

COSP16

13 juni 2023

Opening remarks

H.E Mr. António Guterres (Secretary-General of the United Nations):

Spreek rond de 3 thema's

- improving digital accessibility: technology, access - invest in digital literacy - leaving no one offline - making adoptive technologies more affordable
- Access to reproductive health services
- Under representation of underrepresented groups of pwd - shifting mindsets so they're fully included in decisionmaking - involving them from beginning to end - all represented groups and their organisations

H.E. Mr. Csaba Kőrösi (President of the General Assembly)

- crucial to have accurate data on pwd to overcome all barriers

Ms Gertrude Oforiwa Fefoame (Chairperson, Committee on the Rights of Persons with Disabilities)

- Replace the welfare and medical approach with the human rights model of disability
- 186 ratifications reflect as a strong commitment of state parties to our convention
- Mental health: community based services is not mentioned in the CRPD but strategy on this needs to be made
- Guidelines on emergencies on pwd- wat doet België hier rond?

Mr. Gerard Quinn (Special Rapporteur on the Rights of Persons with Disabilities)

- Opportunities due to AI to improve personalised and individual services instead of institutional living but have many risks - we need to include pwd from the beginning, not making the same mistake as we did with the beginning of internet, we're still playing catch-up on making this accessible
- For example: Machine-based decision exclude pwd due to stereotypes

Ms. Maria Soledad Cisternas Reyes (Special Envoy of the Secretary-General on Disability and Accessibility)

- talks about health of women and girls with disabilities
- They should be at the heart of the political debate
- Gender equality is 300 years away
- Gender trolling: silencing women and removing them from public life
- Feminist movements should include women with disabilities in their policies and management teams
- Women with disabilities should be included more, not be a group on our lists

- People with psycho-social disabilities are often left behind in independent living and in this community and underrepresented in an independent way - also in digitalisation
- Common agenda of the UN: 3 important comments: 1: Special envoy for next generations - 2? - 3: examination of the implementation of the uncrpd in states
- Video of UN on rights of women with disabilities (best interessant om eens te bekijken)

Mr. Nawaf Kabbara (Civil Society Representative from the Arab Organisation of Persons with Disabilities of Lebanon)

- In the last year big progress in achievement of the rights of people with disabilities
- Also setbacks at national levels: Physical constraints are leading to cuts on services of pwd,
- war, climate crisis demonstrate how fragile our response mechanisms are for pwd - lack of preparation and planning

Mr. Ghanim Al Muftah (Youth Representative, Qatar)

- 2028 Global summit for disability in Qatar
- Speaks about the accessibility of the Olympics and FIFA World Cup

Matters related to the implementation of the Convention - general debate

Weinig interessante topics voor ons

Australia:

- Speaks about issues of women with disabilities and people with psychosocial disabilities
- Work close with DPO's to understand the lived issues better

Iceland:

- Talks about the lack of access of health services and education
- Women are perceived as unfit to be parents

Tunisia:

- Wants to improve access to education
- Wants to invest in customised vehicles for pwd

Sri Lanka

- Serves as vice president of the bureau
- Ratified in 2016 - first national report in 2018

Morocco

- Pre-recorded message
- new law in 2021 on social protection and increased the budget to help NGO's who work with pwd

International Disability alliance (IDA)

- journey towards to inclusivity is far from complete
- Still physical attitudinal and systematic barriers that restrict our rights on inclusion
- Our access needs are denied, we saw it in covid, now in wars, economic and climate crisis
- Climate change such as extreme weather and rising sea-levels effect pwd
- Less than 8 years to meet the SGD's - concerned that the implementation is not sufficiently inclusive

UNOPS:

- AT Scale
- A lot more needs to be done to increase access to assistive technology - smart thing to do because there is an economic return of a 9 to 1 of all dollars invested - increases educational and employment outcome

Canada:

- Minister of employment, disability rights etc - also has a disability
- Disability action plan: made with the disability movement
- New benefit: payment for people with disabilities in poverty
- Supporting employers to be more accessible

Italy:

- Talks on rights to education and protection on women with disabilities

IDC:

