

Twenty Years of the CRPD: Health Equity as an Enabler of Inclusion

In December 2026, the world marks the 20th anniversary of the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), a landmark treaty that established disability as a matter of human rights, equality, and inclusion. Over the past two decades, the Convention has inspired profound changes in legislation, policy, and public attitudes, affirming that persons with disabilities are rights holders entitled to participate fully and equally in all aspects of society.

Twenty years on, the Convention has achieved near-universal recognition, with 192 States and the European Union having ratified it. Yet anniversaries are not only moments to celebrate progress; they are also opportunities to reflect on the work that remains.

This anniversary provided an important opportunity for reflection, as demonstrated during the 19th Session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (COSP19), where governments, organisations of persons with disabilities, civil society, and other stakeholders came together to assess the Convention's impact. Across the discussions, a common question emerged: twenty years after the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD), how far have we come, and how far do we still have to go?

The answer is both encouraging and challenging.

Progress Worth Celebrating

One of the Convention's most significant achievements is the shift it has driven in how disability is understood and addressed: towards a rights-based and inclusion-focused approach. Today, the emphasis is increasingly on identifying and removing the barriers that prevent people from participating fully and equally in society.

For people living with spina bifida and hydrocephalus (SBH), this means that participation is not determined solely by a diagnosis. Whether a person can attend school, access employment, participate in community life or live independently often depends on factors such as accessible environments, inclusive policies, assistive products, support services and societal attitudes. While medical care remains essential, the focus is no longer simply on treatment, but on enabling participation, dignity, autonomy and inclusion.

During the opening of COSP19, United Nations Secretary-General António Guterres noted the positive impacts of the CRPD on States' policies: 88% of States Parties have adopted legislation prohibiting disability discrimination and 75% have introduced laws supporting the inclusion of students with disabilities in education.

These achievements matter. They reflect two decades of sustained advocacy by persons with disabilities, their families, organisations of persons with disabilities (OPDs), and governments committed to advancing rights, equality, and inclusion.

From Rights on Paper to Rights in Practice

Despite progress in legislation and policy, speakers at the COSP19 repeatedly emphasized a persistent gap between legal commitments and lived reality. As United Nations Secretary-General António Guterres noted "Progress remains unacceptably slow", underscoring the urgency of moving from commitment to the full implementation of the CRPD.

Civil society representatives echoed this concern. For instance, the European Disability Forum stressed that while the CRPD provides a clear roadmap for change, its promise has yet to be fully realised, with implementation remaining uneven across regions and policy areas. They highlighted that in the European Union, approximately 400,000 persons with disabilities are still denied the right to vote due to continued legal inconsistencies with the Convention. They also drew attention to the 66 million women and girls with disabilities in Europe who continue to experience disproportionate high levels of violence, abuse and discrimination.

Across discussions, two interconnected priorities emerged. First, the urgent need to eliminate all forms of violence, exploitation, and abuse against persons with disabilities. Second, the importance of moving beyond consultation towards genuine representation, leadership and influence in political and public decision-making.

This emphasis on participation was a recurring theme. Speakers stressed that persons with disabilities must not only be consulted but actively involved in shaping policies and decisions. In this regard, UN Special Rapporteur on the Rights of Persons with Disabilities Ms Heba Hagrass underlined that participation "must not be symbolic but real", and that persons with disabilities should be engaged as equal members of society across all policy domains.

Reinforcing this message, International Disability Alliance President Dr. Nawaf Kabbara reminded participants that "Meaningful participation is not a favour to us, it is a right we have".

Addressing Emerging Challenges

The discussions at the COSP19 also highlighted a set of evolving and increasingly complex challenges for disability inclusion. Among them, intersectionality featured prominently.

Speakers emphasized that the experiences of persons with disabilities are not uniform, and that barriers are often compounded by gender, age, migration status, ethnicity, or sexual orientation. Women and girls with disabilities, refugees with disabilities, Indigenous persons with disabilities, and LGBTQIA+ persons with disabilities face distinct and overlapping forms of exclusion that require more nuanced and responsive policy approaches.

Alongside these structural inequalities, participants drew attention to the rapid development of artificial intelligence and digital technologies. While these innovations hold significant potential to improve accessibility and participation, they also carry clear risks. Several speakers warned that if designed without the meaningful involvement of persons with disabilities, emerging technologies may reinforce existing inequalities or create new forms of discrimination. Ensuring accessibility, transparency, and disability-inclusive governance of artificial intelligence is therefore becoming an urgent priority for the coming decade.

The discussions also reflected on progress within international systems themselves. The United Nations Disability Inclusion Strategy (UNDIS) continues to guide efforts to strengthen disability inclusion across the UN system, while regional frameworks such as the European Union Strategy for the Rights of Persons with Disabilities 2021-2030 provide additional policy direction. Within this context, Ms. Ana Carla Pereira, Director for Equality and Non-Discrimination at the European Commission (DG JUST), emphasized that meaningful participation requires the involvement of persons with disabilities at every stage of policymaking, alongside adequate funding and strengthened capacity of OPDs.

