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“From Words to Practice”

GC-DI Thematic workshops on the Guidelines on deinstitutionalisation, including in Emergencies (March - December 2024)

Session No. 2:

Equal Rights, Diverse Needs:

Protections for children and women with disabilities and other high-risks groups under the UN Guidelines on deinstitutionalization, including in emergencies.

DRAGANA: Warm welcome to everyone, we are starting our webinar now. My name is Dragana Ciric and I am from Disability Rights International. Welcome to you all and I'll just run through some basic information that may help your accessibility requirements. *[recording in progress]*

So, first I want to welcome you all to our second webinar from the series "From Words to Practice", which is titled Equal Rights, Diverse Needs, Protection for Children and Women with Disabilities and Other High-risk Groups Under the UN Guidelines On Deinstitutionalisation, Including In Emergencies.

If you need interpretation we, the webinar is available in English, Spanish, and Ukrainian. There is a button at the black bar at the bottom, there are a lot of buttons options so one with the globe and the word 'interpretation' underneath is it the one you need to choose. You can click on this and see options of languages and choose the language you need. We also have International Sign Language interpretation, it says American Sign Language because there was no other option so this is International Sign Language interpretation. For closed captioning, there is the Zoom button to start

viewing the captions. I will now copy in the chat external link for captioning if people want to access captioning text in full, so just allow me to do that here. So the captions will be available on this external link now that is posted in the chat, that should be available for everyone to see.

If you want to ask a question, there are two-ways to ask a question. The best way is to write your question in the Q&A box when you think of the question, and we can either answer it right away, if some there are some running issues or wait until our Q&A session. Can also ask a question in the chat box there will be some polls at the end of the webinar in the Q&A section, and to participate in the poll, read the questions and the options provided, choose the option you agree with most or type in your answer. If says multiple choice then it's possible to choose more options, and after a short time the results may show on your screen for questions and these results will be anonymous. Some accessibility tips, please say your name and organisation when you speak. Keep your point as short and as clear as you can. Use plain language, please no jargon. Be respectful of one another's time. Keep your microphone muted so there is no background noise, and please do not use acronyms.

I think we can now start. Without further ado I would like to introduce, Executive Director, Eric Rosenthal who will be moderating the webinar, Eric please start your camera and microphone.

ERIC ROSENTHAL: I would like to ask the moderator to allow me to use my video I am unable to turn on my video.

DRAGANA: I will just ...

ERIC ROSENTHAL: Hello, this is Eric Rosenthal, I am the Director of Disability Rights International and it's a great pleasure to welcome you to the webinar. We are acting today on behalf of a broad coalition, the Global Coalition on Deinstitutionalisation. After 20, 30 years in the disability movement, to be able to work in a global coalition is

extremely important. We not only have the strength of numbers that the disability community can speak with a unified and diverse voice, with organisations throughout the world and organisations representing the diverse opinions and experiences of people with different disabilities. We have moved beyond the days when one token person with a disability can be added to a global committee and expected to represent all people with disabilities. So we act in strength, we act in diversity, we bring to you one of the products of our global collaboration, and that is the UN Guidelines On Deinstitutionalisation which this coalition helped draft, along with the United Nations Committee on the Rights of Persons with Disabilities, and based on regional consultations with people with disabilities around the world. If there is one core idea behind the UN Guidelines on Deinstitutionalisation, is that people in institutions matter. That they have human rights. And that it is no longer acceptable simply to assume that if we work and commit ourselves to creating more inclusive societies, that building the disability rights community and improving services in the community is enough. If you have a limited box of resources you may make the decision that you want to spend them to protect families in the community, so they don't have to put their kids in institutions. But the human rights principles that all human beings are important, and have rights, and are precious, requires us to look beyond what that small box of resources may say. And what we have found is that we cannot assume that institutions will simply disappear by creating inclusive societies. And that horrible, atrocious, life-threatening abuses continue to take place, these are not safe spaces. They are inherently dangerous. My organisation, Disability Rights International, has gone into institutions and orphanages, throughout the world and every continent. Our findings which have been confirmed by our partners in every part of the world is that institutions are inherently dangerous for children, sexual abuse, denial of parental rights for women, so we focus especially on children and women with disabilities today. More important that we challenge the idea that one could simply assume that in a war, in emergency, in working long -- development, those people in the institutions are safe while we work on the long-term prospect of inclusive societies. No. The UN Guidelines adopted by the Disability Convention, say, and perhaps the most important word in the UN Guidelines is the word 'accelerate'.

Where's there's an emergency it's not that you assume let's put people in institutions and assume they will be ok, you must accelerate efforts to reintegrate children with their families, to ensure that people are safe. Our experience derives from the global pandemic where institutions were Ground Zero for the death that was brought, the isolation that was brought by the pandemic. My organisation works in Ukraine and while a war is going on, international aid goes to the communities, goes to the soldiers, the people fighting and what is happening? Our reports have shown that the people in the institutions are abandoned, and the global community talks about creating a more inclusive society, they are resources, they are magnets for resources, excuse me, more money is being put into these institutions and these are being rebuilt as we talk about community integration. The UN Guidelines On Deinstitutionalisation take a strong stand against rebuilding institutions. And more importantly, they draw on the lessons learned of the disability community that an institution is not just a big old crumbling facility, that nice, clean, new small institutions are also institutions. Group homes are institutions. For children, any place that they are not with their family, with emotionally committed caregivers they are at high-risk of violence, schedule violence, abuse, exploitation, that these institutions create increased impairments and disability, so when we speak institutions we talk about institutions large and small. We're now going to learn from our amazing panellists about what are the obligations under international law, and what in concrete ways can we do to protect people. We have an amazing panel, and to save time and ensure they have time to talk, the introductions and bios are in the chat at the bottom of the screen. We have representatives of the Committee on the Rights of Persons with Disabilities, a former member of the UN Committee on the Rights of the Child, a current member of the UN CEDAW Committee on the Rights of Women who was also a member of the CRPD Committee, we have the best of the international law and policy representatives, and we also will hear from victims of abuse, people who grew up institutions, and it is important that the UN guidelines don't simply say, close the doors of institutions and dump people on the streets. We will hear from an abuse survivor, from Mexico, about what it meant when they opened the doors after they found abuse. People need support to reintegrate into the community. Indeed they have up right to reparations

