



General Assembly

Distr.: General
3 September 2019

English only

Human Rights Council

Forty-second session

9–27 September 2019

Agenda item 4

Human rights situations that require the Council's attention

Written statement* submitted by Sikh Human Rights Group, a non-governmental organization in special consultative status

The Secretary-General has received the following written statement which is circulated in accordance with Economic and Social Council resolution 1996/31.

[21 August 2019]

* Issued as received, in the language(s) of submission only.



‘See the child, not the disability’ - promoting Human Rights for children with disability and their neurodiversity

The Human Rights Council and State members are requested to look at an area of human rights and sustainable development goals that often receives inadequate attention. We want particularly to draw attention to UN Sustainable Development Goals 1, 4 and 10 in reference to children with disabilities.

Every child has a right to a clear pathway of support to understanding their full capabilities and have the opportunity to grow and develop those abilities. There is a need for strengthening pathways into society that help respect their capabilities and not ignore them. Pathways that encourage engagement to learn, to work and to integrate. There is a need to enhance pathways that encourage children to take their place in society as engaged citizens and review pathways that discourage or disengage them as citizens.

Parent’s and Carer’s dream of the capabilities that their children will manifest well before birth. But when a child is born, injured, diagnosed with a disability, the questions are many including, “what does the future hold, what do I do now as a Parent or Carer”? How do States help Parent’s and Carer’s with these questions and support them to understand, navigate and utilise a complicated set of systems that are changeable and unclear? How can States support around “What to do when a child has a disability”? How do we as society reduce the stresses faced by Parent’s and Carer’s running from pillar to post searching for answers, solutions, support and how do we ensure children, Parent’s and Carer’s have a voice in how their support is created and delivered?

It is the responsibility of States to create sustainable efficient service models to support families and children with disabilities. And further to create societies that support not shun, that care not ignore children with disabilities. States and responsible organisations should harness the collective good within communities towards the challenges faced by these families and children.

It is often the case that whosoever shouts the loudest in society gets the support. We have thus by accepting this approach, normalised societal structures to accept and reward variances in ability where those deemed most able are rewarded the greatest that those deemed least able rewarded with lack of opportunity. By doing so we have distanced ourselves from the reality that everyone is capable, that everyone deserves the opportunity to realise their capabilities, to have them strengthened and grow ability.

Children with disabilities, particularly with mental disabilities, such as Autism, tend to fall behind and end up growing into poverty, further problems and are vulnerable to exploitation.

We draw attention to 3 of the UN Sustainable development Goals,

- Goal 1 No Poverty
- Goal 4 Quality Education
- Goal 10 Reduced Inequalities

We believe that States should set up structures and guide society to refocus support around the growth of each individual’s development through comprehensive diagnosis, education and support into the work place. This requires pathways designed not through isolation but through collaboration centred on the child, not the disability. Pathways that enable essential support networks that form the essential spheres of a child’s wellbeing, to work more collectively and more efficiently with their capabilities and strengths.

States can learn from good practices developed by driven organisations in ensuring there are no shortcomings in the provision of opportunity for development or growth of children with a disability.

For instance, Caudwell Children,¹ a Pan-Disability charity who have developed the Caudwell International Children Centre (CICC) a centre specialising in Autism and Neuro-Diverse conditions, has done tremendous work in the United Kingdom of Great Britain and Northern Ireland with positive results. By continually listening to the needs of a child and their families and giving them a say in what is important to them, Caudwell Children have become a pillar of strength to children and families requiring clearer support pathways, instilling a ‘Whatever it Takes’ commitment to their beneficiaries. A key instigator of ensuring people and organisations collaborate rather than work in silos, Caudwell Children has been able to raise awareness about disability throughout UK society, often challenging the instantaneity in which stereotypes about children with mental health conditions are formed.

Only through such collaboration can states centralise the support around the child not the disability. Only by pursuing collaborative structures to be developed for shared voices between beneficiaries and their families, government bodies, corporations, civil society organisations and wealth creators, can the essential support and awareness be provided to individuals working together to support the capabilities of disabled children and their neurodiversity.

For collaboration to work, structures must enable greater accessibility to knowledge and better training to impart that knowledge to be used more effectively. The effective sharing of conclusive research which becomes best practice is often the barrier to adoption of great techniques by the many. Great practices are being formed, are changing lives, are making a difference. The difficulty is sharing these practices in a timely manner that enables more lives to benefit from such. The role of states should be to create collaborative structures which speed up the rate of knowledge sharing and embedding of best practices.

The Human Rights Council and State members are urged to afford more attention to this area particularly in fulfilling the ambitions of the following Sustainable Development Goals

- 1.3: Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable
- 1.3.1: Proportion of population covered by social protection floors/systems, by sex, distinguishing children, unemployed persons, older persons, persons with disabilities, pregnant women, newborns, work-injury victims and the poor and the vulnerable
- 4.5: By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations

And further

- 10.2: By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status

We thank Trudi Beswick, the CEO of Caudwell Children in providing insight into the possibilities that their work has achieved in empowering and enhancing the abilities of children with disabilities. Trudi’s continual pursuit of developing services to support children to their full potential is testament to her long term commitment as an advocate for the voice of child. Her empowering belief that “being more understanding, aware and educated, would lead to less discrimination in the world”, fuel Caudwell Children’s mission to make the world a better place to live for children with disability and their families.

In closing, Sikh Human Rights Group believe the aforementioned goals can be achieved if members States and UN institutions put their human resources and further attention to this area. The Human Rights Council is urged to consider this matter seriously with the

¹ Caudwell Children www.caudwellchildren.com charity@caudwellchildren.com.

approach 'see the child, not the disability' to provide clear support pathways starting with diagnosis at the beginning of a child's life journey.

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