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Chair: Mr. Saikal (Afghanistan)

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The meeting was called to order at 10.05 a.m.

Agenda item 74: Promotion and protection of human rights (*continued*)

- (a) **Implementation of human rights instruments** (*continued*) (A/73/40, A/73/44, A/73/48, A/73/56, A/73/140, A/73/207, A/73/264, A/73/281, A/73/282 and A/73/309)
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- (c) **Human rights situations and reports of special rapporteurs and representatives** (*continued*) (A/73/299, A/73/308, A/73/330, A/73/332, A/73/363, A/73/380, A/73/386, A/73/397, A/73/398 and A/73/404)
- (d) **Comprehensive implementation of and follow-up to the Vienna Declaration and Programme of Action** (*continued*) (A/73/36 and A/73/399)

1. **Ms. Degener** (Chair of the Committee on the Rights of Persons with Disabilities), presenting an oral report on the work of the Committee, said that the number of States parties that had ratified the Convention on the Rights of Persons with Disabilities had risen to 177, while the number of signatories stood at 30. As universal ratification was not far off, she urged the move from signature to ratification as soon as possible. In its dialogues with delegations, the Committee continued to raise the importance of the Optional Protocol to the Convention and counted on receiving a positive response.

2. During the previous year, the Committee had issued concluding observations following its consideration of the implementation of the Convention in 15 States parties, it had adopted two general comments relating to 15 lists of issues and it had adopted nine lists of issues under the simplified reporting procedure. It had also investigated allegations of grave or systematic violations under the procedure of the Optional Protocol.

3. For the 2018–2019 biennium, one additional week of meeting time had been granted but there had been no corresponding increase in resources. She called for Member States to adequately resource the treaty bodies so that it could provide redress for human rights violations.

4. Pursuant to General Assembly resolution 68/268, the Committee, at its twentieth session, had decided to implement a new time policy in order to increase the effectiveness of constructive dialogues with States parties and had designated two of its members as focal points for the 2020 review process on treaty body strengthening.

5. The Committee continued to benefit from support from civil society organizations, particularly organizations of persons with disabilities and national human rights institutions. At the Committee's first annual interactive debate with the Global Alliance of National Human Rights Institutions and other entities, representatives of those institutions and of independent monitoring frameworks had shared their experience of monitoring and data collection under the Convention. They had also shared good practices to ensure the involvement of organizations of persons with disabilities in monitoring the implementation of the Convention, other international human rights treaties and the Sustainable Development Goals. United Nations agencies, funds and programmes also continued to provide invaluable country-specific information to the Committee.

6. The denial or limitation of access to justice was a serious issue in all countries reviewed by the Committee. Access to justice concerned the right to legal capacity, a precondition for the exercise of other rights. Many persons with disabilities were denied that right because of their actual or perceived impairment.

7. The Committee continued to work with the Special Rapporteur on the rights of persons with disabilities and with other mandate holders and independent experts. The continuing human rights violations of women and girls with disabilities in respect of their sexual and reproductive health and rights was a matter of grave concern. In conjunction with the Committee on the Elimination of Discrimination against Women, the Committee had adopted a joint statement reiterating the call of the Special Rapporteur for the respect, protection and fulfilment of the rights of women, including women with disabilities.

8. Since the entry into force of the Convention, the Committee had endeavoured to translate the rights enshrined therein into meaningful changes in the lives of persons with disabilities. The Committee had

challenged the legal concept of incapacity and had led the way for an inclusive concept of legal personhood that outlawed violence and forced treatment against persons with disabilities. A number of countries had started to revise their legislation accordingly and had advanced the right to equal recognition before the law. The Committee had also had an impact on other treaty bodies and human rights mechanisms, promoting a recognition of persons with disabilities as rights holders, increasing awareness of issues such as accessibility and reasonable accommodation, and supporting decision-making and independent living. The Committee had thus helped to make the United Nations system more accessible for many persons with disabilities for the first time.

9. At the regional level, the Committee had called upon States parties that were also members of the Council of Europe to explicitly oppose the draft Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, as it conflicted with the human rights for persons with disabilities recognized by the Committee. Those rights included the right to equality, liberty, security, health and physical and mental integrity.

10. The Committee also elaborated general comments that sought to clarify and promote understanding of the conceptual shift from the medical and charity models of disability, which used to focus on personal impairments as justification for social exclusion, to the human rights model. During its nineteenth session the Committee had adopted general comment No. 6 (2018) on equality and non-discrimination (CRPD/C/GC/6). One of the main contributions of the general comment was the reference to inclusive equality as a model of equality based on human dignity, diversity and difference.

