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**Annual report of the United Nations High Commissioner  
for Human Rights and reports of the Office of the  
High Commissioner and the Secretary-General**

**Promotion and protection of all human rights, civil,  
political, economic, social and cultural rights,  
including the right to development**

## **Intersessional seminar on the protection of the family and disability\***

### **Report of the United Nations High Commissioner for Human Rights**

#### *Summary*

The present report, mandated by the Human Rights Council in its resolution 32/23, summarizes the presentations and debates held during the one-day intersessional seminar on the impact of the implementation by States of their obligations under relevant provisions of international human rights law with regard to the protection of the family in its role in supporting the protection and promotion of the rights of persons with disabilities, at which challenges and best practices in this regard were examined.

In the report, the High Commissioner reflects the contributions made by panellists, States and civil society organizations during the seminar, which was held on 23 February 2017, and the conclusions and recommendations identified during the debate.

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\* The report was submitted after the deadline in order to reflect the most recent developments.



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## I. Introduction

1. In its resolution 32/23, adopted on 1 July 2016, the Human Rights Council decided to convene, with the support of the Office of the United Nations High Commissioner for Human Rights (OHCHR), and before its thirty-fourth session, a one-day intersessional seminar on the impact of the implementation by States of their obligations under relevant provisions of international human rights law with regard to the protection of the family in its role in supporting the protection and promotion of the rights of persons with disabilities, and to discuss challenges and best practices in this regard.

2. The intersessional seminar was held in Geneva on 23 February 2017. It was divided into three sessions: two held in the morning and one held in the afternoon. The programme of work was prepared by the leading co-sponsors of the seminar — the Permanent Missions of Egypt, Qatar and the Russian Federation — with the support of OHCHR and inputs from relevant stakeholders. The present report contains a summary of the proceedings and the conclusions and recommendations that emerged from the seminar. The agenda for the seminar and the list of panellists are published on the OHCHR website.<sup>1</sup> The seminar was made accessible, with closed captioning and international sign interpretation, and was webcast on UN Web TV.<sup>2</sup>

## II. Summary of the proceedings

### A. International framework on family and disability

3. The President of the Human Rights Council, Joaquín Alexander Maza Martelli, chaired the first session. This session was focused on the international framework on family and disability and was moderated by Maha Kamaleldin Elsayed Helali, a board member of the National Council for Disability Affairs, of Egypt, and President of Inclusion International for the Middle East and North Africa region. The panellists were Catherine Ivonne Pedreros, of the secretariat of the Committee on the Rights of Persons with Disabilities; Mark Mapemba, a self-advocate from Malawi, board member of Inclusion Africa and council member of Inclusion International; and Ms. Helali. There were interventions from the floor by representatives of New Zealand, Chile, China, Ecuador, Belarus, Colombia, the European Union, Uruguay, the Russian Federation, Azerbaijan, Alliance Defending Freedom and Child Rights Connect.

4. Ms. Pedreros started by acknowledging that the almost universal ratification of the Convention on the Rights of Persons with Disabilities reflected a firm international agreement. However, progress still had to be made on the inclusion of persons with disabilities and their families — given that the majority of them lived in poverty — which included the need to combat discrimination on the basis of disability. Ms. Pedreros's presentation was aimed at answering three questions based on the jurisprudence of the Committee on the Rights of Persons with Disabilities, which may help States parties to better provide assistance to persons with disabilities and their families, in a manner consistent with the Convention.

5. The first question was how the human rights-based approach to disability in the Convention related to families. On that matter, she stated that the human rights-based approach to disability recognized that families could have a role in contributing to the

<sup>1</sup> See [www.ohchr.org/EN/Issues/Disability/Pages/IntersessionalSeminarProtectionFamilyDisability.aspx](http://www.ohchr.org/EN/Issues/Disability/Pages/IntersessionalSeminarProtectionFamilyDisability.aspx) (agenda).

<sup>2</sup> The webcast of panel I is available from <http://webtv.un.org/watch/panel-i-intersessional-seminar-on-protection-of-family-and-disability-human-rights-council-/5333037517001>. For panel II, go to <http://webtv.un.org/watch/panel-ii-intersessional-seminar-on-protection-of-family-and-disability-human-rights-council-/5333037519001>, and for panel III, go to <http://webtv.un.org/watch/panel-iii-intersessional-seminar-on-protection-of-family-and-disability-human-rights-council/5334700944001>.

realization of the rights of persons with disabilities. According to Ms. Pedreros, the role of families should be properly framed under the principles of the Convention, as well as under the paradigm shift that the concept of disability brought about. She stated that recognition of gender equality and the rights of women and girls with disabilities, including of their sexual and reproductive rights and health, and protection against violence, including in family settings, also constituted part of the main framework of such a role. She added that support for families should be aimed at facilitating the exercise of the rights of persons with disabilities, as enshrined in the Convention. Her second question was on how the Convention recognized the roles of families. She mentioned three pillars: article 5 (equality and non-discrimination), article 12 (equal recognition before the law), and the interrelation between articles 19 (living independently and being included in the community) and 28 (adequate standard of living and social protection).

