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BRIDGING THE GAP II

WEBINAR N.9 -- ACCESS TO HEALTH

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>> ALESSIA ROGAI: Good afternoon and good morning also to everyone. My name is Alessia Rogai and I'm the Knowledge Management Learning Coordinator of the Project Bridging the Gap II. Bridging the Gap II is a project funded by the European Union and coordinated by FIIAPP, in partnership with three European agencies for development corporation, Spanish, Italian, and Austrian, and international NGOs, European disabilities Forum, and international agency international disability con sort yum, and it is to make development cooperation accessible to include persons with disabilities with an obligation for the European Union and Member States as parties to the Convention on the Rights of Persons with Disabilities and which can have a significant impact on in improving the social inclues and promoting the rights of persons with disabilities. Bridging the Gap supports the mainstreaming of disability in international cooperation and force of five partner countries, Burkina, Faso, Ecuador, Sudan, Paraguay, .

Today, the session of the webinar-based training cycle originalled by Bridging the Gap, which from the beginning is exploring different topics involving international experts.

The webinars are conducted as you know in English, French, and Spanish in separate sessions. You can find all the previous recordings on our website on the Facebook and Twitter pages and on our YouTube channel. You can find the links to these pages here in the Chat Box in a while.

The 9th Session today is about Access to health, inclusion of persons with disabilities and services according to the CRPD Article 25, persons with disability are vulnerable to exclusion in accessing rights to health. They commonly face stigma, discrimination, violation of rights, lack of equally targeted and accessible health services.

Exclusion and access to water and sanitation and have low income levels which can increase their vulnerability to these things.

The 2030 Agenda considers disability in five goals and 7 targets, including commitments in relation to disaggregating data on disability. The emphasis on ensuring no one is excluded is crucial to the goal of ensuring healthy lives and promote well-being for all at all ages and this certainly is also evident in collusion

of universal health target. To attain health-related targets the priority must be given to straightening and making more equitable health system and addressing gaps to equitable and group coverage.

States are encouraged to respect and encourage rights to health. Persons with disabilities are protected by the same general framework of the right to health as everybody else; however, the International Human rights System pays little attention to the health needs and adoption of the Convention on the rights of persons with disabilities. The Convention on the Rights of Persons with Disabilities shifts from medical and paternalistic approaches to disability towards human rights-based approach which considers persons with disabilities as rights holders rather than as residents of protection, rehabilitation or welfare.

This session will provide a general overview and different topics related to health of persons with disability, such as according to CRPD as care needs of persons with disability by way of access to free and affordable general and disability-specific healthcare services.

Well, I'm not -- I'm not taking more time. I will give immediately the floor to our speaker today, Alessandra Aresu. Alessandra is currently works at the formerly Hand cape International as Inclusive Health Policy Lead before this global position she worked as country director of China province 2013 to 2017 and from this position led HI action at country level on sexual and reproductive health and rights, mental health, gender-based violence, and rehabilitation.

Prior to 2013, she worked at the post-doctoral research fellow and advisor on SRHR GBB, and comprehensive sexuality education for INGOs, UN agencies in academic institutions in Italy, China, Haiti, and UK. The authorize of several book chapters and books on these topics and is also the co-chair of the inclusive Health Task Group and core group's disability inclusive health technical advisor group.

While she's a really international expert on this topic. Thank you very much, Alessandra, it's really a pleasure having you today. I give you in a floor in a while, but just before starting, I would like to inform you that as usual the webinar is live captioned and you can follow the transcription of the webinar by linking in on the link in the Chat Box that I'm putting in a while.

So, well, thank you very much Alessandra. I give you the floor and to everybody enjoy the session. Thank you very much.

>> ALESSANDRA ARESU: Thank you, Alessia, and good morning, good afternoon, everybody. It's a pleasure for me to be contributing to Bridging the Gap Training and to be able to speak about access to health and disability and inclusion.

I know that some of you have already been learning about disability and inclusion in relation to other topics, not

necessarily specifically in relation to health. There may be more experts on health and less on disability, so my choice as a start is to give a brief introduction of what disability means and which are the main key concepts we are going to refer to during this webinar, and then dive into a more specific discussion on access to health.

So, I would start in with the reference to how discussions about disability have been changing throughout the years and how during the last few decades the approach to disability has changed.

And if you see this first slide, the first three approaches that we can refer to are the charitable, the medical, and the social model that are highlighted here.

Now, instead of telling you and summarizing for you what does it mean, charitable model, medical model or social model, I would like to use the words of some of the people that we have interviewed throughout the years to -- and that have referred to disability following these models, and so when we discuss about charity models, usually we talk about people with disabilities being considered poor and helpless. And in fact, one of the persons that we have been discussing with about disability expressed her opinion about people with disabilities in these terms saying people with disabilities are poor and helpless and we need to put money aside to help them because they are a burden for society.

And with this approach, of course, the persons with disabilities are far away from being considered full active members of society, and this approach clearly is a barrier towards a full inclusion of people with disabilities.