- Nadia Haddad
- Talks on diversity of pwd - multi discrimination and their unique issues
- States need to step up: lay the foundation for inclusion - setting ambitious targets
- New tools like integration data collection tools

Unicef

- Is building the capacity to build assistive technology and ensure that the services available is adequate

France:

- focusses on protection on mental health of pwd
- Unemployment decreased from 19% in 2017 to 12% in 2023 - but still twice as high as rest of the population - increases the access to employment

Malta:

- Works with ENIL on deinstitutionalising

Inclusion International:

- people with intellectual disabilities often excluded
- Participation is not providing easy to read texts and not including them in making them
- Often discriminated in usage of language

Side Event: Maximising, understanding and monitoring the impact of disability strategies.

Co-Organised by EU commission and EDF

Helena Dali:

- Talks about the 10-year strategy on disability rights: tool to improve the rights of pwd
- Data is not available or collected to identify trends and needs -> EU commission is enforcing data collection also for pwd in institutions

A.H. Monjurul Kabir, Senior Global Adviser, Gender Equality and Disability Inclusion, UN Women

- Topic: How to mainstream disability in other policies (not only in disability strategy) like gender equality?
- Universal design: people talk about cost but if you introduce pwd in the beginning, cost won't be an issue because it's build in already
- UN woman: challenge, how can we bring disability and gender movements closer?
- We need all leaders to have knowledge about inclusion so they can implement it in all areas
- Intersectionality: UN is struggling - UN needs to sharpen in this area - they know a lot when the problem is (afgebakend) but when there's minority groups are not easy accessed (indigenous people) it's hard to collect knowledge on how to proceed

Katarina Ivankovic-Knezevic, Director, Directorate General for Employment, Social Affairs and Inclusion, European Commission

- Topic: Implementation of good practices of accesibility
- Disability needs to be fully mainstreamed in all strategies: human rights, space-activities, environment, energy poverty, climate policies
- Pointed disability focal points - they work together on implementing the different strategies -> resulted in 6 equality coördinators in different strategies of UN
- The EU strategie has 64 actions and 7 flagship actions
 - one flagship resulted in disability employment package - to educate employers in what is needed for reasonable accommodation - for people with disabilities to find a place in education

- Another one being made: EDC - card for mutual recognition of disability throughout the EU
- Guidelines on independent living is being made: ART 19 of the UNCRPD puts it high on the agenda
- guide member-states in what is important to independent living and how to use EU funding for this & how to go to individualized support, how to go to deinstitutionalisation, ...

Gunta Anca, Vice president, European Disability Forum

- Pwd were not involved in the development of the strategy for the implementation of the CRPD in the EU
- Most important for change is political will

Malin Ekman Aldén, Director General, Swedish Agency for participation

- Topic: Active involvement of persons with disability and their representative organisations in Sweden
- Works for a government agency - works on implementation of disability policies in Sweden based on the UNCRPD
- First line of work: collect data on pwd so we can know the key-points they need to work on = increase knowledge / this is quite challenging, due to the lack of data in many areas, so they don't know how pwd are effected in different sectors, so they made it a key point to collect the right data
- Active involvement is also a key element of work: ensure that the government has an ongoing dialogue with civil society (disability organisations) and make a yearly report on how they implement it and use the input for concrete development in their work

Marina Carlsson, Board member, Swedish Disability Rights Federation

- Analysed the implementation of the UNCRPD resulted in 110 civil organisations made 104 recommendations

Questions:

What to do when policies are not implemented?

- We need a monitoring!
- We need to have stated: who does what with which money funded by who
- you need to set targets - otherwise you can't measure
- Information needs to be available to all - so pwd can see what is done for them

14 juni 2023

Matters related to the implementation of the Convention - general debate
Spain

- Dragging attention to the consequences of climate change that affect pwd
- Women and girls wd are more exposed to sexual violence in disasters
- Promote green activism among pwd and their representatives
- Awareness raising and training people about climate change

Greece

- 186 countries ratified UNCRPD
- Adopted the first national action plan for pwd -> longterm commitments
- Human rights based approach