6. She explained the concept of “discrimination by association” against family members without impairments, particularly women, and de facto guardianship within families that deprived persons with disabilities of their ability to make choices. She also highlighted the Committee’s concern about substituted decision-making and about forced sterilization of women and girls with disabilities. She underscored the Committee’s recommendations on guaranteeing respect for the autonomy and self-determination of persons with disabilities in day-to-day decisions, and on ensuring access to services they required and the living arrangements they needed, including choosing their place of residence, which was an important part of moving towards deinstitutionalization. She recalled the Committee’s views regarding the negative impact of the absence of an adequate standard of living and appropriate social protection for persons with disabilities, which perpetuated situations of poverty and exclusion from the community. Finally, she indicated that the Committee had called upon States parties to make sure that persons with disabilities and their families were not disproportionately affected by budget cuts and to ensure income support and social security, taking into account the framework of the Sustainable Development Goals.

7. The final question raised by Ms. Pedreros regarded which articles of the Convention on the Rights of Persons with Disabilities specifically protected the rights of persons with disabilities in relation to the family. She mentioned the following: (a) respect for home and the family (art. 23); (b) health (art. 25); and (c) inclusive education in the regular education system (art. 24). Ms. Pedreros identified violations of these rights, as highlighted by the Committee. These included being denied the right to marry, start a family and adopt or raise children; the absence of appropriate support to raise children and exercise parental rights; and separation of children from their parents based on impairment of either the child or one or both of the parents, which disproportionately affected women and girls with disabilities. She referred to the Committee’s general comment No. 4 (2016) on the right to inclusive education, in which it was indicated that persons with disabilities and, where appropriate, their families, must be recognized as partners in, and not merely recipients of, education.

8. Ms. Pedreros concluded by noting that the Convention provided for the protection and realization of the rights of persons with disabilities and their families and that the jurisprudence of the Committee may guide States to better understand and ensure protection and assistance for persons with disabilities and their families in a manner consistent with the Convention. She recommended that States enhance their efforts on awareness-raising and ensure that their public campaigns and strategies on the rights and dignity of persons with disabilities include families. States should also take measures to combat stigma, stereotypes, prejudices and harmful practices that prevail in society, including within the family. Finally, she recalled the general obligations of States parties to the Convention, which included taking legislative, public policy and administrative measures.

9. Mr. Mapemba pointed out that family-based organizations such as the Parents of Disabled Children Association of Malawi could help families to understand disability differently, reduce stigma or shame that parents may feel and help them to embrace their children’s human rights. He added that the organization had helped his mother to understand his educational needs and how to support him to be included, and had helped him to value self-advocacy. He defined self-advocacy as “expressing oneself and being heard” and “being a leader who fights for others, and working together on one’s rights”,

and said that the importance of self-advocacy resided in the fact that it “makes us equal, builds confidence, gives us visibility and raises awareness of others”.

10. Mr. Mapemba said that he had been a disability rights advocate since the age of 14 and had gained national, regional and international experience in promoting the rights of youth with disabilities. In that respect, he described his family as being very important in supporting him to live a full and independent life and in fighting to protect and promote his rights. However, he warned that families could sometimes be overprotective or controlling. That was usually on account of restrictive laws and customs, and the fear of what would happen to their children when the parents were gone.

11. Mr. Mapemba asserted that persons with intellectual disabilities were often discriminated against and undervalued by society and thus exercised little to no control over their lives (for example, they stayed with their parents when they were adults because they had no other choice). “People do not see us — we are invisible”, he said. “People do not hear us — we have no voice.” He concluded by calling for investing in progressive family-based organizations and in self-advocacy as a key way for governments to meet their obligations to support families.

12. Ms. Helali stated that Egypt attached great importance to safeguarding and supporting the family unit. She underlined the positive role that the family played in the fight against poverty and in combating violence against women, as well as in promoting human rights, development, children’s and older persons’ rights, and the right of girls to education.

13. In that regard, Ms. Helali highlighted the following advances in Egypt: the implementation of benefits included in the Social Security Act and financial assistance for persons with disabilities; the submission of a draft bill on the rights of persons with disabilities, covering employment quotas, political rights, and prosecution for forced sterilization and forced abortion; and the combining of different pension schemes within the same family. The speaker confirmed that it was important to hear the voices of family members, as families often provided support for children and young people, but also for adults with disabilities, particularly in Arab societies where children usually lived with their families until they married. She concluded by highlighting the need for: information and education; the provision of specific services; financial support; leisure and recreation; and support in the formation of associations and groups.

14. Following the presentations, the representative of New Zealand highlighted the need to ensure elimination of discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, and to ensure elimination of the disproportionate effect of discrimination on women and girls with disabilities impacting on their freedom and choices to pursue their own life plans. The representative of Chile affirmed the recognition of various forms of families; the right to personal autonomy, independence and inclusion of persons with disabilities as individual rights holders, including the right to establish their own family in any form they wished; the recognition and exercise of legal capacity, including by persons with intellectual disability; legal advances on the rights to tailored social protection; and measures against the institutionalization of persons with psychosocial disabilities. The delegate of China mentioned the goal of a harmonious society between the old and the young, as well as several legal and policy measures on social protection, education and health.