from the abusers and torture they have experienced and all too often countries simply wash their hands, they say sorry there was abuse we're opening the doors. And the UN Guidelines On Deinstitutionalisation provide valuable insight and direction as to what should be done both to provide reparations and the support that anyone needs to reintegrate into the community after years of segregation. We'll hear from Kenya, from Milanoi who worked with the International Federation of the Red Cross, we will hear from Anastasiia from Ukraine who is on the board of our affiliate in Ukraine with people with disabilities, working to end institutionalisation to protect families and children with disabilities within institutions. Without further ado let's plunge into these, we have got time for discussion at end, very limited time, put your questions in the bottom, we'll do our best to get to them, we hope this is a beginning of an important dialogue, and a greater recognition of the this valuable, valuable instrument, the UN Guidelines On Deinstitutionalisation, our collective wisdom about how to protect people institutions and ensure that they are provided the support needed to get them out of these dangerous places and into the community. Our first speaker today Rosemary Kayess, Vice-Chair of the Committee on the Rights of Persons with Disabilities, due to the time change, and lack of support, has sent recorded remarks and so we will start by listening to her remarks. And then continue with Ana Peláez from CEDAW committee. Can we roll that. *[video playing]*

[no sound].

ERIC ROSENTHAL: There's no sound.

ROSEMARY KAYESS: Thank you for the opportunity to participate in this webinar. The guidelines on deinstitutionalisation including in emergencies, is an important document for State Parties in meeting their obligations under the UN Convention on the Rights of Persons with Disabilities, the CRPD. Segregation and the denial of autonomy are inherent to the nature of institutions. Institutions deny the autonomy to choose where and with whom to live. Deny autonomy in daily decision-making and isolate and segregate people with disabilities from the communities. United Nations Committee on

the Rights of Persons with Disabilities has consistently observed that State Parties do not appear to understand that deinstitutionalisation is critical to meet the obligation under the CRPD. Particularly Article 19 living independently and being included in the community. Article 19 is about ending the segregation and loss of autonomy of people with disabilities, it's about individual choice, security, and being a participating member of the community on an equal basis with others. The segregation of people with disabilities through institutional residential arrangements of all kinds it's a prima facie form of discrimination, which is prohibited under Article 5 of the CRPD. And is a long-established principle under international law.

Many State Parties do accept that institutions are not consistent with human rights standards, but often understand this in the context of large-scale residential institutions, rather than smaller group homes, psychiatric institutions, or forced confinement in family homes. There are often views presented to the Committee that qualify people's ability to live in the community or in non-institutional settings, and a rejection of unqualified guarantees that people with disabilities should not be forced to live institutions, or any other living arrangements.

Although the Committee had already elaborated on State Party obligations in General Comment No 5 on Article 19, and had developed guidelines on Article 14 on the right to liberty and security of the person, it was and remains evident to the Committee that the deinstitutionalisation continues to be a complex and challenging reform area for State Parties. This became even more apparent during the COVID-19 pandemic which starkly highlighted the discrimination and inequalities of people with disabilities institutions. This was the catalyst for the Committee deciding to develop the guidelines on deinstitutionalisation including in emergencies. The guidelines on deinstitutionalisation outline critical steps for the practical implementation of Article 19, noting that deinstitutionalisation requires significant co-ordinated and multi-sectoral change across all levels of Government, in order to affect legislative and cultural change to transform society.

Chapter 4 of the Guidelines, emphasises the need for an intersectional approach to tackling the discrimination, segregation and isolation, loss of autonomy and other forms of ill-treatment that lies at the heart of institutionalisation. People with disabilities are not a homogenous group and do not experience discrimination and inequality in the same ways.

We have diverse personal identities and characteristics that shape our experiences, our lives, decision, where we want to live and whom we want to live with. It is critical that an intersectional approach is embedded in deinstitutionalisation processes, so that our right to live independently and be included in the community is respected and upheld. Intersectionality and intersectional discrimination are concepts that are embedded within the CRPD. All the rights campaigned in the CRPD need to be understood and implement in ways that respect and respond to the multidimensional layers of identities, statuses and life realities for people with disabilities. In Chapter 4 the guidelines specifically acknowledge the multiple discriminations experienced by women and girls with disabilities, the heightened risk of violence, exploitation and abuse. The greater denial of rights to exercise legal capacity, to access justice and to make choices. The guidelines also highlight the need for protection of children and adolescents with disabilities, to their right to grow up in a family. The need for support as early as possible for children with disabilities and their families. For protection from the removal of children from their parents on the basis of disability of either the child, or the parents. And the right for children with disabilities to be able to express their will and preferences and to have their views given due weight on an equal basis with other children.

Chapter 4 of the guidelines acknowledges older persons with disabilities, including those with dementia who are at greater risk of institutionalisation and need access to support and services in the community in their own homes. While the guidelines highlight women and girls with disabilities, children and adolescents with disabilities, and older persons with disabilities, the CRPD recognises intersectionality broadly. This means that deinstitutionalisation processes need to take an intersectional approach

that also recognises the broad diversity of people with disabilities in including in relation to sex, age, race, ethnic origin, indigeneity, and LGBTIQ+ status.

Intersectionality needs to be considered throughout all aspects of deinstitutionalisation processes, including planning, implementing and monitoring closures of institutions. In designing accessible housing and community support systems, and inclusive mainstream services, and in consultation processes and mechanisms. Deinstitutionalisation processes need to be underpinned by the CRPD to ensure that human dignity and the diversity of people with disabilities is respected, protected, and fulfilled. Thank you. Unfortunately I am unable to participate in this and the report of the discussions due to the time differences with Australia but I look forward to hearing about the outcomes of this important webinar.