New Zealand

- FIKAHA was established - responsible for supporting other government agencies to incorporate disability in their work, finding disability financial support -> doet nog veel meer, lijkt me relevant om eens te bekijken

Disability federation of Ireland

- Being part of life like everyone else is not possible yet
- Geeft uitleg over het ontstaan van de UNCRPD en de moraal erachter

Commonwealth secretariat

- Supports member countries in implementing the uncrpd in national policies
- Provide guidelines and assistance on how to implement

Switzerland

- Pwd are often the forgotten victims in emergencies like war

Inclusion Canada:

- Working for people with intellectual disabilities
- They have no access to inclusive education, no voice in choosing, much higher risk for poverty

Austria:

- Made action plan on longterm policies and strategies for pwd
- Concrete measures to implement - evaluated
- For example: pilot project on personal assistance: national framework to provide personal assistance in all areas in life. Harmonizing the local existing systems and include service features, and evaluate and do quality control.

Side Event: Promote democratic participation, ensure inclusive elections

Focus: sharing knowlegde and examples on promote democratic participation - accessible elections and voting - how to have pwd on the voting box

-> Article 29 of the convention

State Secretary Gry Haugsbakken, Norwegian Ministry of Culture and Equality

- Opening remarks
- Creating society where people have a say in the governance and participate in political life like others
- Norway:
 - high on democratic index but still pwd are underrepresented in governance decisionmaking
 - Due to lack on accessible information and communication
 - Step forward: Pwd can bring their own assistance in the election booth
 - Special focus on underrepresented groups of pwd

Siri Espe, The Norwegian Association of Youth with Disabilities

- Physical and social barriers: non accessible and lack of information in accessible format
- Social barriers: pwd who have a invisible disability are often not believed in having a disability, pwd who is visible state that they are often underestimated in their abilities to be political active
- Being invited to political events is not enough for them to contribute
- We need to train election officers in making voting accessible

Malin Ekman Aldén, Swedish Agency for Participation

- Practical opportunity to vote and form a political opinion is still lacking in a lot of countries especially for pw intellectual and learning disabilities

- Project: My vote : studygroup which focused on pw intellectual disabilities so they can learn about political parties, statements and how to vote -> increased political participation of pwd

Alejandro Moledo, European Disability Forum

- Last year: published report about article 29 - EU Elections
- Political participation of pwd depends on the country they live in
- Looks at the different elements like right to vote, equal access, voting when you move to another citizenship, looking at cases that brought good practices
- Main issue: lack of voting rights of pwd : estimated that 400.000 pwd in EU where deprived of their right to vote

Dewlyn Lobo, President, People First Canada, Inclusion International

- Consider people with an intellectual disability - plain language - accessible communication
- Importance of training officials in voting stations and making sure that the process is consistent for pwd than for non-disabled people

Bridget Snedden, President, Down Syndrom International

- We need fully accessible education so these people can learn about the world

Abir Al-Sahlani, Swedish Member of the European Parliament

- What is needed to close the gap and have inclusive elections?
 - Rule of law and liberal democracy is the way to protect human rights
 - Voting itself: when we exclude pwd we degrading their rights to citizenships
 - Enable accessible information to voting
 - Keep the dialogue alive and take all the proposals of pwd -> political will is needed to make them reality

Emma Bishop, Self-advocate, Down Syndrom International

- People with an intellectual/learning disability need help in understanding how the election works, what candidates focus on, what the issues they talk about are, where the priorities lay
- Politicians need to understand their needs
- Pwd should have the opportunity to have a social worker or family member to help them understand what voting is, explain the voting paper so they can all joining the elections

Ambassador Magnus Lennartsson, Deputy Permanent Representative of Sweden to the United Nations

- Closing points

Questions:

- How can we give people who are not certified to vote a political voice? Are there instruments we can use to give to political election offices?
 - European commission will make a guide on accessible elections - we don't know how good it will be
 - Report of EDF
 - All depends on the voting system and the context of how the elections are held - you need to look at the range of users, context etc before you can make up a strategy on inclusive elections -> ask pwd and DPO's for advice
 - Plain language improves voting for non-natives also - not only for pwd
- How can political role-models with a disability collaborate more? How can we encourage pwd to be part of the political proces?
 - Knock on doors, raise your voice, talk to national disability organisations - take up room