11. At the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, held in June 2018, the Committee had provided updates on its work and other relevant matters. The Committee on the Rights of the Child had extended cooperation and expertise to the Committee throughout the consultation and drafting process to ensure the inclusion of a child rights perspective in general comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (CRPD/C/GC/7), adopted following the day of general discussion held within the framework of the Conference.

12. Gender was recognized as one more aspect of the diversity of persons with disabilities; women with

disabilities were not a homogeneous group and were often faced with intersectional or multiple discrimination. Although gender parity had not been restored after the Committee elections in 2018, she was confident that the new Committee membership would continue to promote equality and non-discrimination and the enjoyment of rights by all.

13. Persons with disabilities deserved more and better attention from the United Nations system and there were positive signs in the right direction. The Convention provided valuable guidance for ensuring that implementation efforts were based on a human rights-based approach. Moreover, it was also a powerful tool for achieving the 2030 Agenda on Sustainable Development.

14. **Ms. Miyazaki** (Japan), affirming the importance of a holistic environment for individuals, including persons with disabilities, said that her country had been working to remove social barriers in order to build an inclusive society where everyone could fully enjoy his or her rights. Since inclusive education was a fundamental human right and a prerequisite for enhancing individual development and effective participation in society, she asked how such education could be achieved. While article 24 of the Convention recognized their right to education and article 9 affirmed that States parties should commit themselves to eliminating barriers to accessibility in schools, she asked what the Committee on the Rights of Persons with Disabilities could do to further enhance their social participation, especially in education.

15. **Ms. Fréchin** (Switzerland) said that since some disabilities called for constant care, the high cost of certain treatments exposed persons with disabilities to a heightened risk of poverty. While disabilities were not to be confused with illness, States must ensure that persons with disabilities could enjoy the best possible health and guarantee access to health care throughout their territories, including in peripheral regions. She enquired about the main steps to be taken to ensure that a country's health-care system was accessible to all persons with disabilities.

16. **Mr. Forax** (Observer for the European Union) said that the Convention had allowed a paradigm shift in disability rights. The European Union affirmed its support for the work of the Committee on the Rights of Persons with Disabilities in developing general comments, which were useful tools for States parties to further promote the human rights of persons with disabilities. The interplay of those rights within the United Nations development agenda was facilitated, in particular, by Sustainable Development Goals 4 and 5

on quality education and gender equality, Goal 8 on decent work and economic growth and targets 11.2 on transport systems for older persons and 11.7 on access to public spaces. He wished to hear how States could effectively mainstream the rights of persons with disabilities in the implementation of the 2030 Agenda.

17. All States members of the European Union were parties to the Convention and were fully committed to improving technical capacities, statistical information and mechanisms to guarantee the participation of persons with disabilities. Welcoming the decision by several States parties to withdraw their reservations pertaining to specific articles of the Convention, he urged all States parties to consider withdrawing any further reservations and to ratify the Optional Protocol. He asked how the rights of persons with disabilities could be further mainstreamed into the work of the other treaty bodies.

18. **Mr. Playford** (Australia) said that implementing the Convention was a priority for Australia domestically and also under its international commitments to human rights, development assistance and humanitarian action. His country's National Disability Strategy and National Disability Insurance Scheme were spearheading reforms to create an inclusive Australian society. Ensuring that Australians with disabilities had fair and equal access to the full range of services and support in education, employment, transport and infrastructure were key objectives of the country's reform agenda. He looked forward to the consideration by the Committee on the Rights of Persons with Disabilities of the second and third periodic reports of Australia and its observations on his country's approach to promoting and securing the rights of persons with disabilities.

19. **Mr. Holtz** (United Kingdom) said that his country had embedded the Sustainable Development Goals in its work at home and abroad and, in March 2018, had published a report setting out its approach to achieving the Goals. His Government had demonstrated its commitment to implementing the Convention by launching a new inclusive transport strategy, revising its national policy framework to ensure that the housing market worked better for persons with disabilities and creating a new interministerial group to drive forward coordinated action to tackle the barriers to full participation in government. The United Kingdom had also co-hosted the Global Disability Summit with the Government of Kenya and the International Disability Alliance. That Summit had adopted a Charter for Change, which outlined commitments by stakeholders closely aligned with the aims of the Convention itself.

20. Nationally, the United Kingdom aimed to place at least 1 million more persons with disabilities in decent work by 2027. His delegation welcomed the efforts made by the United Nations on inclusive development and wished to know how States could be encouraged to develop larger-scale programmes in support of access to decent work for persons with disabilities.