15. The representative of Ecuador underscored the importance of ratification and implementation of the Convention and its Optional Protocol, as well as the Sustainable Development Goals, and the employment quota as an example of affirmative action. The representative of Belarus pointed to national legislative measures such as tax benefits and increased social protection benefits for children with disabilities, in the framework of a national plan and a gender equality policy. The representative of Colombia addressed the topics of family members from different ethnic groups and victims of armed conflicts, the transition from the patriarchal system to a democratic configuration inside the family, and the role of families in promoting the individual rights of persons with disabilities and as agents of social and sustainable development. The representative also mentioned the new roles of men for the promotion of gender equality and ways to prevent domestic violence

and other harmful practices within families. The representative of the European Union underlined that various forms of families existed, and affirmed the need to support families in their role of strengthening societies and upholding the rights of each individual within families without discrimination of any kind.

16. The representative of Uruguay referred to ways to prevent the exploitation and abuse of children, and the prohibition on separating them from their biological mothers because of impairment of the child, the mother or both. Furthermore, the delegate emphasized the importance of the right to sexuality, the right to accessible and affordable sexual and reproductive health and the right of women with disabilities to maintain their fertility. The representative of the Russian Federation posed questions on supporting the family and on the role of the family in giving support to persons with disabilities, as well as on support from the State for the work of organizations of persons with disabilities. The delegate of Azerbaijan described a policy for strengthening the social protection of persons with disabilities to achieve relevant aspects of the Sustainable Development Goals. The representative of Alliance Defending Freedom considered that families were promoters of collective and intergenerational solidarity and described domestic abuse as a human rights violation. Finally, the representative of Child Rights Connect stated that children, including children with disabilities, were rights holders, and that they could not be discriminated against, including on the basis of family status.

17. In response to these interventions, Ms. Helali said that as the family played a major role in supporting persons with disabilities, it was very important to support the family itself. Ms. Pedreros underscored the importance of recognizing persons with disabilities as the main rights holders under the Convention. Ms. Pedreros also underlined the importance of freedom of choice and empowerment of persons with disabilities, when drafting public policies in line with the Convention (see, for example, arts. 12, 19 and 28). In regard to combating specific forms of discrimination, she recommended focusing on stereotypes and prejudices that were still deeply rooted in society, through specific training and awareness-raising campaigns and by ensuring the participation of organizations of persons with disabilities. She acknowledged the connection between the Convention on the Rights of Persons with Disabilities, the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child. She recalled concluding observations from the Committee on the Rights of the Child on the deinstitutionalization of children with disabilities and the promotion of foster families. She also referred to general comment No. 4 (2016) on the right to inclusive education, of the Committee on the Rights of Persons with Disabilities, and to the role of the family in supporting persons with disabilities as rights holders. Finally, Mr. Mapemba recommended working with organizations of persons with disabilities, promoting inclusive education, sharing information and promoting awareness-raising for families.

## **B. Roles of families as caregivers and supporters of persons with disabilities for their enjoyment of human rights**

18. The second morning session was also chaired by the President of the Human Rights Council and focused on the roles of families as caregivers and supporters of persons with disabilities for their enjoyment of human rights. This session was moderated by Edwin Romel Béjar Rojas, a family judge of the Superior Court of Cusco, Peru. The panellists were Sue Swenson, President-elect of Inclusion International; Catalina Devandas Aguilar, Special Rapporteur on the rights of persons with disabilities; and Sovann Phon, a self-advocate, of Komar Pikar Foundation. There were interventions from the floor by representatives of the Netherlands, Sweden, El Salvador and Mexico, and Human Rights Watch.

19. Ms. Swenson's speech revolved around creating a picture of the reality of family support for persons with disabilities, including its different stages and on the basis of her experience as the mother of her late son Charlie. She described the fact that he had lived with his parents until he was 26 years old and that he was enrolled in a regular school after she learned what the best practice would be for him. She pointed out that families consisted not only of a person with an impairment and a mother or a caregiver, but also of a broad

range of people participating in the family, including siblings and fathers. She described her frequent fight with systems, with programmes and with members of her community for the recognition and inclusion of her son. She addressed key policy issues, in order to support families of persons with disabilities.

20. She stated that in many cases, families of persons with intellectual disabilities ended up sheltering them for all of their adult lives because societies were not designed to make it safe or affordable for them to live independently; this was also the case in developed countries. This led to a profound dependency on the family, and such a paradigm pushed against respect of the rights and desires of the person with disability. She noted that in some cases, individuals may feel controlled by their families, which was also a consequence of the lack of support for them and their families. She described the participation by her son Charlie and herself in negotiating the Convention on the Rights of Persons with Disabilities with respect to legal capacity and inclusive education. She stated that rather than a guardian, her son had had a team of supports. She pointed out that training on education and inclusion should be provided for families, too.