The medical model, however, is also a model that does not support the full inclusion of people with disabilities in societies because as one of our contributors shared, we see the numbers of people amputated because of accidents are on the rise and that's a terrible problem because we don't have enough prosthetics for everyone.

So if we look at the disability from this perspective, we only focus on the impairment of the person having one leg being amputated, having one arm, not being fully -- not having a full body or full mind functioning according to the standards that we are used to. And these models, the charity model and medical model, have been widespread for a long time.

When we look at the social model, however, we look at a model that looks not only at the impairment per se and status of person with disability in relation to his or her health, but also it looks at the overall context and the environment and where the person lives to give you another, a neighbor or person with disabilities shared with us, yesterday my neighbor went to register her child at primary school and was very disappointed when realized the director didn't have time and gave her information on a printed leaflet and did not

explain anything verbally and my neighbor is blind.

That means that the environment around the person was not offering communication to us that were adjusted to the person, in this case the person with disabilities with vision impairment or vision disabilities. And in this case, the environment was representing huge barriers to accessing information that would have been easily understandable for the person if the communication tools wereadapped.

So throughout the years a lot is changing in the way we have been discussing disability, and this -- and the reason I'm mentioning them is because, of course, the which we look at disability and the way persons with disabilities are perceived, do make a difference when we want to promote the rights of persons with disabilities and we want to, in this case, promote the right to help for persons with disabilities.

Now, throughout the years, a third -- a fourth element comes into the picture and this is more recent but is essential for the work or for the topic that we are going to discuss today, and it is of course, the rights-based approach.

Throughout the years people with disabilities have organized themselves more and more, the Disability Movement is present in every country and disabled persons organizations are active in countries at regional and international level to advocate for their rights and to implement projects and implement actions that are oriented in being fully included in the society.

And globally, disability is increasingly discussed from a national rights perspective, and of course the key tool we have in our hands when we talk about the rights of persons with disabilities is the United Nations Convention on the rights of persons with disabilities that is dated 2006, and since 2006 it's the work we do, work on health, education, or any other area.

Now, this is the definition that the yaition's Convention on the Rights of Persons with Disabilities offers persons with disabilities (united Nations) -- and it is a very important because it not only exclusively mentions that the disabilities refer to different types of impairments, no matter if they are physical, mental, intellectual, or sensory, but also that when we discuss about disabilities, it is essential to consider the interaction between the impairments and the different barriers and that the overall society and environments are really in front of people with disabilities and that prevent them from fully realizing their rights.

This is the -- this is also the definition that the international law of the one that is now used and all of us that work in the field of disability and inclusion encourage highly this definition as the one that should be used every time we discuss disability no matter which is the work that you do.

Jumping into the health and diving in a little bit more on health, it is important to say that among the articles of the CRPD, Article 25 is fully dedicated to health, and it is important to highlight this because the article that you will slide, on the next one, really highlights the key elements related to the rights to health, not only the commitment of the states that have assigned — the state parties that have signed the Convention, but also which are really the responsibilities of the State parties, knowing that when we talk about health, we talk not only about health as services in general, but specifically also rehabilitation services, so this is a very moment to highlight that rehabilitation is part of health.

And I'm highlighting this because many actors working in the global health sector have for a long time considered rehabilitation as somehow an appendix, somehow an external element that was only defined and discussed separately, but in fact rehabilitation is part of health and health -- when we talk about inclusive health, and when we talk about access to health, it is essential to remember that rehabilitation is an essential part of health.

Now, when the CRPD refers to the rights of people with disabilities to access health, information, and services, it also reminds us of what does it mean of access to health. And first of all, it means that people with disabilities has the right to free or affordable health services in the same way people without disabilities are accessing it.

And it is important, because as you know, when many people with disabilities in many countries, especially developing countries, suffer from lack of opportunities to employment and very often people with disabilities in the world are among the poorest. And having to pay for services related to health means automatically being excluded to the access to health, so free and affordable is a key element.

Another point that's important to be highlighted is that the Convention goes out of its way to highlight very much that sexual reproductive health services needs to be included in the overall access to health and rights to health. And one of the reasons why this is highlighted is because for many years sexual and reproductive health and rights have not been discussed as a high priority for people with disabilities, and the reason why this is or was happening is because for a long time people with disabilities have been considered — have not been considered subjects of sexual rights but instead as people who needs to be protected and people who have no sexual desires, sexual needs.

With this perspective in relation to people with disabilities and their sexual and reproductive health and sexual and reproductive life, very often access to sexual and reproductive health services have been considered a non-priority. In the past 10 years, you will

see an increasing number of actions directed to promote the rights of people with disabilities in the field of sexual and reproductive health.

I will say a little bit more about this topic later when we come to analyze this data we have available on that -- on health in relation to persons with disabilities.

Other key elements of this Article 25 refer to the fact that not only people with disabilities have the rights to access health services that are general health services that are common needs of everybody, but also specific services that they really need linked to their disability, and this is as important.