6. Meeting with IDA

Talked to Waqar Puri, works for TPI on rights for people with psycho-social disabilities and is a part of IDA's youth Comitee

Ik heb hem uitgelegd dat ik een beetje in het duister tast betreft IDA, ik ben ooit toegevoegd aan een whatsapp groep (EDF gaf mijn naam door) en daardoor deel van hun Youth Comitee, maar eigenlijk weet ik niets over IDA of wat het Youth comitee doet. Hij vroeg me wat nodig is voor meer jeugd participatie, ik vertelde hem mijn mening, namelijk dat we moeten starten met het opleiden en informeren van jeugd voor we hen echt kunnen betrekken bij wat ze doen. Dat was iets wat bij mij ontbrak waardoor ik 0 feeling voel met IDA. Hij geeft mijn bezorgdheden door, ik stelde voor om eens een meeting op te zetten met een stafmember van IDA zodat ik wat meer info kan vergaren.

Daarnaast is Waqar op zoek naar mensen met een psychosociale handicap of organisaties in België die hierrond werken om deel uit te maken van hun movement. - Welk lid van BDF kan ik best met hem in contact brengen?

Side Event: Amplifying the participation and protection of deaf women and girls in humanitarian, crisis and emergency situations

Co-organised by Belgium - maar geen panelist van België?

Opening remarks:

Mr. Kasper Bergmann – World Federation of the Deaf, Vice President

- explains the many difficulties deaf women and girls have
- Purpose of today: look at their situation during emergency situations

H.E. Philippe Kridelka – Permanent Representative of Belgium to the UN in NY

- Welcomes everyone
- Talks about his meeting with a deaf civil society member of last year and the fact that he doesn't know much about deaf people beforehand.
- Mentions the action plan in Belgium with 145 actions

Direct weg nadat hij moest spreken... Zegt niets over het effectieve thema of wat we in België doen...

Panel:

Dr. Samuel Njuguna KABUE, Member of the Committee on the Rights of Persons with Disabilities, member of the Working Groups on Women and Girls with Disabilities, on article 11, and on Communications and Inquiries.

- In emergencies is communication very difficult, for deaf people it's even more difficult. Emergency responses are not adapted.
- Women are even more vulnerable. They are often forgotten.
- How can messages be passed?
- There is need to rethink how we can bring deaf women to the forefront. We need to take them in account in planning, implementation and monetising emergency responses.
- In media, sign language is not often provided (in news f.e.) if people don't have information, they remain ignorant.

Ms. Laura Lesmana Wijaya and Ms. Lia Nur Rochma, of the "Indonesia Association for the Welfare of the Deaf – Gerkatin" on the situation of deaf women during crisis in Indonesia.

- Big gap in education for women with disabilities in Indonesia - they have difficulties in understanding information that is given to them - even if they can go to school, they are often only engaged in home-activities after education and not in economical activities
- They engaged in training events, specially for deaf women on sexual health and reproductive rights
- There are many examples of deaf women who don't know they're pregnant until their waters break due to lack of information which causes in several cases in still birth or death of the mother
- Recommendations:
 - There should be better training and access to information
 - We need to create materials who are suited for deaf people

- Deaf women should be able to access regular services and their needs need to be considered (sign language interpretation should be provided)

- We need funding directly to deaf women organisations

- Training needs to happen locally for government officials and humanitarian workers - so they're more sensitive to their needs

Ms. Pamela Molina, Executive Director of the World Federation of the Deaf, presenting the WFD report "Barriers to Healthcare Access for Deaf Nigerian Women and Girls during Emergencies: Analyzing the Additional Impacts on Their Intersectional Identity".

- Explains how they set up the report

- Resulted in the findings that deaf people in Nigeria have little access to medication, testing, vaccination during COVID - some were not aware of the virus, some didn't know the vaccination existed or that it would kill them

- For a lot of women sign language is the only language they understand easily, but it is very limited provided

- Deaf people should be involved in decision-making processes in all levels

- There needs to be further research into the issues deaf women and girls encounter of course with an intersectional focus

Ms. Shirley Keoagile, Executive Director of the "Botswana Association of the Deaf", on deaf women's participation and access to health in humanitarian, crisis and emergency situations in Botswana.