21. She noted that impairments could occur in all contexts, regardless of a person's wealth, ethnicity or sexual orientation. Finally, she suggested that the Committee on the Rights of Persons with Disabilities could draft a general comment on the role of the family, and that the United Nations and Member States could share data and knowledge about relevant public policies in plain language, as well as supporting training efforts by progressive family-based organizations, investing in employment (also for parents) and in inclusive education, and promoting public policies with benchmarks on sexual and reproductive rights and on the prevention of violence and forced sterilization.

22. Ms. Devandas prepared a video message in which she addressed the right of children and adults with disabilities to support services and assistance within the framework of international human rights law — the theme of her latest report which was going to be presented at the upcoming thirty-fifth session of the Human Rights Council. She stated that while States had established some forms of assistance and had provided public funding for their implementation, provision of the support required by persons with disabilities remained delegated almost exclusively to the family. She stressed that both developed and developing countries were struggling to guarantee the availability of sufficient and adequate services and that women and girls were disproportionately assuming support duties. Similarly, family members providing support faced a reduction in their social relationships, income levels and general well-being, and States generally did not consider them as qualifying to be recipients of benefits or social services.

23. She indicated that the Convention departed from the traditional understanding of families as being caregivers and of persons with disabilities as being dependent members who needed to be “cared for”. Instead, as individual rights holders, persons with disabilities should have the freedom and opportunities to choose who gave them support and what kind of service they wanted to receive, in order to have full choice and control over their own lives. She recommended that policies should avoid reducing the autonomy of persons with disabilities, compromising their safety and making them vulnerable to coercion and abuse, and isolating them from society.

24. In conclusion, she mentioned the importance of consulting persons with disabilities in all decision-making processes related to the design and provision of support. She also said that States needed to rethink their policies relating to the role of families as unpaid care givers and to secure availability of a sufficient number and sufficient types of support. Finally, States should adopt a community-based approach to the provision of support.

25. Mr. Phon spoke about his early life and about how, after joining an organization in 2011, he had started being supported in his communication and interaction with others and in acquiring new vocabulary and performing everyday activities. He said that the support he preferred was based on education and explanation. Finally, he also mentioned the discrimination that the members of his family suffered, and how his mother was concerned about what would happen to him after she passed away.

26. Next, the representative of the Netherlands identified advances in the implementation and establishment of monitoring mechanisms, pursuant to article 33 of the

Convention, as well as in enforcement of the rights of persons with disabilities, promoting their autonomy as a way to reduce the care duties of relatives. The representative also addressed sexual and reproductive health and rights as stated in the Convention, the need to recognize the existence of and guarantee support for diverse types of parenthood and all forms of families as a non-discrimination measure, and the role of the private sector in the implementation of rights (e.g. employment). The representative of Sweden underscored the role that family played in protecting the rights of persons with disabilities, and identified children, women and indeed all persons with disabilities as individual rights holders, regardless of whether they lived in family environments or not. That representative also mentioned the rights of children and adults with disabilities to be heard, to participate, not to be discriminated against on the basis of family status, and to be protected from all forms of violence and abuse in all settings, including the family. The representative of El Salvador emphasized the importance of helping families to cover the needs of individuals, and also highlighted legal developments on the road towards equal opportunity for people with disabilities. The representative of Mexico underscored the need for support systems and measures to be designed in a way that was both individualized and participatory, and the need for protection of the rights of all children, both those with and those without impairments.

27. Finally, the representative of Human Rights Watch stated that families were important sites for the transmission of values, and that the role of policies was to encourage those values to be consistent with the international principles of equality, dignity and respect. In addition, efforts to protect and assist families were highlighted, as a way of supporting and strengthening not a particular family structure, but rather the functioning of all families in their educating and nurturing roles.

### **C. Challenges faced by parents and other family members**

28. Amr Ahmed Ramadan, Vice-President of the Human Rights Council, chaired the afternoon session that focused on the challenges faced by parents and other family members in supporting persons with disabilities. Sheikha Hissa Khalifa bin Ahmed Al Thani, of Qatar, former Special Rapporteur on disability of the Commission for Social Development, gave opening remarks. This session was moderated by Ms. Swenson. The panellists were Fauzia Haji, Secretary-General of Inclusion International, and Mr. Béjar Rojas. There were interventions from the floor by representatives of Estonia, the United Nations Population Fund, Argentina, Egypt, the Gulf Cooperation Council, Pakistan, the Bahamas, Saudi Arabia, Brazil, International Disability Alliance, Global Helping to Advance Women and Children, Save the Children, Fiji, Colombia, Qatar, Portugal, the Russian Federation, Iraq, Plan International, Associazione Comunità Papa Giovanni XXIII and Inclusion International.

29. Sheikha Hissa Khalifa bin Ahmed Al Thani emphasized in a video message that, during her mandate from 2003 to 2009, her main areas of focus had been supporting families with members with disabilities, particularly children, the relationship between disability and poverty, and the increase in the occurrence of impairments caused by wars and armed conflict. In that capacity, she had led awareness-raising campaigns on ratification of the Convention on the Rights of Persons with Disabilities, and other campaigns directed at legislators in the Arab countries.