21. **Mr. Elizondo Belden** (Mexico) said that, in following up on the observations and recommendations issued by the Committee on the Rights of Persons with Disabilities, his country had established an inter-agency working group which operated jointly with civil society and had been instrumental in preparing the consolidated reports of Mexico on its compliance with the Convention. He asked what measures the Committee had undertaken to enable persons with disabilities to participate politically; to ensure recognition of their legal capacity; and to guarantee equality before the law. He would also welcome information on any best practices relating to the participation of organizations of or for persons with disabilities in implementing the Convention. While welcoming the recent ratifications and signatures of the Convention, his delegation wished to know what actions the Committee had in mind for encouraging those countries that had not yet joined to do so.

22. **Ms. Sukacheva** (Russian Federation) said that her delegation was grateful to the Committee on the Rights of Persons with Disabilities for its consideration, in February 2018, of the initial report of the Russian Federation on the implementation of the Convention on the Rights of Persons with Disabilities ([CRPD/C/RUS/1](#)). While welcoming the constructive assessment of the work done by her country to safeguard the rights of persons with disabilities, her delegation wished to reiterate that general comments were solely the views of the Committee experts and could not impose on a State any new obligations additional to those undertaken by it when ratifying the Convention. It was inappropriate for general comments to be used when considering a State's periodic report or to include them in the concluding observations.

23. **Ms. Degener** (Chair of the Committee on the Rights of Persons with Disabilities) said that general comment No. 4 (2016) on the right to inclusive education ([CPRD/C/GC/4](#)) provided guidelines on the right to education, in particular the need to make the mainstream education system accessible for all children with disabilities and to leave no one behind. Those guidelines, which related to article 24 of the Convention, contained many concrete measures that would enable States parties to overcome segregated education. Accessibility at all levels of the mainstream

education system was a prerequisite under article 24 and inclusive education was impossible without it.

24. With respect to the question on the right to health, particularly for persons with severe disabilities, she said that abolishing discrimination within the health-care system was one of the first steps towards ensuring respect for the right to health of all persons with disabilities. Persons with disabilities should not be reduced to their impairment and members of the medical profession should view them as rights holders rather than objects of rehabilitation. As such, they needed to have access to health care on an equal basis with everyone else. Their right to reject treatment was also of the utmost importance, especially in the mental health system where persons with disabilities were sometimes made to undergo forced treatment.

25. As far as mainstreaming the issue of disability in other treaty bodies was concerned, it would be helpful if more experts with disabilities were elected to those bodies. However, thanks to close collaboration with her Committee, the treaty bodies were already engaged in more disability-inclusive activities.

26. The Global Disability Summit had been a very successful and laudable event that represented an important step towards realizing inclusive development and complying with article 27 of the Convention on the right to work. Her Committee had been holding discussions with the organizers of that event to align implementation of the Summit outcome with implementation of the Convention and avoid duplication of work.

27. The delegation of Mexico had effectively outlined the most important issues for the second decade for the Committee. General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (CRPD/C/GC/7), provided helpful guidance. Furthermore, all the Committee's concluding observations contained guidelines on how to recognize legal capacity and implement a system of supportive decision-making.

28. With respect to the comment by the representative of the Russian Federation, the general comments were, indeed, non-binding. However, the Committee did view them as authoritative statements of international law. The Convention gave the Committee members a legal mandate to interpret certain provisions of that instrument in line with its jurisprudence, based on concluding observations and dialogues held with States parties either in Geneva or at the Conference of States Parties in New York.

29. **Ms. Devandas Aguilar** (Special Rapporteur on the rights of persons with disabilities), introducing her report (A/73/161), which was available in easy-read and Braille formats, said that its essential message was that health care must take into account the rights and requirements of persons with disabilities, who had the same health needs as other persons. Hence, barriers to primary and secondary health care must be eliminated, and services and specialized programmes must be developed in response to the specific health needs of such persons. Unfortunately, persons with disabilities had less access to health care and thus worse outcomes in terms of health than the overall population. They were at higher risk of accidents and were also susceptible to secondary and co-morbid conditions, including chronic health conditions such as diabetes, high blood pressure and cardiovascular diseases. Indeed, their life expectancy was lower. According to studies, persons with intellectual disabilities died between 15 and 20 years earlier than the population as a whole. The life expectancy of adults with psychosocial disabilities was about 20 to 25 years shorter.

30. Yet having a disability was not the same as having poor health. Gaps in the enjoyment of the highest attainable level of health were the result of inaction on the part of States. They were also due to stigma and discrimination, a lack of health literacy, barriers to accessing primary and secondary care, the limited availability of specialized services, and neglect and poor treatment in health services. Other factors were poverty and social exclusion.

31. States could take a number of steps to improve the realization of the right to health of persons with disabilities, including reviewing their legal and policy frameworks; taking concrete measures in the areas of universal health insurance, accessibility, non-discrimination and participation; and mobilizing resources for the implementation of the relevant measures.