- Videomessage

- Human and disability rights advocate

- Access to information and sign language interpreters is a challenge

- Deaf women have difficulties in participating in decision-making processes

- Many first responders don't know sign language -> not able to communicate to deaf people -> difficulties to access emergencies

- It's important to know how to contact deaf people and leaders in your countries and ensure better communication in order to have better access to needs such as food, water, clothes, ...

- There's a limitation in access to training and employment opportunities

- It's important to make sure you're working with the deaf community and deaf associations and communities to activate services

Ms. Susana Stiglich, Sign Language Rights Officer at the World Federation of the Deaf, on the advantages and importance of the use of sign language in humanitarian, crisis and emergency situations.

- Developed a toolkit to help national associations for deaf to better advocate and achieve their legal recognition for their national sign-languages.

- 3 aims of the toolkit:

- Inform and raise understanding to the importance of legally recognition to sign language and to deaf people in civil society
- Provide recourses on human rights to sign language rights
- Enabled anyone to identity issues and work with national associations of the deaf specifically to work with their local governments to achieve sign language recognition
- Several categories in recognition:
 - Constitutional level of recognition
 - National sign language recognition in a national sign-language law
 - The sign-language is recognised as well as additional forms of communication (for example tactile communication for deaf-blind)
- UN has a 193 countries but only 76 have legally recognised their sign language
- UNCPDR art 21B: the government must persue the legal recognition of their national sign languages
- 8 minimum criteria:
 - Must include language policy and liberty so deaf people can express themselves in that language
 - Equality and non-discrimination
 - Educational provision: explain how can deaf children gain acces to quality education - also how the family can acquire sign language
 - Sign language interpreters: critical in emergency situations via media, television, ...
 - Outline the training guidelines in sign language interpreters their education and professionalism and the government who is obligated to pay for these services
 - (Rest niet kunnen noteren, wel op te zoeken, heel interessant! Hoe zit het in België?)

15 juni 2023

Side Event: Digital participation of persons with intellectual disabilities (PWID)

Guiding questions:

How can people with intellectual disabilities participate more and better in the digital world? What are the success factors for better participation of this group of people? How should support services be designed?

Jürgen Dusel, Federal Government Commissioner for Matters relating to Persons with Disabilities, GER

- Explains difficulties that pwid face

- Setting up devices takes a lot of steps
- Victim of fraude
- Difficult language
- They have fear of using it
- Don't know the opportunities that digitalisation can offer
- Fact that there is often little help available for them
- Good practises: read aloud functions, voice messages
- These people should be involved in the development of digital services

Tom Pursglove MP, Minister of State for Disabled People, Health and Work, UK
Connie Laurin-Bowie, Executive Director, Inclusion International, UK

- Higher level for pwid of digital exclusion
- Good practices UK: libraries are open to give support on digital services / government fund and train the telecom dividers to support people with pwid on technical difficulties / did awareness campaign around this topic / digital skill courses for this group to gain access and knowledge / provides easy to read language on this topic / involves DPO's in taking actions
- Support services should always be accessible and workers there should be trained in how to work with pwd

Connie Laruin Bowie, inclusion international

- LISTEN - INCLUDE - RESPECT - guidelines (interessant om eens op te zoeken)
- Easy to read: we need to look further than just adjusting texts, pwid are more busy trying navigate the web, managing how to send messages
- COVID: very difficult for pwid to search information about the pandemic
- Pwid need to be involved in design, language context and navigation features!