Another very important element is related to the fact that very often the majority of people with disabilities live in rural areas in developing countries and therefore it is important that these services — those services we will call in the rest of the discussion as inclusive services, are close to the communities where people live, and because especially for people with disabilities, if we are talking about physical disabilities, transportation can be — transportation and mobility can be an issue and not only because transportation services are not available, but also because they may cost money and then the issue of affordability comes back to us.

The quality of the services needs to be the same as provided -- as the ones provided to others. And another key important point is that not only persons with disabilities have the right to access to services, but the CRPD clearly highlights the importance of non-discrimination against persons with disabilities in the insurance sector because very often we have people with disabilities who, because of their conditions, are denied a certain type of insurance or asked high coverage prices, so this is also the insurance element that is extremely important.

Together with this, including medical care and services also needs to be prevented and prohibited but you may be surprised to find so explicitly this element in the CRPD, but if you work a little bit in the field of health and disability, you might find out that often the discrimination against people with disabilities in access to health services is more common than what you may imagine.

I will now move on and show you a little bit more about what is the situation of persons with disabilities in relation to access to quality health information and services and the barriers that we usually discuss and that persons with disabilities face when accessing quality health information and services.

I stress the importance of information and services here because the lack of access of information automatically prevents the access to the services per se, so cannot be forgotten.

What to highlight in this light, that first of all we have to remember how many people with disabilities are in the world

according to WHO it's between 15-20% of the population has a disability or lives with multiple disabilities, and 80% live in a developing country.

I would like you to keep this data in mind, specifically, because when we come to discuss how to achieve the SDGs and specifically SDG 3 on Access to Health, these triggers will be extremely relevant in discussing how the limited access to health of people with disabilities can limit the action of Goal of SDG Number 3.

But staying on the barriers and disparities of access to health information and services of persons with disabilities, we know from WHO that at least persons with disabilities are at least two times more likely to find healthcare providers and facilities in other ways. Three times more likely to be denied health care, four times more likely to be treated badly in health care facilities, and we also know that more than 50% of people with disabilities in the world cannot afford health care, and more than 50% of people with disabilities have an unmet need for rehabilitation.

This data comes from the World Report on Disability and that was now it is a few year's old, so additional information is provided by the United Nations Flagship Report on Disability and Development that was published at the end of 2018. This addition of data tells us that today only 6 countries have explicit laws that guarantee access to healthcare to people with disabilities.

If we look at the data that the survey has produced, the most recent surveys on access to health that persons with disabilities have been produced, we discovered that 42% of persons with disabilities perceive their health being poor versus only 6% of people without disabilities perceiving their health being poor.

We also know that the percentage of people with disabilities who perceive their health as poor goes up to 80% in countries with the lowest GDP and goes down to 20% in countries with a high GDP.

So this tells us something that is very important when we discuss about access to health and inclusive health, that the income and being rich or being poor and being a person with a disability, the interaction between these two elements highly affects access to health, especially in countries where the universal health coverage is not in practice, and especially where there is not welfare, especially where insurances are needed to access to health and this is a key element because poverty and disability and health are tied together.

The Flagship Report also tells us something, very initial data on gender-specific data on access to health of women with disabilities. But it's very, very limited. In fact, women with disabilities, we are told actually will have unmet needs for healthcare than men without disabilities. And women with intellectual disabilities and those living in rural areas are among

the most disadvantaged.

Now, here I want to take a chance to highlight the importance of this data, but also the lack of gender, age, and disability disaggregated data when it comes to access to health.

In fact, the entire report doesn't offer much more than what I summarize in these slides in relation to gender health and disability, and it's highlighted that the need for disability data is an urgent need because there is in fact several research, several studies on women and health and there are increasing number of data on disability and health, but when it comes to gender and disability and health, the intersection is not explored enough. We are not fully aware of which kind of health needs women with disabilities -- what kind of health needs remain unmet when it comes to women and girls with disability, and this is one of the first barriers that of course we face that when we want to design services that fully meet the needs.

When we talk about women and girls, of course our mind often goes back to the topic of sexual and reproductive health and rights, which is one of the top priorities discussed when it comes to women, and it is important to highlight that when you're a woman with a disability in a developing country, in a situation and living in a situation of poverty, access to sexual and reproductive health is limited, and often women with disabilities who are pregnant have less access to maternal health and services and information, and this obviously can affect the health of the mother and of the child.

But it may surprise you to know that after today, we do not know how many women with disabilities have currently access or are currently accessing the overall services related to maternal health because disaggregated data on disability on maternal health are very rare, and this is just one of the examples that I wanted to bring you to make sure you understand what I mean when I talk about lack of data.

I have to be brief and I could speak more on the situation in different countries and I'm happy to do so if the data we have available can give us some answers, but all of this, of course, somehow clashes with what we define or what WHO has defined as health, that is of course a state of complete physical, mental, and social well-being and when we have limited or no access to health information and services, when we face barriers to access information and services related to health, it's very difficult to ensure a full social, physical, mental, and social well-being.

And this is, you know, it's always important to go back to the original definition when we want to -- when we have an objective that you want to reach, and when we talk about objectives and goals, of course, we can talk endlessly about the SDG 3 and how it is important to achieve SDG 3 and how working on inclusive health and access to health for all, including people with disabilities, will

be important to achieve SDG 3.