30. She explained that, in her current capacity as Humanitarian Affairs Envoy of the League of Arab States, she had been visiting families in refugee camps, stressing the importance of equalizing opportunities for persons with disabilities and safeguarding their rights. She said that families, societies and governments faced obstacles in emergency and refuge situations with regard to upholding the rights of persons with disabilities. She noted that persons with physical impairments usually received medical attention and assistive devices, thanks to the Red Cross and Red Crescent, and in cooperation with organizations of persons with disabilities. However, persons with intellectual disabilities did not always receive essential services and development opportunities. She also pointed out the prevalence of psychosocial impairments (including depression), which were caused by the traumas of war, violence and displacement and which largely remained invisible.

31. She described the impact of humanitarian crises on families of persons with disabilities, which endured negative social attitudes that resulted in discrimination and isolation. Huge populations from Africa, Asia and the Middle East were seeking refuge in the developed world, fleeing from countries with shattered economies or devastation from war. In that context, she underlined the necessity of improving gender equality in education and providing recreational opportunities for refugees, and of supporting host countries in providing better family services. She also pointed to the need for continuity and improvement in the provision of services to persons with disabilities and their families by humanitarian organizations, including mental health services. She concluded by calling for support for an adequate standard of living; awareness-raising campaigns on the potential and contributions of persons with disabilities; and ensuring that children, adults and older persons with disabilities were protected from abuse and exploitation occurring within and outside the family.

32. Ms. Haji indicated that persons with disabilities faced several barriers daily, from physical obstacles in buildings to systemic barriers in education, health, access to justice, employment and general inclusion in their communities. Environmental barriers often limited them or prevented them from participating fully in social, occupational and recreational activities. Parents of persons with disabilities also had barriers to confront, particularly parents of children and young people with intellectual impairments and parents of those with multiple impairments.

33. Ms. Haji added that the most difficult barriers to overcome were other people's attitudes regarding persons with disabilities. Attitudinal barriers could prevent a person from becoming a productive, successful and active member of society. In addition, they created the false notion that persons with disabilities could not accomplish goals in day-to-day life, therefore that group was usually forgotten when policy and programmes were being formulated. Ms. Haji gave examples of barriers that currently existed in society, such as the lack of relevant assistive technology, as a violation of the right of access to justice; people's negative attitudes against inclusive education; and services, systems and policies that were either non-existent or hindered the involvement of persons with disabilities in all areas of life (e.g. with regard to giving free and informed consent to treatment).

34. However, she added that negative attitudes against persons with disabilities could be changed through education and public awareness-raising and by showing good practices. She advocated for family-based organizations to be consulted and to be involved in the enforcement of the rights of persons with disabilities. Therefore, they needed support from governments to develop and conduct their campaigns. She also called for greater engagement and inclusion, and involvement by self-advocates.

35. She recommended that States ensure that information is made easily understandable and accessible, that inclusive education is guaranteed, and that persons with disabilities are included in their communities throughout their lifespan. She added that children who were included in school were less likely to live in poverty and more likely to have friends and relationships outside their families. Finally, she stated that our diversity brought uniqueness to each one of us and enriched the world, and affirmed that every individual was capable of contributing to society.

36. Mr. Béjar Rojas opened his presentation by affirming that States should provide more support not only to persons with disabilities but also to their family members. He referred to his experience as a family judge since 2012, adjudicating cases concerning families with members with disabilities, both children and adults.

37. He noted that the cases he most frequently adjudicated on were related to guardianship. In 90 per cent of them, family members were the ones who requested the deprivation of the right to exercise legal capacity for their relative with disability. In general, those cases were filed as a prerequisite for individuals with disabilities to obtain social security benefits and free health care upon reaching the age of majority. He observed that even where this was not legally required, many countries in Latin America had adopted that precondition in order for the person concerned to have access to social protection.

38. He described the history of discrimination and exclusion that persons with intellectual and psychosocial disabilities faced in many countries, and found that

guardianship processes were discriminatory and exclusionary as they were aimed at declaring a person incapable of taking their own decisions and at having their will substituted by that of a third party or a guardian. He affirmed that this amounted to deprivation of autonomy, and had a negative impact on the exercise of all human rights. He explained that guardianship was the rule in almost all Latin American civil codes. However, he noted that Peruvian judges had been adopting innovative measures to implement the principles and provisions of the Convention.

39. He described, as a good practice, the conventionality control, as conceptualized by the Inter-American Court of Human Rights, meaning the direct and mandatory application of the provisions of the Convention to a particular case. As a judge, he had adjudicated cases that had set precedents on the upholding of legal capacity and he had declared the guardianship system to be incompatible with article 12 of the Convention. He underlined that judges, as part of the State, were obliged to respect and uphold the Convention.