ERIC ROSENTHAL: Thank you for that wonderful presentation and Rosemary the members of the CRPD Committee are a great resource that we can always go back to. And speaking of great resources, I am so pleased now to introduce Ana Peláez from Spain, Chair of the United Nations Committee on Elimination of Discrimination Against Women. Ana?

ANA PELÁEZ NARVÁEZ: Hola, hello, can you see me well? Thank you very much, I would like to present my intervention in Spanish. Well first of all I would like to say that for me it's an honour to be able to participate in this webinar. I truly would like to thank Disability Rights International for their invitation. It's a particular pleasure to be able to do this along with colleagues whom I greatly admire and I highly recognise and with whom a great friendship joins me just as the case of Rosemary Kayess and Jorge Cardona. Talking about women -

DRAGANA: Can you just move your camera so we can see your face? Perfect thank you.

ANA PELÁEZ NARVÁEZ: Thank you, so sorry about that. As I was saying, talking about women and children with disabilities is not talking when we are targeting people with

disabilities about just one group of our population, it's talking about 60% of people with disabilities. What this means is that of every five people with disabilities, three are women. That information, if we extrapolate it to the general information of women it's less of course, but it's still remains very high. 20% of women around the world live with some type of disability. This means that one out of every five women. As Rosemary has already mentioned during her intervention, Paragraph 42 of those guidelines of the CRPD committee out of which I truly would like to express my deep congratulations, this Paragraph 42 presents specifically the situation of women and girls with disabilities, within the environment of institutionalisation and in a way allows us to see what would be needed for them if we needed to look at the process of deinstitutionalisation.

For me, however, I would now like to highlight some issues that are sometimes nameless. We actually only have one paragraph within the guidelines that looks specifically at the situation of this population that in broad terms can go up to 800 million of women and girls with disabilities around the world. Only one paragraph look at this specific situation, within this guidelines. So I believe it is essential also to put a focus on other points that really inconvenience. I also talk about the fact with independence of course that these guidelines will be inspiring and important for what would be the deinstitutionalisation processes, I consider it to be important for them to work as a foundation so that the work also performs on this regards for the global movement for the deinstitutionalisation can work as a basis for preventing the institutionalisation and for taking care of people who remain within a situation of institutionalisation and in this case I am going to be talking about women and girls with disabilities, and of course also to make reference to the deinstitutionalisation, but as I said prevention and attention of those who are already institutionalised I believe is essential.

We have observed that the main idea that we can get of Paragraph 42 of this guidelines is the risk such an elevated and exacerbated risk that women and girls with disabilities suffer of being violent, exploited or abused within the framework of these

institutions. But let's start really looking at how we get to this situation, what type of situation would be necessary to keep into consideration for the prevention of institutionalisation of women and girls, because at the end of the day, when we give whatever little data available we have we will see there's a great number, far above boys and men of women and girls who are institutionalised. That's why I say it's also very important to put a focus on the prevention of that institutionalisation in the first place. In that prevention we need to take into consideration the greatest risk that specifically girls have and women with disabilities of being abandoned. Because of stereotypes of course that are known, but also because of lower value that is given to the life of these women, of these girls who are abandoned also as a consequences of for example the dissolution of a family or violent situations. There is a lack of security that is aggravated in the case of girls with disabilities, or perhaps there's a level of scholarship only in specific special schools, and this circumstances is well scholarised, even if they do it in schools at the end of the day, they are still going to be able to transport into greater risk in order to be institutionalised. Now when we -

ERIC ROSENTHAL: Ana, we have lost your camera again, could we adjust your camera so we can see your face?

ANA PELÁEZ NARVÁEZ: Listen, unfortunately am blind, I cannot control I am so sorry about that. For me the most important is also my message.

ERIC ROSENTHAL: Your message is very important, so we will listen thank you.

ANA PELÁEZ NARVÁEZ: I am so sorry for the image because I cannot control the result of the camera. Thank you so much. So as I was saying, the lack of scholarship of girls is going to be linked to the performance of domestic tasks in the family environment. And when it's not this way, I must also say that the transition of girls who have been for example in special education schools later on in their adult life, this is usually related perhaps if not with domestic work round the house, with the permanence in occupation centres. Being a victim of violence and abuse particularly within their home is one of

causes or gives origin to institutionalisation. Once this station is detected, especially in the face of accessibility and inclusion of specialised programmes and services to take care of victims of gender violence or victims of human trafficking, the solutions that many cases find for the states is to offer some sort of institution to these women and girls that have been violence against, in order to ensure their security. There's really this type of important family dependency of a lot of women with disabilities, when their parents die, specifically their mums, are left on their own and left out of their own homes. And there are continuously a derivation or a result and we can observe this in countries in the European Union, we see this a lot and I don't know if it also happens in other places round the world, but there is a result or an outcome of services when a woman is victim of violence or human trafficking that they get disability as a consequences of those mistreatments and then being sent to an institutions for disability is sometimes the sole response that the states can provide. So what issues must we take into consideration throughout deinstitutionalisation -

ERIC ROSENTHAL: Ana could you begin to wind up for us, thank you just one more minute.

ANA PELÁEZ NARVÁEZ: Ok. Shall I go?

ERIC ROSENTHAL: Yes you have one more minute thank you.

ANA PELÁEZ NARVÁEZ: All right, I don't know if I am going to have time in one minute but as I was saying things to take into consideration during deinstitutionalisation, well some of the main points I believe is the fact for example that a lot of women are victims of gender violence and sexual abuse. Because they come from an event that either caused them or because the institution itself is producing them, and these women and these girls that have served this violence are unfortunately left without any type of protection in this very same institutions. Aside from all of these things, the lack of attention to their sexual and reproductive health throughout their life within these institutions, the lack of respect to their private life and dignity also with regards

to their personal life is another aspect that must also be developed.

ERIC ROSENTHAL: Thank you Ana, thank you I am very sorry to have to cut you off but we appreciate your message and have learned a lot. And very glad to continue this discussion with you as a wonderful, wonderful resource in the area. Our next speaker is Jorge Cardona, a Professor of Public International Law and a former member of the UN Convention on the Rights of the Child who has always being a great voice and ally of the disability community. Thank you Jorge.

