing this report for, and why?

Should the narrative and wording of the report be designed for persons with deafblindness, and made easy to read and convey for those assisting persons with deafblindness in accessing and acquiring the information?

Of course, the answers were given. And we all reach a common consensus.

We made a choice of making the report harder for us to use given our communications challenges. However, the choice we made, allowed us to produce a report speaking the same language as the stakeholders we wanted, and needed, to influence.

As parts of our work included internal surveys among our member organizations, DPOs by and for persons with Deafblindness, we needed to develop surveys.

These surveys revealed another strategic challenge to discuss and address.

Should we conduct these surveys in a fashion we knew would be easier for our members, persons with Deafblindness? Or should we conduct these surveys the same way as surveys in general are conducted, using the same tools? Well knowing that the latter would be internally criticised, leading to less responses and lower quality.

We chose the difficult path.

The report was developed to influence stakeholders that potentially could help us achieve the level of reasonable accommodation we need, through funding and technical assistance among others.

Therefore we needed both to produce a report that in structure and language was recognisable for them, and to show in practice how current methods and tools in reality prohibits persons with Deafblindness to interact on this level, without the proper reasonable accommodation.

Conducting these internal surveys as we did would also support our claim regarding what type of support services persons with deafblindness needs to be able to not only function and participate in daily life, but also to respond to a call to action as self-advocates.

These challenging strategic questions are just two examples on how we needed to discuss our work internally, before starting, and along the way while developing our report.

All decisions made were aimed at producing a report connecting our own experiences with academic research and literature. We needed consistency throughout the report, and the conclusions had to be in line with not only what we wanted, but what we were funded for.

In essence, what support would be needed to ensure a stronger democracy in society at large, through ensuring gender equality and full enjoyment of human rights for all. Globally, regionally and nationally.

THE WORLD FEDERATION OF THE DEAFBLIND (WFDB)



Speech manuscript, Geneva, February 4th, 2019.
IDA SDG-CRPD Workshop

Geir Jensen, President.

Political considerations

Strategy, politics and fundraising go hand in hand.

We needed partners that could assist us in our work. Someone with the capacities the WFDB lacked. Partners like Sense International who could provide technical assistance and an outreach that we ourselves could not, on national and international levels.

We needed partners like IDA who could provide knowledge, connections and technical assistance on financial and logistical matters.

SI and IDA enabled us to overcome our difficulties and insufficiencies, caused by critical lack of funding.

Transitioning from strategy to politics is itself a strategic question.

The lack of funding we, the WFDB, are experiencing is not unique for us. So, for us it was important to be in front, leading the work on the Global report.

Having completed the global report, we have a clear message.

- Persons with deafblindness are still left behind and in need of a stronger recognition.
- Persons with deafblindness are still left behind and in need of proper support services, especially interpreter-guide services.
- Persons with deafblindness are still left behind and in need of proper funding to conduct even the most basic advocacy on all levels: Nationally, Regionally and Globally.

Most importantly, the political message saying that achieving a strong and real democracy, where all humans fully enjoy their human rights, equally regardless of origin, sex and status, is not possible without including persons with deafblindness.

The report itself also developed into a monitoring tool, as it presents a baseline a snapshot of today. Giving us the indicators needed to measure the development of our inclusion.

Now it must be up to us to advocate for this, with the support of our partners.
Again, we must be in front.

Examples on how we have managed this, is with the assistance of IDA hosting side events at the UN in New York and Geneva. Presenting the findings of the report, that Morgan Banks of the London School of Hygiene and Tropical Medicine will present for you during this workshop.

Through Sense International, we were invited to present the findings to the House of Lords in London, UK. Among the attendants were high ranking politicians working in or with DFID.

The strategic choices we made enabled us to present a message anchored in a solid report, in a language that was recognisable for policy- and decision makers.

Using these events in our advocacy has also contributed to an awareness among stakeholders we were not in touch with previously, opening new doors, hopefully leading to achieving the three main recommendations of our report, mentioned a few minutes ago.

Placing our statement and request in the context of the CRPD and the SDGs makes it challenging for stakeholders to argue against support, at least in principal.

For us it is a significant improvement of our position.

THE WORLD FEDERATION OF THE DEAFBLIND (WFDB)



Speech manuscript, Geneva, February 4th, 2019.
IDA SDG-CRPD Workshop

Geir Jensen, President.

Capacity, Advocacy and Fundraising

The attention and interest we have created for our work, through the launch of the report, must be maintained.

Maintaining such a broad attention implies a strong need for capacity building on all levels. Doing advocacy work on any level requires capacity, both within the group and in the shape of technical assistance.

To strengthen our position and increase the chance of more funding, we need to have consistency in our messaging. If not totally coherent, our messages must be recognisable on national, regional and global levels.

The finding of the global report gives us a foundation for that consistency.

Starting at a base level we are conducting what I would call regional entry-level workshops elaborating the Global report in the context of the principles of the CRPD and its connections with the SDGs.

The purpose of the workshops is to develop a common understanding on how to utilize the global report in a local context, yet at the same time presenting a unified global message.

A message that will grow stronger as it no longer will be fragmented voices bearing it forward.

We are convinced that this approach will strengthen our base advocacy, even with the capacity constraints we face today.

With this strengthened advocacy we are convinced we will have better funding opportunities, enabling us to strengthen our capacity to improve our advocacy.

It all connects.

We have come full circle.

To maintain funding, we now also need to promote the report as the monitoring tool I mentioned earlier.

We need to follow up our recommendations, and the urgent steps, by developing a report on how this best can be achieved.

So in addition to having a report on the status, and a tool for improvement, we developed a tool for fundraising.

We aim to launch the follow up in four years, presenting a “how-to” to civil society on inclusion of persons with deafblindness.