32. Too often, persons with disabilities were denied access to primary care on the assumption that they needed specialized services or, worse, that their ailments were the inevitable and incurable consequence of their disability. In most cases, their health requirements could be met through primary care. In other cases, primary care was needed for proper referral and subsequent follow-up. Excessive dependence on specialist care could result in medicalization of the disability and higher costs.

33. Health was essential for sustainable development. If persons with disabilities did not have access to medical and rehabilitation services, they would

probably be unable to attend school, keep a job or participate actively in the development of their communities. On the contrary, they would be subject to a higher risk of institutionalization and violence.

34. Development must go hand in hand with human rights. In many countries, the rights of persons with disabilities were violated by their very health services. The denial of free and informed consent was a widespread practice in mental health services. Girls and women with disabilities constantly faced grave violations of their sexual and reproductive rights, including practices such as forced sterilization and forced abortion.

35. An increasing number of controversial treatments were being practised, including psychosurgery, packing for autistic children and limb-lengthening for children with restricted growth. Many such interventions were invasive, painful and irreversible and therefore should not be performed on minors. Health without inclusion was oppression. Quality services were required that did not detract from the exercise of the rights of the persons in question.

36. Even in difficult circumstances, human beings had found the means to support and respect diversity, as illustrated by the remains of the Nazca mummy of a lame child who, despite his handicap, had been cared for appropriately and had received good hygiene and frequent changes of position. Given the progress recorded in the past 1,300 years, that child should not be an exception.

37. **Ms. Swatz** (South Africa) said that 10 years after the Convention had come into force, persons with disabilities continued to be viewed as objects of medical treatment and social protection instead of as full and equal rights holders of a diverse humanity. The year 2018 marked the centenary of Nelson Mandela's birth. His recognition of the presence of disability as an enrichment of the diversity of humanity echoed the articles of the Convention, which attempted to change the mindset of society away from a medical and paternalistic approach towards a human rights-based approach.

38. Having recently presented its initial country report to the Committee on the Rights of Persons with Disabilities ([CRPD/C/ZAF/1](#)), South Africa had undertaken to implement the concluding observations emanating from the constructive dialogue ([CPRD/C/ZAF/CO/1](#)). The Special Rapporteur had made strong recommendations for States to review their policy and legislative frameworks in order to combat outdated approaches that led to stigmatization and stereotyping. Of even greater importance was the

implementation of those revised policies to ensure that persons with disabilities enjoyed non-discriminatory, inclusive and accessible health-care services. Training health-care professionals to engage with persons with disabilities without discriminatory attitudes was therefore imperative. Her Government was keen to learn of best practices where public-private initiatives had addressed the high costs of the assistive devices and technologies required by persons with disabilities.

39. **Mr. Bastida Peydro** (Spain) said that promoting and defending the rights of persons with disabilities was a priority of his Government's foreign and domestic policy. Spain was therefore concerned by the conclusion in the Special Rapporteur's report that persons with disabilities experienced poorer access to health care than the general population owing to various structural factors and discriminatory legislation and policies. The Spanish Strategy on Disability sought to guarantee the needs of persons with disabilities in the exercise of their right to health. Health coverage had been established as an important tool for increasing access by persons with disabilities to health assistance. Since the families of persons with disabilities also suffered discrimination by association, his delegation asked the Special Rapporteur for recommendations on how public policies might prioritize their needs.

40. **Ms. León Murillo** (Costa Rica) said that persons with disabilities must be allowed to participate actively in the design, application, monitoring and assessment of health policies and programmes, since they knew best what obstacles they faced and how their lives were affected. The denial of free and informed consent and the imposition of involuntary treatment continued to be an infringement of their rights. Indeed, a considerable amount of national legislation, in particular with respect to mental health, authorized forced hospitalization and treatment based on criteria of medical necessity and risk.

41. The Promotion of Autonomy for Persons with Disabilities Act of Costa Rica did away with guardianship, recognized the full legal capacity of persons with disabilities and prohibited any type of involuntary treatment. She asked the Special Rapporteur for her view on how such measures empowered persons with disabilities to enjoy their right to health fully and on an equal basis with other persons. She also wondered whether those measures were indispensable for the implementation of the Convention on the Rights of Persons with Disabilities.

42. **Mr. Gonzalez** (Colombia) said that his country's national public disability policy cut across all sectors to guarantee that persons with disabilities fully enjoyed

their rights. Colombia would submit its consolidated second, third and fourth periodic report on the implementation of the Convention on the Rights of Persons with Disabilities no later than 10 June 2021.