JORGE CARDONA: Thank you. Good morning, thank you for inviting me to participate in this event. I will be speaking in Spanish also. My intervention, I am going to be dividing it into four quick blocks. The first one is going to be facts, second one is going to be the causes for those facts, the underlying facts or causes, and the third how to view this from the perspective of human rights, and fourth what you do.

The facts are very simple. There are so many, so many thousands, so many tens and hundreds of thousands of girls and boys that are institutionalised, and among them the proportion of boys and girls with disabilities is higher than the proportion of the general population. That's a fact. The guidelines, the excellent guidelines that have been approved by the Human Rights Council has no paragraph for girls and boys with disabilities, it only contains 9 paragraphs and they point out you know the importance and the severity of this. The second point I would like to touch upon is why, what are the underlying cause causes for this reality, well there are many causes, but looking either the underlying causes within benevolent, well-intentioned perspective, we could perhaps say that in the first place the existence of an adult-centric stereotype based on a tutelage perspective that takes into consideration that children should be protected by creating a protection system consistent in creating institutions to provide roof and food to children who lack this family environment, or whose environment is dangerous for any child.

Having these stereotypes that is adult centric of tutelage will also evolve in

something that is more regarding capabilities that is the best way to protect a child with disabilities is to institutionalise him or her in order for him or her to be with their peers and separated from all others. If that's the benevolent perspective we could also have malevolent perspective, and behind many of these so-called protection centres we have companies we have business that are looking for an economic profitability to investments now those causes and effects, how do you fit with the human rights model. The centre of the human rights model for childhood in general with and without any disabilities, get their support in a main principle. The principle of the best interest for the child. And what is this principle regarding this causes and affects tells us, the first thing it tells us is that children do not need any protection, children don't need to be protected, what needs to be protected are their rights. If the rights are being protected, then they are protected.

Just like the Committee for Children's Rights has pointed out in Paragraph 4 done in the general interests of the child is not what I or many other persons would consider to be in the best interests of the child, but simply the respect of the grouping of his/her rights and the holistic development. Meaning their physical, mental development, their spiritual and moral development, psychological and social development. That is this higher interest. And within this framework all studies showcase that the best and natural environment for the plain and harmonious development of the capabilities and environment of a child is to grow within a family, surrounded by family in an environment as a UN Convention on the Rights of the Child states, is surrounded by love, happiness and understanding. If this is necessary for any child, it's even more so for a child with disabilities. All children need family support for their development but a child with disabilities requires even more so of this support. On the other hand, all child that have been institutionalised whether they have a disability or not, see their rights [inaudible] Rosemary really explained that correctly one child with disability, his or her rights, even more so violated the probabilities of developing some sort of deficiency or to worsen the existing ones are increased with institutionalisation. To finish up how can we change these facts, how can we start implementing the perspective of human rights? Well on the first place, we need to prevent

institutionalisation, this means specifically and understand other causes, from the first place the need for supporting the biological family in order to avoid the separation. As it has been stated by the Committee of Children as well as the one of the committee for people with disabilities, together, the disabilities or the poverty should never be a cause for separating a child from their family. They should be the cause for providing support, not for separate children from their own families. When it's not possible to avoid the separation or the family no longer exists, we must look for an alternative family. A second family or an alternative family whom we ought to provide the necessary support for them to execute these efforts and it's always possible working also with the biological family in order to achieve the safe return of the child to their biological family. In the third place accepting that all models of families are valid so long as they allow a good relation in a loving environment. It might be a straight family, a homosexual family, a mono parental family or trying at all cost to stop multiple types of harassment and forming those professionals that work a with first child particularly family judges and professionals within the protection system, in order for them to understand the importance of preventing these separation and it's one thing to prevent, but second place we need to deinstitutionalisation and how can we deinstitutionalisation a great number of boys and girls who are institutionalised and boys and girls with disabilities. In the first place we individualised, customisable, or personalised plans. There are no two same child, there's not just one childhood, not one childhood with disabilities. But there are several different types of different childhoods this is where the need and the importance of this personalised plan. In second place -- and don't worry Eric, I am about to be done -- look for the right family for every single child, and not the right child for the family. This is why we need to start looking for that right family. On the third place always listening to the child and taking into consideration his or her opinion, regarding their age and development by facilitating them with opportunities to state who and where to live, but this can never be done by the institution. Prioritising boys and girls with any disabilities for the deinstitutionalisation because they are the ones that are institutionalised the most and lastly as Rosemary explained so well, with an intersectional perspective, understanding the holistic perspective of every single child, boy or girl. This is something that the

same standards that have been approved the guidelines that have been approved lead us to and we need to continue analysing them. Thank you so much.

ERIC ROSENTHAL: Thank you very much Jorge, you have squeezed an enormous amount of wisdom into very few words, we are grateful for your message. Our next speaker, we're truly honoured to hear from, Eduardo Verduzco who is a survivor of a terribly abusive institution in Mexico known as Mama Rosa. Where terrible abuse as we were exposed, unfortunately many survivors were given little support by the state. This is another era where the UN guidelines need to be enforced, support for safe transition to the community. But we hear directly now from the words of a truly heroic activist and survivor, Eduardo thank you.