This slide, I want to share with you to summarize a little bit the information that I shared with you on the status of people with disabilities in relation to health. It is eye catching because it has numbers instead of words, many more numbers than words, and also because it also gives you or highlights the importance at the very bottom of the slides, of the importance of some of the barriers that people with disabilities face. One of them is physical barriers that need to be removed when it comes to accessing services. Services may be offered by clinics that may not have a ramp and if a person in a wheelchair wants to access those services, they have no opportunity to enter. Services may be offered at a high price that cannot be affordable, but also services can be offered and information can be offered in formats that are not accessible for people who have visual disabilities or hearing disabilities or certified information needs to be delivered when we talk about persons with intellectual and developmental disabilities, and so I share this with you because I think it's good to have it next to you when you are working on health to remind yourself which are the barriers and the difficulties.

This slide doesn't talk about one aspect that is also more than to highlight that is gender-based violence that is of course related to health and goes beyond health, but it's important to bring it into this discussion because not only of gender-based violence that can develop impairments and disability as a result of abuse and maltreatment, but also because gender-based violence is one of those aspects that affects access to health overall.

And as for the cases of access to health information and services, not only people with disabilities are more exposed to gender-based violence as adults and as children, but also have limited access to the basic services related to gender-based violence. And this is an element that also needs to be brought into the discussion when we talk about access to health.

So, the question now is, why? Why the situation is so difficult? Why so many barriers are faced by people with disabilities? It is important to ask why because that is the first step towards finding solutions or to improve the work we are doing when we discuss about access to health.

This list of these points are not, of course, limited and only highlight some of the points that I want to highlight or to discuss with you, but of course there are many others.

However, one of the main reasons why people with disabilities have difficulties in accessing health services and information is of course because at the country level, in many countries, health policies are not disability inclusive, and we know that when disability and inclusion is not fully included and explicitly included in our policies, it's very difficult for the services to

offered and implemented in an inclusive way and that changes in policies is really one of the important steps that we always have to consider when we discuss about access to health.

As I said, services are often not inclusive. What does it mean in reality? It means that the majority of health providers are not trained on disability and inclusion, and this means that they can be -- they can have some attitudinal -- they can become a barrier for people with disabilities to access the services no matter if the service is available -- or even if the service is available in the area where they live.

I'll give you an example. Going back to the sexual and reproductive health issue, many people have been convinced for so many years that as we say, people with disabilities are not subject of sexual rights and they are not sexually active. They cannot get pregnant or have children, or if they do, is it because of a result of violence, because nobody would be attracted by a person with a disability? All of these ideas and create a discriminative attitude towards women and men with disabilities who go and look for sexual and reproductive health information and services and if we do not train our service providers to look at people with disabilities as everybody else, any other customer, any other client, any other patient that is looking for services, the result is that there will be -- the needs of people with disabilities will be ignored, overlooked, or that simply a request for services will be denied, and this is why it's so important to invest in training of health providers around the world, and this can be done in many ways and we can discuss about this later, but in addition to the policy-makers level, the service provision level is the second level a we need to focus our attention on when we discuss about disability and inclusion and access to health; because of course, when health systems are not inclusive, access for health to all is not translated into practice.

We also mention the limited disaggregated data available so far, and if we do not have data, we don't have food for advocacy on disability and health to push our agenda on disability and inclusive health on the policymakers, so the data remains crucial elements that we need to keep in mind.

And we also have to look beyond the work that we do on disability and health, and that people like myself do on disability and inclusive health and look at what, for example, the international NGOs, we call them mainstream international NGOs do to promote access to health for all in an inclusive way.

And if you look closely, you will find out that the majority of the measured global health interventions implemented today by major NGOs are not disability inclusive. Sometimes because of the lack of disability disaggregated data, they do not even know if they are reaching people with disabilities or not. But most of the

cases, because people with disabilities are living in remote areas, they are difficult to reach, they are sometimes not looking for services because it has been frustrating in the past, they are not easily to reach and the result is that they are left behind.

Why this happens? We know there is so much funds for global health right now out there and that global health is one of the key areas where we work, and the lack of major interventions on global health that are inclusive goes hand in hand with the lack of funds fully dedicated to inclusive health when it comes to access to health for persons with disabilities, and I'm saying this because if you look the as an example of how do I explain my statement is that if you look at the major call for proposals that donors put out, that major donors put out regularly on global health, we realized that disability and inclusion are not always -- is not always explicitly mentioned and is not listed among the essential requirements that the implementers of the project include people with disabilities.

So, these are some of the why and are some of the elements that it is important to keep in mind when we discuss access to health and disability inclusion. At the end of the presentation, I will also make sure that I give you a couple of hints and recommendations about how we can work on the whys and step forward to improve a little bit the situation.

This is just a reminder but we already mentioned it, the sustainable development goal number 3 is it with the CRPD and will work hand in hand with mainstream organizations working on global health to achieve Goal Number 3 and how the partnership between the disability-focused actors and global health, the mainstream global health actors, how it's going to make a difference in achieving SDG 3 is something I will discuss towards the end of the presentation.