However, civil society organisations also underscored persistent structural barriers within these very systems. Despite progress in policy frameworks, accessibility challenges remain within international institutions, including in global forums intended to advance inclusion. As several speakers noted, the credibility of global disability rights commitments depends on ensuring that participation in these spaces is itself fully accessible.

Taken together, these developments point to an evolving agenda for disability rights. Beyond the implementation of existing commitments, the future of inclusion will be shaped by the ability of systems to respond to intersecting inequalities, technological transformation, and the need for genuinely accessible global governance.

Health as a Fundamental Human Right

As the CRPD enters its third decade, one message has become increasingly clear: without health equity, the promise of inclusion cannot be fully realised. Health is not a separate or secondary issue within the Convention; it is a foundational condition that enables the enjoyment of all other rights.

For the International Federation for Spina Bifida and Hydrocephalus, one important observation from the COSP19 was the relatively limited visibility of health and the right to health, a core principle of the CRPD (Article 25). While themes such as participation, independent living, accessibility, violence, humanitarian crises, and political representation were extensively addressed, health was rarely addressed as a distinct area.

This is particularly significant because Article 25 of the CRPD guarantees the right of persons with disabilities to the highest attainable standard of health without discrimination. However, the realisation of this right is deeply interconnected with the enjoyment of other rights under the Convention. Access to timely and appropriate healthcare, rehabilitation, assistive products, and lifelong support directly influences whether persons with disabilities can exercise their rights to independent living and inclusion in the community (Article 19), personal mobility (Article 20), education (Article 24), work and employment (Article 27), habilitation and rehabilitation (Article 26), and participation in political and public life (Article 29).

In this sense, health functions as an enabling system for inclusion. Where health services are accessible, coordinated, and inclusive, they support autonomy and participation. Where they are fragmented or unavailable, they become a structural barrier that limits the realisation of rights across all areas of life.

As IF President Victoria Sandoval emphasised:

"Twenty years after the adoption of the CRPD, far too many people with spina bifida and hydrocephalus continue to face barriers to their fundamental right to health. Essential health services remain inaccessible or unaffordable for many. Access to assistive products continues to be limited, and too many individuals still struggle to obtain the supplies, equipment and services they need to live healthy, independent and dignified lives. Geographic, financial and systemic inequalities continue to leave too many people behind. Achieving the promise of the CRPD requires ensuring that health equity becomes a reality for everyone, everywhere."

For people living with SBH, this interdependence is particularly evident. Lifelong access to specialised care, rehabilitation, continence care, assistive products and follow-up support is often essential to enable participation in education, employment, independent living, and community life. Health systems therefore play an important role in shaping whether inclusion is achievable in practice.

It is within this context that IFSBH convened a COSP19 side event, ["Health as a Pathway to Inclusion – Advancing Equity for Persons with Spina Bifida and Hydrocephalus"](#), positioning health equity as a central component of CRPD implementation. The event brought together persons with lived experience, disability leaders, health professionals, and other advocates from multiple regions to explore how strengthening health equity can support the implementation of the CRPD as a whole.

The opening of the session featured key interventions from UN Special Rapporteur on the Rights of Persons with Disabilities Ms Heba Hagrass, International Disability Alliance President Dr. Nawaf Kabbara, and IFSBH President Ms Victoria Sandoval. Each underscoring the structural importance of health equity in advancing inclusion.

As highlighted by IF Secretary General Dr. Sylvia Roozen during the event: “Health is not separate from inclusion. Without health equity, inclusion remains out of reach for many people living with lifelong conditions such as SBH”.

IF's engagement on these issues extends beyond COSP19. Through its ECOSOC accreditation, collaboration with the WHO Health Equity Disability Network, engagement with European institutions and participation in international disability networks, IF continues to advocate for disability-inclusive health systems and the rights of people living with SBH worldwide.

Looking Ahead: The Next 20 Years

Twenty years after the adoption of the CRPD, there are clear reasons to celebrate. Rights are more widely recognised, accessibility, participation and inclusion have received more attention, and more countries have adopted disability-related legislation and policies.

Yet significant gaps remain.

Across contexts, implementation continues to lag behind commitments. Healthcare inequalities persist. Violence and discrimination remain widespread. Political participation is still restricted in many countries. Humanitarian crises disproportionately affect persons with disabilities. Civil society organisations face increasing pressures on resources and sustainability. As a result, many persons with disabilities continue to encounter barriers that prevent the full enjoyment of their rights.

As COSP19 demonstrated, the next chapter of the disability rights movement is not about defining new rights, but about ensuring the full realisation of the rights already enshrined in the CRPD.

For our global SBH community, this means sustained advocacy for health equity as a foundation for the realisation of rights enshrined in the CRPD, including independent living, personal mobility, access to assistive technologies, and full participation in society. Achieving these goals will require stronger implementation of the CRPD, sustained investment in inclusive systems and services, and the active involvement of persons with disabilities in decisions that affect their lives. Only then persons living with SBH will be able to fully enjoy their rights and participate equally in society.

As youth representative Nilshani De Silva from Sri Lanka reminded participants during the COSP19 opening session “The CRPD is not just a document, it is a promise”.

Twenty years on, that promise remains as urgent and relevant as ever.