40. As examples, he described some of his rulings. In the first one, in which guardianship measures had been requested for two brothers in order for them to be able to access their respective pensions, he had declared the guardianship petitions unfounded and had adjudged that the Peruvian Civil Code articles on guardianship were inapplicable. He had ordered the State to grant the pension without any deprivation of legal capacity and had established a supported decision-making system with safeguards. He had held a meeting with the two brothers with psychosocial disabilities and had provided procedural accommodations so they could understand the procedure. An interdisciplinary team made up of a social worker, a psychologist and an educator had also provided support in the process. Finally, training on supported decision-making had been provided for relatives. In another case, the guardianship petition had also been dismissed and the judge had ordered the social security agency to provide indefinite health-care services without any assessment being required. He also described a third case, which had been filed by siblings of a woman with disabilities who wanted to deprive her of her right to dispose of inherited property. He explained that his role had required him to determine her support needs and which supported decision-making system she required. Once again with the participation of the interdisciplinary team, the procedure was explained to the woman, who was finally empowered to make her own decision.

41. Furthermore, he mentioned that among the cases coming before him concerning persons with disabilities, marriage annulment based on the impairment of one of the partners was also frequent, and that women with intellectual impairments were usually deprived of their parental rights. In cases before his court, he had dismissed petitions that would have violated human rights, had enforced conventional rights, including social protection, and had provided support for persons with disabilities.

42. He concluded by saying that awareness-raising among judges was fundamental to upholding the Convention. He also added that persons with disabilities still faced many structural, normative and social barriers created by the State, and that it was necessary to strengthen the support role of family members. The role of the judiciary should not be limited to preventing the restriction of rights; rather, the judiciary should expand rights, in accordance with the will and preferences of all persons with disabilities, including persons with intellectual and psychosocial impairments.

43. Following the presentations, the representative of Estonia stressed the importance of valuing dignity and individual autonomy, of realizing the right of persons with disabilities to receive assistance at home in order to live independently and as part of the community, of developing accessible spaces, goods, services and homes, of assistive technologies, including e-services and information and communications technologies (ICTs), and of access to social protection for relatives who assisted family members with disabilities, as they faced higher poverty rates. The representative of Argentina emphasized that the social contribution of the family was also based on the family's diversity. She highlighted the interdisciplinary approach for assessing the kinds of support needed, and mentioned local laws and programmes covering basic services for persons with disabilities and specific training for assistants. The representative of Egypt described the family as a pillar of society and as being essential in the promotion of human rights, including the rights of women and children. The representative also mentioned the right of the child not to be

separated from his or her parents because of disability, and stressed the need for cooperation and for the exchange of data and best practices, internationally. The representative of Pakistan described the linkage between the State-supported financial strength of a family and a high quality of life for its members.

44. The representative of the Bahamas described a national social protection policy consisting of a monthly disability allowance for parents of children with disabilities. The representative of Saudi Arabia stressed the importance of awareness-raising campaigns and explained the country's national social protection scheme. The representative of Brazil underlined the importance of accessing information on family planning and reproductive rights. The representative of Fiji presented a broad definition of family that included the entire clan and community, and also promoted the active participation of persons with disabilities in all decisions affecting them. The representative of Colombia underscored the relevance of rights-oriented training, and of family planning methods. The representative of Qatar defined family as the fundamental unit of society, which made a paramount contribution to the enjoyment by all individuals of their human rights. She called for the family to be considered a stand-alone subject, indicating that that perspective would address the contribution of the family as well as the promotion and protection of human rights of persons with disabilities.

45. The representative of Portugal proposed flexible working arrangements to reconcile the family and professional lives of the person with disability and of other members of the family. The representative of the Russian Federation put forward the view that the provision of support to organizations of persons with disabilities was an important measure. She also described a policy of a barrier-free environment in education, employment, health care, social protection, sports, information, communication, culture, transportation and public spaces. The representative of Iraq described specific assistance and services for victims of terrorism.

46. The representative of the Gulf Cooperation Council underscored the need for freedom of choice, equal opportunities and effective participation of persons with disabilities, so that they could contribute to economic and social progress and to the attainment of the Sustainable Development Goals.

47. The representative of the United Nations Population Fund stated that, according to the International Conference on Population and Development, held in Cairo in 1994, families in their various forms should be strengthened and enjoy comprehensive protection and support. He added that, in accordance with the Conference's programme of action, it was necessary to develop policies to provide better social and economic support to families, acknowledging the rising cost of child-rearing. In addition, according to the framework of actions for follow-up to the International Conference on Population and Development beyond 2014, the world had seen shifts in household composition, with a rise around the world in the number of people living on their own, and more women-headed households. He underlined that the framework called upon States to provide financial support to help combat poverty, advance gender equality, ensure work-family balance, and promote intergenerational solidarity and quality of care for both children and older persons. He also mentioned that, according to the International Conference on Population and Development global survey conducted in 2014, single parents represented a significant proportion of all households across all regions, especially in Latin America and the Caribbean, and they were less likely to receive financial assistance and social protection. In addition, he informed the seminar that only 61 per cent of countries provided support to families assisting persons with disabilities, and that persons with disabilities living in single-parent households more often experienced economic poverty and limited access to basic services in the area of education and health.