EDUARDO VERDUZCO: Good morning everyone, my name is Eduardo Verduzco, I am a victim of La Gran Familia. For many different locations I was deprived of my freedom for 6 years, they gave me food that was spoiled, I was living in inhumane condition. This orphanage was directed by Rosa del Carmen Verduzco, also known as Mama Rosa. In this refuge they had thousands of teenagers, people with disabilities, and also grown-ups that had been detained. One child was left blind in this institution because of the violence that he underwent. We normalise the violence we underwent, that we live in this place so much that at the end of the day nothing that happened would continue to scare us. Mama Rosa would receive Government support, even from ex-Presidents of the country as well as other international organisms. However, she had us living in filth. In over 50 years that this place operated nobody had been able to leave. In 2014 after a police operation, once we were rescued from this refuge, the other 520 victims who had been deprived of their freedom in this place, the Executive Commission of Attention to Victims left us adrift. Giving us simply a faked birth certificate and locking me down in a psychiatric facility in Mexico City. From November to December 2014, after I left the psychiatric institutions they told me that no institution was going to take charge of me and these threw me out on to the streets. After that, I was living in different annexes and working in cleaning companies. My wage was minimum, I was not even able to cash my cheques because I wasn't an

existing member of the country. One of my works was in the now extinct District Office of The Republic, but in 2017 a friend of mine also a victim of the big family, [name], killed himself by hanging. I was the one who found him hanging. I unhanged him, and I tried to give him air but it was too late. The personal of the Executive Commission for Attention to Victims got there and they told me that they had a place to put him to rest. That's where I realised that a general law for victims existed and it's the victims that were supposed to receive psychological support, medical support, help, and that we had the right to a holistic reparation for damages. Ever since 2017 with the help of a private lawyers' department, I was able to start looking for a just reparation of damages and to fight for my colleagues and myself, to be able to receive this support. So I would go and I would close institutions by simply standing there and this was how in 2019, the Director of Legal Business set up in that moment sends me to jail because I was looking for justice. I was able to leave this because there was really no crime to follow. Out of those who I know and people I met from La Gran Familia at least 20 of them have killed themselves. This year, will be 10 years since they closed this place and the victims of La Gran Familia we continue looking for a holistic repair of all these damages, without any further victimisation that the victims who unfortunately killed themselves over the past 10 years are not forgotten, that those responsible for the damages are not left unpunished. In the case for me personal reparation, they wanted first to give me round \$600 because of the sexual abuse. \$600 for psychological damage. As well that throughout the process, I was revictimised again and again. So in my case I continue fighting for a fair conciliation, because the amount that they stipulate is not enough for healing years and years of abuse. Also, my repair would set, I wanted a public apology, a memorial for victims in order to avoid any repetition of the cases to La Gran Familia case part of my work do is support more victims. Today I have been able to support over 10 in order for them to accomplish a successful reintegration to society and to get money to repair the damage that is fair. Just to conclude I would have liked this place to have never existed perhaps my life would have been different. Today I have a better present. But the wounds they are still there and despite the fact now I have received psychological treatment and help and psychiatric help it's very difficult to overcome this victimising

attitude. I want to highlight that mental health is very important and mental diseases and illnesses are also a form of disability. Lastly, in 2022 I published my first book, called 'The Story of Eduardo Verduzco' where I tell my personal story living in this refuge, La Gran Familia, I am a composer, writer, activist, independent singer, conference speaker, and activist and personally I have also been an entrepreneur. Thank you that's it.

ERIC ROSENTHAL: Eduardo, we thank you for your very moving words. Your message is one that we all need to hear, and we are just so inspired by your courage in speaking out and your strength in continuing on the fight, so we thank you so much. We have so much all to learn from you. And there are so many people who need to hear this message. Our next speaker is Milanoi Koiyiet who is speaking to us from a rural area of Kenya, so we hope she has a good connection. She is the Protection, Gender and Inclusion Co-ordinator for the International Federation of the Red Cross and Red Crescent in Africa, specialising in women with disabilities. She has also been a great friend through Disability Rights International helping to us investigate and report on abuses institutions in Kenya. A true friend, thank you very much Milanoi for joining us.

MILANOI KOIYIET: Thank you very much. My name is Milanoi Koiyiet. As mentioned I work with International Federation of the Red Cross supporting Africa region but at the same time I have been working with Disability Rights International for a very long time looking at investigations at the situation of children institutions in Kenya, looking at adults' institutions in Kenya as well. And we have done a study with DRI on the same, that is what I will be speaking about today. So we had a study as well looking at where the children with disabilities institutions and we went round various institutions in Kenya and it was a sad state of affairs realising that there are very many children with disabilities locked up institutions in Kenya, locked up in children's homes in Kenya. And there's a lot, they are living in very poor condition. The staff do not have expertise in even in handling children with disabilities. There's a lot of mistreatment of children with disabilities. We saw children with disabilities being made to sleep as early as 4 o'clock and where they are sleeping is locked up with padlocks, so in case of an

emergency in case of a fire they cannot leave. Children with disabilities as well are really being mistreated and even in one of the investigations we were conducting we could see that when we turned our backs you would hear children with disabilities crying because the staff were punishing them if they refused to eat. They were being tied down, being forced to eat and swallow and the likelihood of choking is very high as well. I think the standards is really, really sad in Kenya. We know we welcome the Government mandate we have put moratorium to ensure that children, there are no more children's homes being registered in Kenya, but at the same time it's really calling on removing all children, including children with disabilities from institutions and putting them in homes. That's why we really, really, really welcome and ensuring readvocating for the Government as well to ensure that the guidelines are really, really followed as well for us on Chapter 4 as well on deinstitutionalisation, dignity of people with disabilities. I think it's very important to ensure happens. No child should live in an institution whether they have a disability or not, I think that the call to action as well because our findings show that there are children being locked up institutions yet they have families, so you can see there's a lack of awareness in communities, lack of community support, there's need for creating awareness to understand the different forms of disabilities, to understand the right of everyone to live in the community as well. I think there's a lot that needs to be done in creating awareness even for families as well, we did visit also be able to investigate mental health institutions in Kenya, Government institutions that call themselves mental hospitals and it was terrifying to see adults both women and men who are brought to institutions by family members. Even the doctors were saying the family members will bring them having tied them up in really inhumane ways and forcing medication and institutionalisation of adults both men and women in those institutions as well. It was sad so to see the state of affairs where men and women with different disabilities were being locked up, given medication, and they have really bad side effects, they were getting reports the medication used is not very good quality. Lots and lots of side effects which is really disheartening to see, and this adults as well like women with disabilities being locked up institutions have been there for years. Years and years and years with no-one coming to take them out so their families lock them up and that's it. They are at the