We mentioned the importance of leaving no one behind and that is linked directly with the SDGs. And as Alessia already mentioned some of the SDGs are referred to specifically on disability and inclusion and more work is increasingly done and the goals on under the rights highlight, are those that highlight the most disability and inclusion, and health is not listed there. However, health can be also, you know, discussed within some of these SDGs listed here but we are still far away when we discuss about SDG 3 to -- we are far away from saying that SDG 3 has a strong component on disability inclusion. We still have to work on that.

Now, I'm looking at the time and we are at 40 minutes more or less from the beginning of the discussion so I will go to a bit in discussing about the, let's say how we can ensure through disability inclusion a better access to health for people with disabilities.

When we talk about disability inclusion or disability inclusive health, we talk about the way we have to follow to ensure or to improve access to health of people with disabilities.

But what does it mean, disability inclusion? What does it mean disability inclusive health? When we talk about disability inclusion and disability inclusive health we talk about, of course, three fundamental principle, participation, equality and non-discrimination, and accessibility.

And I think there are -- I have brought here some words to define more specifically what these three concepts or three principles mean, but I would like to, knowing that equality and non-discrimination are those that are most familiar or that you may be more familiar with, I would like to focus with you on participation and then refer briefly to accessibility that we already discussed about earlier on.

So in relation to participation, what does it mean? Participation means full involvement of boys and girls, women and men of different age groups and with different disabilities in the design, implementation, monitoring, and evaluation of actions and policies that affect people with disabilities.

Not only effect, but it's limiting words, but relate to people with disabilities because if we do not work on participation and full involvement, it means that every action that we, for example, want to put in place in relation to health will not see the opinion, the contribution, the participation of people with disabilities who will be the main beneficiaries, the main users of those services, of those informations. But also it means that when we are going to design an action, no matter if it's a service, a project, a advocacy work, we will not know from firsthand from persons with disabilities what is needed.

This means that the result may be affected in terms of quality, so when we talk about ensure full involvement and participation of people with disabilities, we certainly have organizations that work in a more responsive and effective way because the decision-making process is informed and is fully aware of the perspectives and needs and experiences of people facing the discrimination, facing the barriers, and therefore is really essential.

When we talk about disability, I already mentioned this before, we have to make sure that we identify the barriers that prevent people with disabilities to access information and services related to health. And knowing that barriers can be different according to the context, according to the type of disability, we can talk about a physical barrier like the ramp, or as you say the attitudinal barriers or financial barriers, and then work hand in hand with representatives of people with disabilities and DPOs at the different levels to make sure that those barriers can be addressed and eliminated.

Accessibility is a prerequisite of inclusive health and of ensuring access to health. Now, I will now bring you to look at health, and taking my next step and one of the concluding steps is

to make sure that you also look at health within the bigger picture, and this will help you to identify how or which are the different elements and the different steps that are necessary when we work towards a daily mission of barriers that we just mention and therefore towards an inclusive society that fully allows access to health for all, including people with disabilities.

And of course, when we discuss about health, we can have the mainstream services that are already available, they need to be made accessible, but we also have the importance of what we call the support services, and there are some listed there, and some specific services. The three elements together and the adaptation of what is really available as mainstream services results into the elimination of barriers and towards an inclusive society and knowing that, of course, health is always linked also to all the other elements that we mention really. Without proper transportation, access to health is difficult to obtain. Water and food and sanitation are part of health. Protection is part of our bigger picture of health and we want to keep it right and not to limit it, and also employment, meaning access to having an income, being able to pay for services, it's part of how we go and promote access to health.

So this is just to summarize a little bit, and keep in mind the big picture that within which health is discussed.

And again, in this picture also we see the importance of the continuum of care knowing that not only when we discuss about health we discuss about going to health services because a person is ill, but knowing that health is also prevention, early detection, is information and education, and it's just in a different picture summarizes the same concept by knowing and making sure that the person, in this case the person with disability, is at the center of our analysis when we do the needs assessment, when we do the design, when we do the implementation, and the monitoring and evaluation because this is what will keep the quality of our actions high.

And again, when we talk about quality and quality criteria, this slide also summarizes the elements that we already have mentioned that goes from accessibility to adaptability and participation, technical quality of the services, non-discrimination, I don't need to repeat it, but having access to the slides may be a good summary of what we have said.

I want to show you this because this is also quite essential to make sure that we remember at the end of this presentation which are the key elements that allowed us to have inclusive health as a real practice and which is the flow of informations and actions that we're usually informed of and contribute to.

Because at the bottom we have, at the bottom of this cycle we have, of course, the users as we say, people with disabilities,

vulnerable population, DPOs, disabled persons organizations, they have not only the power to advocate for better services, but also are the participants of all the actions, or are supposed to be the participants of all the actions that inform the work of service providers and that request services and monitoring the quality of those services.

And at the bottom, of course, we also have the service providers who need to be put in the condition of doing their work properly when they come and when we request them to be inclusive, so here we go back to the training that we mentioned before.