43. The establishment of the Office of the Presidential Advisor on Disabilities had recently been announced. Other legal developments in Colombia had led to a process of ownership, which implied redefining disability in social and human rights-based terms. All sectors should be recognized as competent to fulfil their duty of upholding rights and not merely of providing programmes and services to cope with requirements. Legislation should be amended in line with the international framework relating to the right to health and the rights-based approach to disability.

44. Colombia had established the National Council on Disability to verify, monitor and evaluate the national disability system and related public policies, which his Government would continue to strengthen in order to guarantee the rights of persons with disabilities.

45. **Mr. Mero** (United Republic of Tanzania) said that his Government's Vision 2025 and National Five-Year Development Plan (2015–2020), together with the Health Sector Strategic Plan IV (2015–2020), provided guidelines for addressing the challenges of providing health-care services to persons with disabilities, particularly those relating to poverty, stigmatization and stereotypes.

46. Several legislative instruments had been put in place to afford access to health care for persons with disabilities. In conjunction with various stakeholders, the Government supported initiatives to serve the health needs of women and girls with disabilities, particularly in connection with HIV/AIDS and cancer.

47. Despite those efforts, the health services faced challenges such as a lack of sign language interpreters for deaf persons and limited specialized services such as cancer screening and treatment for persons with albinism. Furthermore, some families lacked awareness and continued to hide children with disabilities. In response to those problems, his Government had removed tariffs on raw materials and products for assistive devices and was strengthening health services, especially in rural areas, and conducting programmes to raise awareness in the community, identify children with disabilities and provide them with the relevant interventions.

48. **Mr. Playford** (Australia) said that a healthy population was critical for achieving the 2030 Agenda, as health was both an outcome of, and a path to, achieving sustainable development. States were

expected to further mainstream disability into health services, remove barriers and promote productive and healthy lives for all, including universal access to sexual and reproductive health services and rights. Australia remained firmly committed to fully implementing the Convention. Respect for the rights of persons with disability would continue to be a priority for his country not only domestically but also in the context of its international commitments to development, humanitarian action and human rights. His delegation welcomed the Special Rapporteur's ongoing advocacy of disability rights and inclusion.

49. **Mr. Ri Song Chol** (Democratic People's Republic of Korea) said that his country had become a party to the Convention on the Rights of Persons with Disabilities in 2017. The Special Rapporteur had visited the Democratic People's Republic of Korea in May 2017, following which the Government had taken further steps to protect the rights of persons with disabilities, who needed more family and social care than other people.

50. His country's entire population had become the target of coercive and discriminatory sanctions imposed by the Security Council. Persons with disabilities, including women and children, were among those who had suffered the most from the negative impact of those sanctions, which blocked the import of medicines, medical equipment, tools and basic life-saving materials. He asked the Special Rapporteur what recommendation she could make for the swift removal of such life-threatening sanctions.

51. **Ms. Ahmed** (Kingdom of Bahrain) said that, in order to further the rights of persons with disabilities, government ministries and agencies had been working towards rehabilitation in cooperation with civil society organizations and the private sector. Persons with disabilities received social care, health care and training. Many initiatives had been launched to increase their participation, including a reduction in related fees by up to 50 per cent. Special areas throughout the Kingdom had been set up for persons with disabilities and efforts were being made to transform them from mere recipients of care to productive members of society. Steps had also been taken to boost their creativity and competitiveness and to provide them with a high level of training.

52. **Ms. Sukacheva** (Russian Federation) said that providing access to quality medical services, rehabilitation and training for persons with disabilities was a priority of Russian social policy. Such persons received comprehensive health-care services, including high-technology medical care, and the procurement of technical rehabilitation equipment was financed through

the national budget. Unfortunately, not all States had the necessary financial resources or access to cutting-edge technology. Her delegation wondered what measures might be the most effective in assisting such countries to implement the provisions of article 25 of the Convention on the Rights of Persons with Disabilities.

53. **Mr. Aziz** (Iraq) said that the principle of non-discrimination against persons with disabilities was enshrined in his country's Constitution. The law in Iraq ensured full rights for persons with disabilities, non-discrimination against them, integration in society, a life of dignity, and a culture of respect. Disabilities were recognized as a form of diversity. He asked how the Special Rapporteur was cooperating with the World Health Organization to ensure that women living with disabilities had full access to health-care services and programmes without fear of discrimination.

54. **Mr. Forax** (Observer for the European Union) said that the European Union was concerned about the prevalence of multiple and intersecting forms of discrimination affecting persons with disabilities, in particular women and girls. In that regard, he wondered what might be considered the main challenges to the right to health, including the provision of health services, and what response could be envisaged. He also wished to know what recommendation the Special Rapporteur would make for alternative means to ensure the right of free and informed consent, thereby preventing involuntary treatment and hospitalization.