mercy of the institution, it's something we're advocating for really, really ensuring that the UN Convention on the Rights of Persons with Disabilities on deinstitutionalisation is really, really followed to the core. Because then they're mechanisms to ensure that persons with disabilities can live in communities, in dignity like anyone else. So I think it was really, really important to highlight these key issues in Kenya than the Government needs to take action as well on that. Another sad reality as well is really just looking at the access to justice in Kenya. Our Constitution talks about Article 48 where everyone has the right to access justice. But then we see really a gap in implementing this law where persons with disabilities psychosocial and intellectual disabilities are being locked up for different forms of crime, really not accessing just is this they are locked up in remand where their case takes years and years to be heard. The justification is saying the Government is waiting to do an assessment to see whether they are justified or they are able or fit to stand trial. 95% or more do not have legal representation. Some of them have been locked up currently in remand being given different forms of medication, being locked up in really inhumane conditions I remember for a fact we were there even with Eric looking at institutionalisation, it's really sad to see some them have been locked up over 10 years just waiting to stand trial, never have been heard because they are still waiting to be assessed on whether they are fit to stand trial which is really sad state of affairs. Therefore I think implementation of the Chapter 4 is very, very critical in ensuring we do not have homes that are locking up children with disabilities, we do not have hospitals institutions that are locking up women with disabilities in different institutions as well. Ensuring there's access to justice for everyone, including persons with disabilities. Which is not happening. At the same time, it's really enhancing the level of legal support to ensure that have persons with disabilities who are being said to be in conflict with the law but they actually have right to representation, this not happening as a fact. So being locked up in institution as long as you don't even know how long, not accessing justice as well we have a constitution that ensures access to justice for all. So I think deinstitutionalisation is a really critical component in working together in collaboration with different aspects, bring together persons with disabilities, organisations, experts with the law to ensure that we actually work

together in ensuring that Chapter 4 is implemented is very, very crucial at all levels, in Kenya, the African level, the global level. We really need to bring all experts on the table to ensure that this happens. We're hoping that even though the Government had committed to close down children's homes, it happens as soon as possible. That children's homes in Kenya are closed down where children with disabilities are being locked, some of them have been there for all their lives, they don't even know anything else yet most of them have parents and families. None of them could be said they are orphans and don't have anywhere to go. Children are placed in communities and schools ensuring we have the right school system which is one of the challenges, where most of the institutions are saying there's nowhere for children with disabilities to be taken. So ensuring that all schools in Kenya are actually accessible, and children with disabilities can access is very, very critical in ensuring that we move them from institutions so they can live a normal life like any other child, going to school, being happy at home, playing like any other child at different levels. So I think that gap needs to be addressed really, really urgently. I think it's really important, even as we in different countries in terms of program we're making I think Chapter 4, it's really, really important component and really looking at the intersectionality as well aspect of Chapter 4 as well, or understanding that gender and disability is a huge aspect in Africa as well. Speaking to women with disabilities and mothers of children with disabilities, there's a lot of misinformation out there where doctors are not supportive even as mothers give birth to children with disabilities. They give birth to children with disabilities and the hospital never tell them anything, they let them go, no support, no services, nothing, no information which leads to mothers of children with disabilities going back to community with lack of information. Most of them are feeling like they are being, they have no-one to speak to, ending up being isolated, and sent home with nothing [inaudible] in churches and in schools and communities is where they feel most discriminated against as well. It's creating awareness to ensure that communities actually understand what disability is all about, ensure that work closely with Government, with others, with institutions to ensure they are actually closed down. So I think co-ordination and collaboration is very, very important and bring different experts to ensure that this doesn't continue to happen at all. Thank you.

ERIC ROSENTHAL: Thank you very much Milanoi, your perspective is invaluable, and your work on this on women with disabilities and all children with disabilities is so important. Our speaker from Ukraine unfortunately appears not to be here, we know there are connectivity problems and power outages in Ukraine, and so much as it is essential to hear from the perspective of people in war, I regret we're just going to have to move to our next speaker. We're running late anyway. We will now hear from Cat Byrne, the Lead Humanitarian Advisor Child Protection to what I believe is the largest international children's humanitarian relief organisation in the world, Save the Children. Her practical experience in the reach of her organisation is so valuable and we are truly pleased to have Cat join this discussion today. Thank you Cat.

CAT BYRNE: Hello everybody, it is really my pleasure to be with you today. And as mentioned I am going to speak about some of the challenges and opportunities we have in operationalising the guidelines within our child protection programming in emergencies. And I will speak to you based on the past 18 months I have spent working with children in Poland who are evacuated from institutional care centres in Ukraine and also our current work on the Gaza response.

As a child's rights organisation, Save the Children has got a long history of ensuring that children are safe and protected within their own families and where that really is not possible, to make sure that they are in family-based alternative care within their community. Small group homes are not a substitute for a family, and transitions to smaller group homes really don't equate to deinstitutionalisation. At Save the Children we support children in institutional care but we don't support the institution itself, and whilst they are in institutional care we advocate strongly and support their transitions to family-based care. But working with children who are currently in residential care, is really challenging and complex in humanitarian responses. And one of the biggest challenges we face to operationalising the guidelines, ensuring there is sufficient human and financial resources for family strengthening in emergencies, so to prevent the initial family separation. As we know State Parties have an obligation to support

families in their diversity, to avoid that separation and promote care within the family and community. And an organisation we see one of the best ways to do that is to strengthen the social service workforce, where that is social workers case workers other support workers but to make sure they are trained on a rights-based model of disability they avoid triggering or recommending institutionalisation. They also play a vital role in supporting children to transition back into family-based care placements. I think we all know on this called impact of institutional care on children's short and long-term outcomes, that's really well documented in practice, and in the research. But I would like to emphasise that what we have seen in the Ukraine response is similar to what was seen towards end of the Soviet era, by that I am referring to nursing approach to care, in which some but not all legal guardians and caregivers tend to see their role as keeping children clean, dry and fed but not providing them with nurture or stimulation or recognition they need as diverse, valuable unique individuals. Really sadly we're still seeing a tendency to treat children institutional care as a problem to be solved, rather than unique human beings.