And the exchange of information and exchange of with the industry makers at all the levels is the interaction that we always have to monitor when we try to promote inclusive health in the best way possible. None of these elements can be taken out if we want to have a full approach to inclusive health.

And this, of course, summarizes the fact that all of these elements together gives us the power to work on inclusive health in a full and comprehensive way.

I think I am -- I will soon stop talking and I would love to hear about your questions and ideas, but before giving back the floor to you, Alessia, I wanted to give those inputs that I promised at the beginning of the presentation and say that today the number of actors actively promoting inclusive health, disability inclusive health remains limited, it is increasing but remains limited, and DPOs are increasingly working on inclusive health and disability-focused NGOs like humanitarian inclusion is on the frontline on this topic and some UN agencies today are also working on it.

If you think about the We Decide Project of UNFPA is fully focusing on SRH and gender-based violence and sexual reproductive health for women and girls with disabilities is a nice and good example. And some selective donors have also started promoting work on health on family planning and on sexual and reproductive health. I can talk more about this if there are questions related to this.

Of course, IDDC is on the frontline in promoting inclusive health from the advocacy perspective, and I fully contribute to the inclusive Health Task Group as Alessia mentioned, but then of course the members of the IDDC and majority of disability-focused organizations, but then the news is that there are the awareness is also raising also among global health actors, global health mainstream organizations that are now looking at inclusive health with more interest as a result of the commitment to leaving no one behind and the SDG 3.

And the CORE griewp is a platform that also has create the a Disability Inclusive Technical Advisory Group that promotes inclusive health among mainstream organizations working on global

health. And in this I can spend a few minutes on this if some people who are attending the webinar are interested to know more. And looking forward to conclude we said about the lack of gender, age, and disability disaggregated data, in relation to health status and sk toes had health remains more supported and encouraged at the country region and in global level using at least the six questions or the short questionnaire of the Washington Group, and again it is as many of you may already know what the Washington Group is and what the Short Set of Questions is about and I'm happy to talk about it a little bit more during the discussion if this is something that you have not been informed of in the past.

And looking forward at funds, of course, my recommendation is that if we want to improve our work on inclusive health in the global health major actions that are currently taking place, it is important to explicitly promote this in all the calls, in all the actions that donors are promoting today, and no matter if they are private or institutional donors.

I will stop here and I look forward to hear from you and to hear your questions. Thank you.

>> ALESSIA ROGAI: Thank you very much, Alessandra. It really was a really comprehensive illustration of this important topic. Thank you very much. You also introduced so many really crucial elements that it's a pity that our webinar is just one hour because also you started talking about some central concepts to arrive to a practical implementation of some tools, so I think that our participants really, really want to know more about it so I really invite our participants to make your questions in the Chat Box or also raise your hand and take the floor and ask detectively to Alessandra your question. I encourage the participants to raise your hand or your impression or sharing with us some experience that is in your country at country level.

We have already some questions so don't be shy and take the opportunity in this last half hour that we have to have with us Alessandra.

I took some notes about a lot of things that you said or several elements that you shared so I'm not really an expert about the health topic, so also I should have a lot of questions but I would like to leave this time to participants, but I would like to highlight some elements or barriers or needs, like for example the need to overcome from the charity, medical, and social approach to the human rights approach, for example. And another element that really triggered my attention was the lack or just as you said, the lack of -- the intersection between gender, disability, and health is not well explored so the lack of data in that case really affects a lot of some steps forward.

But overall, I think that the slides that you shared, the last slides that you shared about the mainstream services from the theory

to practice and continuing of care and quality of criteria, for us are elements that we really would like to dig deeper.

I know that the time is not allowed and I'm going quickly to read a couple of questions from the Chat Box and I will give you again the floor, Alessandra, to maybe just go through these elements that, that are really triggered our curiosity about the topic.

I start reading a question from Florence that asks, how can we involve government to ensure that persons with disabilities have access to affordable healthcare? NGOs are doing a lot, but the government seems not to be really concerned. I think that Florence raises an important element, in how really we can work in concert with NGOs with government supported by OPDs and persons with disabilities to reach these important goals of access to health. Thanks, Alessandra, to reply.

>> ALESSANDRA ARESU: Thank you, so of course when we talk about working with governments, we talk about the importance of first of all informing the policymakers. That is our first step. Collecting data is -- that's why collecting data is so essential.

So if you -- when we talk about governments, of course we can talk about local government, we can talk about the country governments, we can talk about policymakers that have the power to change things, so but the very first step is to inform them because we cannot assume that they know what people with disabilities are facing every day when it comes to access to health.

The reason we cannot assume they know is because the majority of people who are working today as policymakers that have the power are not people with disabilities, and the representation of people with disabilities at the government level in most of the countries in the world is very low together in some countries.

And so again, as we worked -- I would make a parallel between gender and disability just because it's so important and because we really need to bring that together as you say, Alessia, to build on the experience of already as we have promoted gender within or with the different governments and quite successfully in many countries and to make sure that women and girls are considered in the work that the governments do, the same comes with disability.