48. A speaker from International Disability Alliance stated that diversity was part of the human experience and that disability was a form of human diversity. She emphasized the need to demedicalize disability and to shift from a stigmatizing care-oriented approach to a human rights-based and support-oriented approach. She affirmed the right of persons with disabilities, including persons with intellectual and psychosocial disabilities, to exercise legal capacity, to be the heads of families, to get married and to decide whether to have children or not. Finally, she emphasized that institutionalization was a clear and direct

violation of the Convention. The representative of Global Helping to Advance Women and Children stressed that families, as the primary support for relatives with disabilities, merited protection.

49. The representative of Save the Children underlined that children with disabilities were individual rights holders, and drew attention to the specific vulnerabilities they faced, such as violence, stigmatization and discrimination, including within their homes. The speaker also stressed the importance of supporting and strengthening parents and caregivers to ensure that they had the necessary skills, capacities and attitudes to fulfil their responsibilities to children and to empower them in the realization of their rights, including the right to be heard. The representative of Plan International stressed the importance of gender equality and the rights of persons with disabilities to access gender-sensitive sexual and reproductive health services without discrimination and on the basis of full, free and informed consent. The speaker also touched on the misconception that children and adolescents with disabilities were asexual, and on the effect on women's and girls' rights from patriarchal family structures reinforced by discriminatory family laws. The representative of Associazione Comunità Papa Giovanni XXIII stated that support networks among families with persons with disabilities were essential for sharing information and helping each other.

50. Finally, the representative of Inclusion International defined institutionalization as a deprivation of liberty and as a failure of societies. She stated that challenges were not related to the impairment but rather were rooted in society's failure to support children with disabilities and their family unit, and that the definition of family was not limited to parents and siblings — it included the extended family and those with whom a person with disabilities chose to share their life. The speaker stressed the importance of the following State measures: (a) cash transfers, tax relief and benefit programmes to offset disability-associated costs; (b) short breaks for parents; (c) support for working parents, including employment protection; and (d) capacity-building for parents and their organizations, so that they could obtain information, navigate systems, plan for the future and provide opportunities to connect with other families.

51. In response, Ms. Haji underscored the role of family members, not as caregivers but as supporters of children with disabilities, and added that States needed to fulfil their obligations to provide support for those families. Mr. Béjar Rojas highlighted the role of ICTs in supporting persons with different types of impairments and called for the adoption of new social programmes to support persons with disabilities and other family members.

## **D. Conclusions and recommendations**

### **1. Conclusions**

52. Ms. Haji reminded all Governments that they should consult with persons with disabilities and their families when designing public policies and awareness-raising campaigns. She affirmed that the best way to support families was to guarantee the inclusion of persons with disabilities in their own communities by ensuring accessibility and by celebrating their contributions and diversity.

53. Mr. Béjar Rojas recommended to States that they fulfil their international obligations effectively — including the Convention — by reforming legislation, practices, administrative structures and attitudes that undermine the effective enjoyment of these rights. He noted that, as a part of a State, the judicial branch also had a role to play in ensuring full respect and enjoyment of rights for persons with disabilities. He added that public policies should start to regard persons with disabilities as heads of families too, and governments should make support available to those families. He recalled that all persons with disabilities, including persons with intellectual and psychosocial disabilities, were entitled to respect for their legal capacity, and therefore innovative mechanisms and measures should broaden the enjoyment and exercise of their rights and prevent their restriction.

54. Ms. Pedreros emphasized that the jurisprudence of the Committee on the Rights of Persons with Disabilities offered guidance and a framework on how to provide protection for the rights of persons with disabilities and their families. The Convention and the Committee provided several elements for creating and developing public policies, programmes and laws. Those elements related to various articles of the Convention, such as article 8, on awareness-raising, and article 12, on equal recognition before the law, among others. She stressed the importance of article 19, on independent living and how the support should be aimed at enhancing inclusion in society and in the community. In addition, article 23 was important, as it concerned persons with disabilities not only as sons or daughters, but also as parents, with the equal right to start a family and have children. With that end in mind, training and support had to be provided by States. Finally, article 25, on the right to health, including sexual and reproductive health, was essential, especially for women with disabilities.

55. Ms. Helali indicated that families of persons with disabilities had specific needs, but in general they were confronting the same challenges as any other family. She agreed that ICTs, as accessibility tools and assistive technologies, could greatly change the lives of persons with disabilities and that Governments should make these available also for families. She also commended the solidarity shown by families in the area of exchanging knowledge. Finally, she considered that relatives should have time to rest from their assistance activities, should receive financial support, and when requested, should receive psychological counsel.

56. Mr. Mapemba acknowledged that families faced challenges due to the lack of support and services and that everyone wanted to live a full life in their own community. Therefore, inclusion was important and families needed information about human rights and how to support persons with intellectual impairments. He recommended that States invest in family-oriented organizations to build inclusive communities. Finally, he said: “When I have a typical life, my family has a typical life too.”

57. Mr. Phon reinforced his commitment to his self-advocacy group in order to enable persons with intellectual impairments to receive quality educational and job opportunities. He underscored the importance of living independently, especially when parents had passed away.