We're noticing that that approach is also creating new and exacerbating medical conditions and impairments that could have been managed with the child and their family with relatively little support, such as speech impediments becoming non-verbal children and withdrawn children becoming unable to communicate. And on this issue of this kind of nursing approach, there is a need for a national and regional behaviour change strategies. Within Save the Children we're advocating strongly for behaviour change strategies and action planning to be in integral part of the deinstitutionalisation agenda in Ukraine and elsewhere. There's a really strong need to ensure that advocacy and campaigns emphasise the intersectional characteristics of children in care to counter those harmful narratives. We have been working with children in institutional care in Poland on storytelling and writing their own storybooks, so we'll find a way with Dragana and Eric to share the stories when they are finished to amplify the voices of children in institutional care in their displacement into Poland.

From a child protection perspective, it's also well documented that institutional care

is an absolutely enabling environment for sexual abuse and exploitation. We know that institutionalisation makes it difficult for children to set boundaries and form healthy and safe relationships. In 2024 we're seeing that institutional care creates additional challenges for digital and online safety, and that children in those institutions face increasing risks of grooming and sexual abuse and exploitation. That combined with the level of neglect they experience, that risk is just through the roof.

I would also like to mention briefly on the topic of medicalisation and pathologisation of children with disabilities in institutional care. We have seen under-diagnosis, under-diagnosis, misdiagnosis, leading to range of issues. We're seeing in evacuated centres over medication and misuse of prescription medication for behaviour management. And very sadly that means walking into centres and seeing children who have been given things like sedatives or ADHD medication, rather than care and support to manage their emotions and behaviour. So as well the as those healthcare issues in terms of exclusion from mainstream education, the misdiagnosis, under-diagnosis, over-diagnosis is also affecting the ability of children in emergencies to realise their basic right to education. And we know that institutionalisation makes it more likely for children with disabilities to either placed in special education institutions when that's not necessary, or completely excluded from education. So I wanted to emphasise today that ensuring that children in that situation can attend school, and crucially that school is separate from the institution, is vital for children who might not otherwise come into contact with the local community. And who might literally not be observed or have people have their eyes on them by adults who are outside the institution. So the safety of schools and the importance of ensuring that children in emergencies can attend schools is there, it's also very manageable to implement with functional or semi-functional educational systems and with more and more NGOs and organisations specialised in providing formal and informal education support. There's no excuse for it in these days.

So it's a bit of a bleak and sometimes overwhelming picture but there are ways to address all the things that I have mentioned. As I say, within Save the Children we

don't support institutional care but it's absolutely vital that we provide support to children whilst they are there, and as they transition to family-based care. And that looks different in different settings, but it particularly requires one-to-one case management, or social work type interventions in order to promote the individuality and individualised care that all children require. There's a significant need for capacity building and support to caregivers, who can be resistant to interventions and resistant to change, particularly when they think organisations are trying to shut down the centres and that they might lose their jobs, so building capacity and also letting those practitioners know there is a role for them when children transition to foster care. Shall I wrap-up?

ERIC ROSENTHAL: Yes please, as quickly as you can.

CAT BYRNE: Will do. The last couple of things to emphasise, there needs to be a significant investment of time and money to create pools of trained foster careers who are adequately supported to look after children so when children are not able to return to their family of origin that there are temporary foster carers until that is a possibility. Just to mention in terms of Gaza response, to show that even in the most extreme situation family-based care is possible and always the preferred option. In Gaza the community is protecting itself, we are supporting kinship care of the local community. Absolutely the creation of any new residential facilities must be out of the question, and where there are children where it's not possible to re-unite them with their biological families and establishing the pools of trained supportive foster carer is vital. I will wrap up there, thank you very much for your time. Bye-bye.

ERIC ROSENTHAL: Thank you Cat, your work and message is so important. We look forward to working with Save the Children on these issues and your commitment to accepting nothing those lean family inclusion for all children, especially children with disabilities is a great resource to us all, thank you very much. I am very pleased to say that Anastasiia from the Ukrainian Child Rights Network has been able to join us. Anastasiia, we are very short of time here as we wrap up towards the end so I hope you

will be brief, but we are truly pleased hearing about the situation of children with disabilities in a situation of war time Ukraine is vital and we welcome you thank you.

ANASTASIIA STEPULA: Thank you very much Eric, hi all I am sorry for being late due to circumstances here in Ukraine I will try to tell you briefly how important is deinstitutionalisation process today in Ukraine. Regarding the full-scale invasion of Russia we will give you some data first then conclusions. As of the onset of the full-scale Russian invasion of Ukraine out of 104,000 children in institutions, over 400 were ever created in large groups abroad, we have data that many children with disabilities were not evacuated at all and even mixed institutional care facilities where children with disabilities had been residing, with children without disabilities, when only children without disabilities have been evacuated. It's very concerning and it's fully understandable where in the system how it works and the institutional care facilities are I don't know, they are very large in Ukraine like 100, 200 children can reside in one building. Workers of those facilities didn't have any possibilities to evacuate them, transportation, special routes *et cetera*. It is unknown totally unknown how many children remain under enemy occupation for today, as we know children from temporary occupied territories in Ukraine have been deported to Russia, their identities have been changed, they are forcibly adopted to Russian families, illegally adopted, and the process or reunification of children with disabilities in Ukraine is not even concerned, is not even possible because it is the process to that needs a special mechanisms, special logistics and special algorithms. And it is really concerning because those children who have been the most vulnerable, became even more vulnerable in this situation. The process of reintegration of Ukrainian children who reside in institutional facilities who have disabilities today is some something that is on the very stage of the beginning, maybe many of you know that in Ukraine was Strategy of Better Care presented last week, and many participants today participated also in development of this strategy, and children with disabilities are included in this process, but I would like to emphasise also the stigmatisation and belief of many people who work in the system in Ukraine that it is impossible to create and to make family-based care for children who have high support needs. This is a problem of medical model to

disabilities that is very common in Ukraine. And look in general concerns are really deep because of the vulnerability of those children, and what would I say it is of utmost importance today to start deinstitutionalisation process as we see the result already of absence of services, of education, of social services, of support of the families who leave their children because they cannot raise them because they have disability. Just to be briefly I would ask just for international community for temporary support of the topic and for the topic to be stressed all the time, from your side, because we stopped the deinstitutionalisation process to it's mostly focused on children age before 3 years old and it is not enough of political will, it is not enough of ready built system to provide deinstitutionalisation for children with disabilities and it is very needed from international community to make it possible for us. And this moment of deportation the Ukrainian Rights Network we always emphasise that deportation itself became possible because of unexecuted deinstitutionalisation reform in Ukraine, because most of children who have been deported they have been deported because they lived and resided in institutional care facilities because their families left them there, not because they didn't have parents, not because they resided, it was orphanage, they had parents most of them they have, just because the system is built like that that is much more comfortable for Ukrainians who have some challenges in their lives to raise their children in institutions. Thank you I am sorry if it was a bit messing, but I was trying to be brief.