So, keep in mind that they may not know and we need to inform them. This is the first step, and doing advocacy is the very, very first step. And DPOs in this case are the driving force for advocacy at the country level because they focus on people with disabilities, because they can be part of each project that collects those days and present those data to the government. That is certainly the first steps.

Of course, then there are opportunities that go beyond the local action that we can do at a country level and is, for example, the opportunity to attend major events where policymakers are present and need to hear our loud voice, and for example, the meeting

we call it -- the meeting that every year takes place in New York in June that goes to or discusses the achievements at the country level, at the global level, in promoting the Convention on the Rights of Persons with Disabilities is one of those.

If we have the opportunity to promote the persons with disabilities at the country level to participate to these events and speak out in front of policymakers about what they need and about what is important when it comes to access to health, that is also an essential step.

I'm saying this because, in fact, this is in theory but very difficult in practice because disabled persons organizations lack funds to not only do the project at the country level and to collect the data, but also to travel, to go to advocacy events, to have their voice heard.

At the same time, we need to support the capacity and build the capacity of persons with disabilities at the country level and the DPOs to make sure that they become the driving force.

Can you say this from the advocacy perspective? We also know that most of the major funds that come to global health projects are funds that require the collaboration between international NGOs and local governments and the Minister of Health, for example, when it comes to global health.

When we ensure that the calls out by donors are disability inclusive and the disability is mentioned, we not only put pressure on the international NGOs to work in a disability-inclusive way but also on the government that becomes the partner of the ministry of Health that is part of that project and it's another channel, another way to make sure that funds are channeled through this project for the service provides' training and for the health systems strengthening that needs to be disability inclusive. Because there is a lot these days done on health system strengthening to make sure that we all have the opportunity to have better health systems in countries, for universal health coverage achievement, but if we miss the opportunity to take disability into the picture when these strengthening actions are taking place, then that opportunity is really mixed and it — that's why we have to work from different directions and in different ways.

>> ALESSIA ROGAI: Thank you very much, Alessandra. I have several questionings about data and also on how to measure, I think step forward on inclusion of persons with disabilities.

One asks regarding the discussion, we have suggestion for standard outcome indicators that mainstream organizations should use in inclusive project, but also one asks, how we can measure the accessibility to inclusive health rights?

So I think on the basis of this question, but also of this work, there is always in my understanding, the same issues with the lack of data and the lack of intersection about disability and health

data.

Thank you, Alessandra, to give us your point of view about it.

>> ALESSANDRA ARESU: Yes, thank you for the question, and creating indicators that can be used is part of the process of promoting inclusive health because as you mentioned, data disaggregation and collection specifically on disability and health are limited, or is limited, and little work has been done so far to really create proper indicators that serve this purpose.

So going back to the idea that I mentioned on partnership earlier on, that so much work has been done on global health and indicators to monitor and to measure the quality of services and the quality of work done on global health, that the experience of the global health is huge, of the global health actors is huge. However, they lack the experience of working in a field of disability. On the other hand, the work done on disability is also extremely, extremely relevant.

However, so for so reasons, measuring access to health for people with disabilities has never been a focus that has been pushed when it comes to indicators.

So the answer I could give and the direction that I would recommend is to work in partnership to put together the capacity and the strength of both fields to finally translate into practice what we mean with disability inclusive health. And this is something that really needs to be encouraged and that, for example, in my work, I'm involved daily.

And of course when it comes to data and to indicators and to the collection of data, it's essential but the distribution, the sharing of the data then is also an essential point which are the areas where we can and the context where the data needs to be shared.

But I'm happy to further discuss this maybe also beyond this webinar on working indicators for health and disability because this is really a crucial point.

>> ALESSIA ROGAI: Thank you. Thank you very much, Alessandra. I have a question from a participant. I really don't understand your question, if you want you can take and raise your hand and take the floor and just explain better your thoughts about it.

I'm going ahead with a question again from another participate and and I think it's curiosity of everybody if you really in the last 10 minutes that we have, if you can share really some successful experience in the facility of the health and some experience also from my side, I would like also to ask how to really improve the exchange of information and really putting in connection all the key actors to improve on it. Thank you very much, Alessandra.

>> ALESSANDRA ARESU: Thank you for this question, and I'm happy to share -- so having saying that work on inclusive health

is promoted, but we don't have a long history of monitoring and accessing the results of it.

I choose to answer to you and am am sharing with you an experience I'm fully involved in that is a promising experience when it comes to inclusive health.

One of the major donors that today is promoting inclusive health more than others, as many of you may be aware is DIFD and they have launched many calls to launch it around the world and one of them was a global call of women integrated sexual health.

It is a call that came out two years ago and that now finally sees the implementers of the project have been receiving fees funds are really in the process of put together forces to make sure that global health action is an inclusive health action. This is the example, and HI is part of it so I'm able to talk from experience.

The request, the objective is to improve sexual and reproductive health of the overall population and the most difficult to reach around the world. The project I'm involved in is covering seven countries. I know that some colleagues from Ethiopia may be on the line and Ethiopia is one of the countries where the women integrated sexual health program is going to be implemented.