55. **Ms. Widyaningsih** (Indonesia) said that her country's policies relating to persons with disabilities had advanced to a more human rights-based approach, designed to empower and create a more inclusive environment for them. Her Government continued to provide access to reproductive health services and assistive devices for persons with disabilities, who also benefited from community-based support. In addition, the Government had undertaken preventive measures such as free, regular immunization programmes and early detection screening. Several strategies had been established, including social protection schemes for poor families with persons with disabilities and a universal health-care programme. She asked the Special Rapporteur to elaborate how South-South cooperation and triangular cooperation could further promote the rights of persons with disabilities with special reference to the area of health.

56. **Mr. Elizondo Belden** (Mexico) said that there was a fundamental right to health in his country. In that regard, medical and surgical procedures for diagnostic or therapeutic purposes could not be conducted without the written and signed authorization of the patient, who,

moreover, must be informed of the potential risks and benefits. His Government wished the Special Rapporteur to explain what, in her experience, constituted the best practices for obtaining the free and informed consent of persons with disabilities or for determining their wishes and preferences. His delegation would also be grateful to hear her experience regarding the training provided to ensure that health personnel respected the preferences of persons with disabilities without imposing their own decisions or exercising undue influence on them.

57. **Ms. Mc Dowell** (New Zealand) said that her country's national disability strategy was co-designed and co-monitored by the Government and persons with disabilities. Access to mainstream health services was free and inclusive, and services specific to persons with disabilities, including mental health and home care services, were of a high quality, available and accessible. The priority was to improve health outcomes for persons with disabilities with a specific focus on persons with learning and intellectual disabilities. Her delegation wished to know what the Special Rapporteur considered to be the most important step in improving accountability for violations of the right to health for persons with disabilities.

58. **Mr. de Souza Monteiro** (Brazil) said that, since 2002, Brazil had implemented its national health-care policy for persons with disabilities, which served as a framework for the provision of health services to members of that population within the universal and free public health system. The approval in 2016 of the National Inclusion Act, which was fully aligned with the Convention, was another step forward, especially for guaranteeing the autonomy of persons with disabilities by recognizing supported decision-making. He asked the Special Rapporteur to elaborate on the affordability of measures designed to make health-care systems more inclusive, bearing in mind that Governments were reluctant to incur higher health-care costs.

59. **Ms. Shlein** (Israel) said that the Ministry of Social Justice and the Ministry of Health in Israel provided financial assistance to representative organizations of persons with disabilities. They also invited such persons to participate in all decision-making processes and to attend various government and parliamentary committees that reviewed relevant policies or discussed their rights. The regulations adopted during those consultations had increased the scope of accessibility requirements relating to sites and services, including for the construction of public buildings, educational facilities and other open public places, such as cemeteries, beaches, archaeological sites and nature reserves. The violation of the terms of an accessibility

order was a criminal offence punishable by a court-imposed fine.

60. Employment discrimination against a person with a disability by reason of his or her disability, or against the family members of such a person for the same reason, was strictly prohibited under the Equal Rights Act. Failure to make adjustments to meet the special needs of persons with disabilities in order to facilitate their employment was also defined as discrimination. She asked the Special Rapporteur if she saw any role for national Governments in promoting international guidelines to safeguard the rights of persons with disabilities.

61. **Mr. McElwain** (United States of America) said that his country recognized that persons with disabilities deserved the same dignity and freedom to live autonomous lives as others. Businesses in the United States realized that hiring employees with disabilities brought new creativity and skills that strengthened their performance, increased competition and drove innovation. The year 2018 marked the fiftieth anniversary of the Architectural Barriers Act, which had laid the foundation for accessibility standards requiring public and private entities to be accessible so that persons with disabilities could lead fully independent lives in the communities. He asked the Special Rapporteur what recommendation she would have for Member States, civil society and United Nations agencies to truly shift the conversation from the medical charity model to the rights-based view of disability.

62. **Ms. Devandas Aguilar** (Special Rapporteur on the rights of persons with disabilities) said that new technologies and new devices deserved to be embraced as long as they supported the active participation of persons with disabilities in the community as equal citizens and did not lead to their isolation.

63. The full recognition of the legal capacity of persons with disabilities and of their right to provide free and informed consent was fundamental. Some 30 countries were already in the process of adopting new legislation that recognized legal capacity. While such legislation might not always be fully in compliance with the Convention on the Rights of Persons with Disabilities, it would enable persons with disabilities to enjoy the highest attainable standards of health because they would be able to give their informed consent on an equal basis.