ERIC ROSENTHAL: Well we thank you very, very much, we know how hard it is to work under conditions of wartime, you are very brave and we standby you and are so in awe of the fact you can keep your focus on your families and on disabilities rights the in a very, very hard time like this. It's a reminder of why the UN guidelines and deinstitutionalisation are so important and so relevant in a time of war like you are experiencing in Ukraine, so we hope to keep up our communication and that you have all of our support.

We are now at the end of formal presentations, and of course running way too late. I am going to now turn back to my colleague Dragana, we're using something of a poll to

learn more from the perspectives of our audience, and Dragana can you explain how this poll will work?

DRAGANA: Yes of course, thank you very much Eric. You will see on your screen there the question will pop-up automatically, of course you are free to answer or not, polls will end in certain amount of time and some questions, some answers will be visible. We're trying not to take too much of your time but this feedback is really valuable so we can plan next webinars in the series, so please provide responses to the best of your ability and knowledge. So without further ado I will start with our first poll and I will read the question aloud. The first question is, "Are the relevant state departments in your country aware of the guidelines on deinstitutionalisation? If yes, have they collaborated with any civil society organisations to increase awareness around the guidelines?" This is an open answer question, so you can type in your answer. If you are aware whether there are efforts on behalf of your Government to implement the guidelines. The poll will be open for another 30 seconds. I am aware it takes some time to type your answers.

DRAGANA: Thank you very much, I will end this poll now. I really appreciate your responses. So the next poll, and the next question is, "To what extent were you aware of the content of Chapter 4 of the guidelines, deinstitutionalisation grounded in the dignity and diversity of persons with disabilities?" Prior to this webinar. So the options are very aware, somewhat aware, not aware at all, and I don't know. Thank you for your responses I am just trying not to take too much of our time and I will launch the next poll. The next question, "To what extent do usual find the Chapter 4 of the guidelines easy to understand?" Very easy to understand, somebody what easy to understand, not easy to understand at all, and I don't know. This will help us of course to follow up with some useful information and prepare possibly material in plain language that can help with better understanding. Thank you very much for your responses. The next question is, "To what extent is Chapter 4 relevant for your work?"

The answers are very relevant, somewhat relevant, not relevant at all, and I don't know. Thank you. There is one question that you can, it's an open question and is, "Which high-risk groups are you working with?" In case that you are working with children, women or other high-risk groups we just wanted to hear and to see who our audience is.

ERIC ROSENTHAL: Dragana, we're going to turn to the wrap-up, is that it for the polls?

DRAGANA: Yes we have one more question if that's ok, I will end up very soon so we can start with the wrap-up. Just maybe what further clarifications are needed so people can type in one while we continue, so this will be open and I don't know just if we wanted to address one of the questions, I did try to respond to one of the questions we had in Q&A.

ERIC ROSENTHAL: I think we can try to respond to some of the questions after the webinar, feel free to write in. Feel free to write to any of the speakers and if you send them, I put in the chat, info@driadvocacy.org, any questions you have we have been unable to respond to we'll get to the correct speakers and be sure to respond. It seems we have run out of time here, but really appreciate everything we have heard from a wide variety of panellists. So I hope you will put a few words in poll question number 6, and we now turn to Manel Mhiri from Inclusion International who will give us some concluding thoughts and let us know about plans for the next webinar in the series on the UN Guidelines On deinstitutionalisation. On behalf of Disability Rights International, and on the Global Coalition, we thank you all for participating. We really appreciate the great diversity of experience and perspectives and look forward to working with you on this. Manel.

MANEL MHIRI: Thank you Eric. Thank you everyone. I just repeat all the thanks thoughts to our first speakers, and panellists who had very, very valuable interventions. I would also like to thank all the interpreters, the Sign Language Interpreters, the language interpreters and all DRI team for their support, for this

webinar. And just before we wrap-up so I would just wanted to share with you that our next webinar which part of this webinar series hosted by the Global Coalition on Deinstitutionalisation will be organised next Thursday, 9th of May, it will focus on Chapter 6 of the DI guidelines on support services, networks and systems. So the webinar will be will start at 3pm Central European Time, 9am Eastern Time, and we will hear from self-advocates, from people with disabilities, from families, family members, and from professionals from community-based organisations. We will share concrete examples and practical examples of support, services, and networks that exist in different countries, different regions, and we would love to have you with us, to share your experiences, and yeah your comments, so we will share more information about the webinar including the registration link before the end of this week, so yeah thanks again and we look forward to meeting you again for the next webinar next week. Thank you all. And have a good day, afternoon.

ERIC ROSENTHAL: Thank you Manel, thank you Manel. We are stopping exactly on time here and if we had, do we have, Manel, the link for the next webinar? Are you able to circulate that, that would be very helpful if we could.

MANEL MHIRI: Not yet but it will probably be available later today, so we can maybe add it in the GCDI website where we find information and we will of course share it through the different platforms, social media, and emails.

ERIC ROSENTHAL: Ok for those of you who are on the list of the Disability Rights International we will send that to our list and there is also now a website for the Global Coalition on Deinstitutionalisation, GC-DC.org, feel free to look for the link there as well. We thank you all for joining this discussion and look forward to working with you closely to address these urgent human rights issues. Thank you very much.

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