And this program is an example of how mainstream organizations and disability-focused organizations and DPOs join forces to ensure that this global action on sexual and reproductive health of many millions of pounds will be disability inclusive.

Three different mainstream NGOs are working regularly on sexual and reproductive health and HI have joined forces specifically to ensure the inclusiveness of this project and they will work in the following way.

HI will be the technical partner that will ensure inclusiveness, on the one hand by training our mainstream partners of what disability and inclusion means because they need to be fully aware, but also we'll be working with the DPOs, the disability persons organizations at the community level, to raise the awareness of the community — of the public at the community level for — to share and to make sure that people know that people with disabilities are subjects of sexual rights as everybody else, and also to create a demand for sexual and reproductive health services that has been frustrated for so long so much that people with disabilities stopped to go to clinics in many countries.

Also, we work at the community level to collect those data that are important to identify the needs of people with disabilities, and those needs will be based to design and implement the project.

HI is also the technical partner that -- that supports the service providers and trains the service providers to make sure they are aware of which are the barriers of the services and which is the way to follow to make sure that the services become disability

inclusive and support the entire action throughout the project.

And support the advocacy process to make sure that those information that we have collected at the community level, that those information that we have collected at the service provision level when the project is implemented and the services are offered, can become an important part for advocacy with the policymakers, so this is really translated into the language of SRH, the example of how global health action, that is a classic global health action on SRH can be fully translated into SRH.

The project has not started yet. It's starting now. It will be at least a four-year program that will, as I said, we'll cover seven countries and we are -- I would be happy to update those who are interested in the progress of the program to make sure that we can -- and of course lessons learned will be collected and shared so that more can be learned from this experience because we are far away from knowing what workings and what doesn't work, and so we are exposed to opportunities for learning but also risk of, you know, facing challenges that need to be addressed.

>> ALESSIA ROGAI: Thank you very much, Alessandra. I would like to give the floor really quickly to a participant to explain the question about whether or not training services and sign language with interpreters, so really a specific question. I open you the mic if you want to talk now you can. Thank you.

>> AUDIENCE MEMBER: Thank you so much, Alessandra, for the excellent presentation. My name is Malak from Ethiopia. Inclusive health services is also one of our priorities. Mostly when we implement programs we see differences, like competing arguments, one on the service providers where people say training service providers in sign language would breed the communication gap between deaf clients and the service providers.

On the other side, people say no, since this is a very sensitive thing and we don't have to compromise the level of communication, so we have to hire sign language interpreters. Is there any literature, is there any experience, you know, which would resolve this two competing arguments globally? Thank you so much.

>> ALESSANDRA ARESU: Thank you very much. Thank you for your question. If there is literature available, I'm not at the moment aware of how to, you know, what is the literature promoting, but I can certainly have a look and maybe we can exchange on this topic, and I could also ask among the other colleagues who have been involved on this topic to see if we could find a good answer.

But you certainly touch upon a very important topic that is how to guarantee for people with disabilities, in this case people with hearing disabilities, the privacy and independence of when they go and access and ask for services.

And it is one of those elements that comes with the respect and dignity for the person with disability, but also to make sure

they can be independent because just to extend a little bit your question and to share something that may be relevant for everybody, sometimes we see people with hearing impairments arriving at the services accompanied by a family member, but we cannot assume that the person can always be fully protected in the rights to access health by being accompanied by a family member, and sometimes family members are very protective, and sometimes their decision is instead to place of the person with disabilities thinking that they are doing it in the best of interest of the person with disabilities, but in reality, by creating filters and barriers, we create -- we limit the autonomy and full independence of persons with disabilities when it comes to access to health.

So I did say that I can look into the literature to better answer your question, but I would say that the core element here is to make sure that the best of service is guaranteed for the person herself or himself.

>> ALESSIA ROGAI: Thank you very much, Alessandra. Unfortunately, I have to say we arrive at the end of this session. I don't know for the others, but for me really the time fly a lot because it was really interesting with a lot of really important elements that I think we shared today for this topic.

So thank you very much again, Alessandra, for your participation and contribution and for having dedicated your time to us to Bridging the Gap today. I also would like to say thanks to all the audience, to all of our participants that really follow us constantly. I really hope that you find also this session useful for your work.

So, as you know, the webinar cycle is composed by 12 sessions, so we have just the last three session, one on advocacy and programs at the local level, another about women and civility, and the last one social protection and livelihoods. We will provide the last three sessions after the summer break, so it means that September, October, and November of 2019.

Welcome back to you soon with further information about these last three sessions with dates and times, but so for the moment, again, thank you very much to everybody, to all of our followers, and to Alessandra for your contribution and to share your experience with us.

Don't stop following us to our audience but also to Alessandra and to all of the experts that we are involving in our action, so thanks again to everybody, enjoy the rest of the day and for whom are going to have holidays and also Easter break and thank you Alessandra again, thank you everybody.

>> ALESSANDRA ARESU: Thank you all. Thank you, Alessia. (session completed at 9:59 a.m. CST)

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