64. Persons with disabilities going through crises and distress should be given responses that were supportive and human rights-based. Alternatives that decreased the rates of involuntary treatment should be used. Indeed, alternative practices had proved to be more effective.

For instance, States could invest in respite services or houses, peer support and community-based services. In short, alternatives to coercion, based on collaboration between government services and civil society, had proved to be successful.

65. Most of the multiple and intersecting forms of discrimination had been seen in the mainstream services. Any public health policy must take into consideration non-discrimination, accessibility and support services for persons with disabilities along with the principle of participation, in consultation with persons with disabilities.

66. Persons with disabilities must receive all the health-care services they needed. They must not be seen only as objects of care but as rights holders with the potential to exercise their rights, to be heard and to have their will and preferences respected.

67. With respect to South-South and triangular cooperation, a lot could be learned from low-income countries, which were coming up with many innovative practices. The support of financial partners could help to scale up practices that were taking place at the community level in low- and middle-income countries.

68. She had always collaborated strongly with the World Health Organization and, since the publication of her report, had started a very fruitful engagement with its officials.

69. **Ms. Ero** (Independent Expert on the enjoyment of human rights by persons with albinism), introducing her report ([A/73/181](#)), said that her mandate had been renewed earlier in 2018 to address ongoing reports of attacks against persons with albinism and continued stigma against such persons around the world. Since the inception of her mandate in 2015, many attacks had come to light but several milestones had also been achieved, notably the development of the Regional Action Plan on Albinism in Africa 2017–2021. The Plan, delivered by her with stakeholders in the region, had been endorsed by the African Commission on Human and People's Rights. Each of the 15 measures and 40 targets, specific to the enjoyment of human rights of persons with albinism, were also linked to the broader Sustainable Development Goals. For example, Goal 1 was highly important because nearly all victims of attacks were poor people. Goal 3 on health was also crucial owing to the disproportionately high death rate of persons with albinism from preventable skin cancer. Goal 4 was also relevant as a better education increased the chance of working indoors and lifting that group of persons out of poverty. Similarly, Goal 5 on gender equality was vital as women with albinism were subject to extreme violence, such as ritual rape.

70. The central pledge of the 2030 Agenda was to leave no one behind and to start with those furthest behind first. That pledge contained the core aim of ending absolute poverty and discrimination by prioritizing action. Persons with albinism, although representing a small segment of the population across the globe, were disproportionately affected by poverty, mainly in developing countries and least developed countries. They faced multiple and intersecting discrimination on the grounds of disability and colour and were often structurally left out of policies in the areas of health and education. They were clearly among the furthest behind worldwide. Accordingly, Member States and relevant stakeholders should fast-track affirmative action for them. Those in sub-Saharan Africa deserved to be given the highest priority, considering the urgent need to eradicate witchcraft-related harmful practices. Moreover, countries with high sun exposure should address the threat of skin cancer as a public health priority.

71. Specific measures on persons with albinism required the specific allocation of funding in national budgets and, in low-income countries, the support of international cooperation. Given the relatively low prevalence of the condition, the resources needed would be modest and affordable by most Member States, while the returns on such an investment would be invaluable to persons with albinism.

72. In the spirit of Goal 17 on partnership, she urged delegations to support the website actiononalbinism.org by providing their input and reports. That platform was an exemplary initiative and, although still a work in progress, it highlighted the power of partnership and the utility of technology in the implementation of the 2030 Agenda.

73. **Mr. Mero** (United Republic of Tanzania) said that his country was aware that proper data collection on persons with albinism was important for ensuring their socioeconomic development. His Government remained committed to improving infrastructure and outreach to ensure that communities and families hiding children with albinism received appropriate education. The assistance and cooperation of the international community in that endeavour was of paramount importance. His Government was committed to protecting persons with albinism, in keeping with the Constitution of 1997, the Persons with Disabilities Act of 2010 and the other institutional and legal frameworks to which the United Republic of Tanzania was a party. He encouraged the members of the international community to heed the recommendations contained in the Special Rapporteur's report.

74. **Ms. Miyazaki** (Japan) said that, having engaged with the international community for 25 years in the development of Africa through the Tokyo International Conference on African Development, Japan welcomed the Regional Action Plan on Albinism in Africa endorsed by the African Commission on Human and People's Rights. She would also welcome the Independent Expert's views on how similar initiatives might be fostered and duplicated in other regions. Japan had launched an initiative to eliminate discrimination against persons affected by leprosy. Her delegation would be pleased to listen to and apply some of the lessons learned by the Independent Expert in her efforts to eradicate discrimination against persons with albinism.