58. Ms. Swenson stressed the importance of technologies, as a key tool impacting on persons with disabilities, and noted their relevance in the collection of statistical information. She also encouraged international and transnational cooperation, and national support for organizations of persons with disabilities. Furthermore, she recommended training and capacity development strategies for families, including online programmes, as not all families may have all the skills and knowledge to support their child with disabilities. She underlined that we all belong to the human family, and that this topic is profoundly important to the goal of freedom, justice and peace in the world, and emphasized the importance of teaching human rights in schools. Moreover, she regretted the fragmentation by diagnosis within the disability community, because it drove families apart with the false idea that commonalities for working and advocating together were built by the kind of impairment. On the contrary, she said, the best way to organize all services, including educational programmes, was through an approach based on person-centred planning, as this helps us discover all the relationships that the child and the family have and how everyone concerned can improve their lives within the family and in the community. Finally, she praised inclusive education as a path to having all children with disabilities included in all ordinary schools, which would lead people to think about human rights in ways that they would not otherwise do.

## **2. Recommendations**

59. Participants at the seminar stressed that persons with disabilities, both adults and children, were individual rights holders. In that respect, implementation of the Convention was encouraged. The jurisprudence of the Committee on the Rights of Persons with Disabilities provided guidance for implementation of the Convention.

60. Families exist in diverse forms and, accordingly, a variety of kinds of support should be made available to all families of persons with disabilities, in order to ensure the individual's enjoyment and exercise of rights and inclusion and participation on an equal basis with others within families and in the community. Information, training and support for parents of children with disabilities and for parents with disabilities must be available for the full exercise of parental rights, as well as to respect the right to family both of the child and of the parents and to ensure that families are not separated on the basis of an impairment of the child or of either parent.

61. Another issue raised during the seminar was gender equality — also in the context of the Sustainable Development Goals (specifically Goal 5): most single-parent households are headed by women, and women and girls (with and without impairments) are commonly primary caregivers for other family members, including persons with disabilities. Therefore, support provided to families should take into account gender dimensions and ensure equal access to employment with flexible working conditions as well as respite services. Furthermore, restrictions to the right to marry and to sexual and reproductive health rights on the basis of gender, disability and other factors must be removed, and practices such as gender-based violence, including forced sterilization, must be abolished by law (in line with Goals 3 and 5). Information and education must be made available on these topics; access to sexual and reproductive health services must also be made available.

62. Given the cycle of poverty and disability, and the fact that parents and family members are often obliged to give up their employment and activities to provide care for the individual with disability, persons with disabilities and their families both face exclusion from society. In order to combat this problem, States should create disability-specific social protection schemes and should mainstream disability in existing poverty reduction programmes (in line with Goals 1 and 2), ensuring that the policies and measures adopted take into account disability-related costs. Access to social protection must recognize the legal capacity of individuals with disabilities, and in no way require that they be subjected to substituted decision-making or other measures that are not in accordance with the principles and provisions of the Convention. Existing requirements and practices that infringe the Convention must be repealed and the requirements and practices replacing them must be aligned with the Convention. In the same vein, laws and practices that restrict the exercise of legal capacity must be repealed, in order to eradicate all substituted decision-making systems and to introduce and make available supported decision-making systems.

63. The heightened risk of violence, abuse, discrimination and stigmatization that persons with disabilities face in different settings, including institutional and family environments, was examined in several presentations. All over the world, persons with disabilities, mainly those with intellectual and psychosocial impairments, are deprived of their liberty. Many others live with their families and may be deprived of autonomy and freedom of choice, even in relation to everyday activities. The right to live independently and be included in the community should be upheld through community-based services and support for persons with disabilities and their families, and by making available housing and personal assistance services to ensure freedom of choice regarding where and with whom to live, on an equal basis with others. Furthermore, as steps towards the promotion of present and future independent living, inclusive education within regular schools (in line with Goal 4) and inclusion within the open labour market (also in line with Goal 4) are key measures which create inclusive communities and which facilitate participation and inclusion across the full lifespan of the individual.

64. In order to tackle violations of human rights faced by persons with disabilities within and outside the home, including in institutions — such as discrimination, denial of legal capacity, denial of the right to live in the community, violence, deprivation of liberty, and barriers to accessing social protection, inclusive education and employment — access to justice should be guaranteed. Support services, education, information and awareness-raising campaigns should accompany the effort to render this right effective.

65. Given the increase in human rights violations during humanitarian crises and emergency situations, persons with disabilities — including child and adult refugees and

migrants with disabilities, and their families — should be priority recipients of services and support.

66. Training and awareness-raising, including for the judiciary, which is responsible for applying the law, is needed for effective application of the principles and provisions of the Convention. At the same time as legal and policy harmonization is taking place, including with the Committee's jurisprudence, innovative administrative and judicial measures can contribute to advancing the full enjoyment and exercise of the rights of persons with disabilities and their families, reversing existing patterns of discrimination.

67. Finally, a cross-cutting concern and recommendation was the need to systematically consult with and support representative organizations of persons with disabilities to ensure that all laws and policymaking concerning them are inclusive and take into account their lived experiences. Self-advocates and their organizations, as well as family-based organizations, are particularly necessary interlocutors, as they represent the key stakeholders.

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