Helen Rademakers und Nicola Löhr, Project "The PIKSL Labs - Making digital participation possible", GER

- Project PIKSL lab: organisation in Germany - bring pwd and others together
- Provides a place where people can use the internet, work, .. with support - there are employers who have intellectual disabilities as wel - they teach others - they know best what is to understand and not / always in a duo: piksl expert (pwid) and another employer (without disability)
- Also open for elderly people - face often the same challenges
- Provides also free printer / workshops (about phishing, tablet, data protection, tablets, AI, fake news, ...) / Games

- Digital learning platform: accessible to everyone, about different topics on the digitale world
- !! Actively involving pwid in every step of developing the project - they give input on difficulties since they know best

Dr. Emma Stone, Project "Digital Lifeline for people with learning disabilities" of the Good Things Foundation, UK

- Project: Digital lifeline fund
- Shortterm emergency project during the pandemic
- Offered devices for pwid (for example a tablet)
- Offered support for partners to include pwid like access to free support, resources from national organisations and a grant towards time spent doing set-up and support for pwid

Side Event: Implementing the Guidelines on Deinstitutionalization, including in emergencies: Challenges, opportunities, and way forward

Vanessa Frazier, ambassador Malta, introduction

- Adresses the importance of deinstitutionalization
- Pwd are still seen as unable to live independently and put in institutions most of the times against their will or without their full consent or understanding
- No child or family should be seperated in order to have care

Nadia haddad, ENIL

- there's a lack of understanding what independed living is

Amelia Gamino, member of the CRPD comittee about one year after the guidelines

- State parties should recognise insitutionalisation as a violence of the CRPD because it makes people live outside of society
- Work group was established on 2020: first step: consult pwid in several regions of the world
- Guidelines were established by the comittee one year ago
- Gives an explanation about chapters on emergencies and underrepresented groups (chapter 8, 9, ..)
- There will be an event later this year to discuss what happened in one year since the guidelines were established

<https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd5-guidelines-deinstitutionalization-including>

Christine Sant, about the way forward on deinstitutionalisation in Malta

- Still a lot of institutions high demanded
- Little self-advocacy on a national level

- Lack of understanding about deinstitutionalisation, institution, independence
- Malta is working on a reformation of their support-system for pwd
 - Looking first of all at individual goals and needs
 - Involving pwd and dpo's (local and international) in this proces: not the right thing to do but the most effective proces
 - Pilot project: 3 persons are processing from an institution to independent living
 - Educating local services
 - Transition is happening while other services are still available

Natalia Mattioli, programme coördinator, UNCRPD about the donor's role in the implementation of the guidelines

- Explains good practises they funded and how they work

Sadam Hanjabam , young representative of TCI, self-advocate

- talks about situation in India: institutionalisation is seen as the only way to support pwd / lot of forced institutionalisation, pwd are picked up from their home and put in an closed institution / forced medication / conversion therapy for LGBTI community / misdiagnosis

Tia Nelis, self-advocate

- explains the situation in Illinois
- Institution is not only a facility, it's every place where a pwd can't make their own decisions
- It's hard to find the right support in community, money should follow the person from the institution to the community to get support but it doesn't work that way
- Workers in institutions are payed better than personal supportworkers

Side Event: Disabled Youth Involvement, Awareness, Empowerment and Leadership in DPOs/OPDs across the Commonwealth
CDPF= common wealth disabled persons forum

Saista Parwin, India Youth Activist, CDPF Executive

- Youth with disabilities are more often in poverty, victim of discrimination, social exclusion, isolation

- When we talk about change, what action is needed? We need leaders who have disabilities who stand at multiple intersections so that they can bring their realities into policies and approaches

Penny Innes, Head of Disability Inclusion team, FCDO UK

- Investing in children: through education, specifically of girls, violence and child labor
- Giving young people a voice: using their voice globally to ask donors to take action in working on the rights of youth with disabilities, to be more disability inclusive

Emile Gouws, Autism South Africa, CDPF Rep. Underrepresented Groups

- Moeilijk te verstaan

- Talks about the situation for youth in South Africa
- We need to mainstream education for all children -> inclusive education
- Highest rate of suicide lays with youth with disabilities

Charlotte Young Youth and Disability Australia

- Talks about the lack of inclusive education in Australia which leads to low employment rates for pwd
- Lot of indigenous pwd are often undiagnosed and often institutionalised
- There needs to be an intersectional approach
- Peer-support is very important - connect youth with each-other but also with mp's