75. **Mr. Forax** (Observer for the European Union) said that the European Union was fully committed to working with the Independent Expert and welcomed her latest report, which focused on the link between albinism and the 2030 Agenda. He wondered whether she could share any examples of best practice for ensuring the participation of persons with albinism in the elaboration of national development plans and policies and data collection.

76. **Ms. Ileka** (Namibia) said that, as pointed out by the Independent Expert in her report, Namibia had the most persons with albinism per capita in the world. While some persons in that category had reported being discriminated against in society, the biggest issue facing persons with albinism in Namibia remained skin cancer and limited access to medical treatment and care. Her Government had enacted progressive and inclusive legislation and policies that sought to afford persons with albinism access to services and resources, including the provision of free medical services, a disability grant to offset the high cost associated with skin-care medication and affirmative action policies for the benefit of persons with albinism. Investment from development partners would be necessary in order to obtain the resources and technical support needed to roll out the specific measures set out in the Independent Expert's report and in the Regional Action Plan on Albinism in Africa. Her delegation would welcome any other recommendations that the Expert might wish to put forward for bettering the lives of persons with albinism.

77. **Ms. Swatz** (South Africa) said that her Government considered partnerships with persons with albinism to be a priority. Multisectoral public awareness and education campaigns on the rights of persons with albinism were being conducted in partnership with the Albinism Society of South Africa, the South African Human Rights Commission, institutions of traditional

leaders and healers, religious communities and schools. As a result of such cooperation, there had been swift arrests, prosecutions and convictions after crimes had been committed against persons with albinism. In preparation for a national albinism conference in 2019, a national strategy on advancing the rights of persons with albinism would be used as a platform for consultations with all relevant public sector institutions as well as within the albinism sector itself. As the lack of disaggregated data on persons with albinism was of great concern, her delegation supported multisectoral partnerships to share knowledge, expertise, technology and financial resources, particularly in developing countries.

78. South Africa was currently participating in a campaign with the Southern African Development Community with the aim of adopting a protocol on the rights of persons with albinism. Her Government looked forward to hosting the Independent Expert in her official capacity in the future in order to demonstrate the efforts by South Africa to protect persons with albinism and to learn from her how its interactions and institutional capacity could be strengthened.

79. **Ms. Shlein** (Israel) said that her country had, for many years, granted asylum to persons with albinism and their families in the hope that they could build a better life out of harm's way. Special assistance and attention were needed for vulnerable populations, such as women and children. Israel encouraged other States to take measures to recognize the urgency of raising awareness and understanding of the condition of albinism and to end attacks against persons with albinism, including by immediately investigating allegations, providing protection, psychological and medical treatment to the victims and taking the necessary steps to end trafficking in body parts. She asked the Independent Expert which specific Member State inputs would better serve her work in 2019 and commended her once again for her vision and leadership.

80. **Ms. Ero** (Independent Expert on the enjoyment of human rights by persons with albinism) said that some countries had received vast amount of money from wealthier States for the protection of wild life. Malawi, for example was receiving support from many States to protect its endangered species. Millions of dollars went into preventing animals from becoming extinct. While that was laudable, she wished to ask for a fraction of the money that States were spending on animals for persons with albinism. The fact that persons with albinism were being hunted down for their body parts could never be emphasized enough. Therefore, she wished to ask for the support of the international community in that regard.

81. Kenya represented a good model of the effective action that could be taken. For example, it had established a national council for persons with disabilities, within which an officer had been specifically dedicated to the issue of people with albinism. The Government of Kenya had also set aside 1 million dollars per year in terms of funding for albinism. That was money could save lives.

82. The Regional Action Plan on Albinism in Africa needed to be replicated in at least two other regions as a way of addressing the issue. While South America did not necessarily have physical attacks, she had received reports from persons with albinism who had no access to sunscreen and many had passed away from skin cancer, which was perfectly preventable. It was not a matter of enacting a new law, hence there was no need for anxiety. Action plans could be used to guide the actions of various stakeholders. She hoped that the same could be done for persons affected by leprosy. If the laws already existed, then the problem was implementation. If implementation was the problem, then action plans were the answer.

83. She expressed appreciation to the European Union for the funding provided to conduct surveys in sub-Saharan Africa on persons with albinism. Those were temporary solutions while waiting for censuses. Disaggregated data would ultimately provide the necessary knowledge to protect those whose lives were in danger. She congratulated those countries that had added a specific question in their censuses on albinism. She also looked forward to visiting South Africa shortly.

84. Solidarity was needed to address the direct concerns of persons with albinism. Member States must therefore act as advocates for them and, as Kenya had done, make the extra efforts required to help those who had been left the furthest behind.

The meeting rose at 12.25 p.m.