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## **Human Rights Council**

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

## 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.

[2 February 2025]





<sup>\*</sup> Issued as received, in the language of submission only.

## **Advancing Neurodiversity Inclusion: A Call for Global Action and Support**

Neurodiversity remains a neglected area of disability. It seems that because neurodiversity is not obvious as a physical disability, little attention is paid to those who are disadvantaged or denied opportunities by virtue of being on the neurodiverse spectrum. As highlighted in the Special Rapporteur on the Rights of Persons with Disabilities (Heba Hagrass) report entitled A/79/179 in which Heba Hagrass:

'[...] examines how persons with disabilities have been included and consulted in the review and follow-up processes to the 2030 Agenda for Sustainable Development. Meaningful participation is a human rights imperative under the Convention on the Rights of Persons with Disabilities. The Sustainable Development Goals could be a catalyst for the practical implementation of the Convention, yet with [five] years left until 2030, progress has been slow and persons with disabilities are being left behind. Ensuring that their voices are heard is therefore critical to make good on the commitment to leave no one behind and to design and review policies and measures that can effectively accelerate the achievement of the 2030 Agenda [...]'

However, the Sikh Human Rights Group (SHRG) and our affiliates have found that these issues can be addressed by implementing support services, raising awareness and enabling neurodiverse children and adults to engage comfortably with challenging environments.

In November 2020, the SHRG established its ongoing disability project entitled the Sikh Neurodiversity Network. We have found that both the parents and carers and the children and young persons that we are presently working with are benefitting enormously from this. The children and young persons are engaging with their communities. The community institutions that we are working with, are taking steps to be sensitive to the character of the children and young persons who are on the neurodiversity spectrum. In short, the parents and carers feel that they can look forward to a better future for their child and the SHRG is hoping that the aforementioned will also translate into better education and skills development options for the children and young people and importantly, promising futures in their careers and jobs.

Our project has shown that increasing awareness in the community, within authorities and within state institutions improves the prospects of children and young people on the neurodiversity spectrum. We also find that the communities that we are working with feel more comfortable and happier at understanding the issue and are extremely willing to help.

Our reason for raising the issue here is that we feel that the United Nations Human Rights Council (hereafter referred to as the UN HRC) should make neurodiversity an important issue and persuade Member States to adopt programmes and make commitments to raise general and specific awareness around this issue, set up support systems, encourage employers to understand neurodiversity and state authorities such as law enforcement agencies to be sensitive to the character of children and adults with neurodiverse conditions such as autism. This, in turn, will significantly contribute to redressing the issues identified by Heba Hagrass. For not only is meaningful participation and inclusion of persons with disabilities in the review and follow-up processes related to the 2030 Agenda for Sustainable Development both a human rights obligation under international law but also a key tool to mainstream a disability rights perspective in the implementation of the Sustainable Development Goals.

We also recommend that a specialist team could be set up with the help of the World Health Organization to offer assistance to countries as part of their improving technical skills mandate.

This is an area of disability that requires fewer resources to address but holds enormous potential for the individual concerned, for the community and the State.

This of course falls under not only the UN HRC's obligation to ensure technical cooperation but also Member States National Development Objectives and the 2030 Sustainable Development Goals aims and objectives as aforestated.

Therefore, what we are seeking from the UN HRC and other relevant stakeholders is:

- (1) For the UN HRC and all other relevant stakeholders to persuade Member State Governments to further focus their attention on offering wider and more comprehensive support to families who are currently seeking a diagnosis. Specifically, in terms of the unbiddable waiting times that are prevalent across the globe, the support both financial and otherwise that is made available to families whilst they wait upon a diagnosis both in terms of their child's home life and education.
- (2) For those who have obtained a diagnosis an increase in the availability of support both financial and otherwise that is made available to families with neurodiverse children and adults. We have found that one of the most pressing issues in the United Kingdom of Great Britain and Northern Ireland is a lack of clear information and support for families once they have obtained a diagnosis. In many instances, the families are left to fend for themselves in terms of finding out what support services governmental or otherwise are available to them in their locality. However, this can easily be addressed by the establishment and maintenance of a central online neurodiversity support resources hub and by requiring charities and other organisations who are registered with their state regulatory body and who are currently working in this area of disability to register their services and programmes on the online portal.
- (3) For there to be a renewed focus on our educational systems. Both in terms of the educational and wider support that is made available to neurodiverse children and young adults but also to those who are considered neurotypical. In other words, in the United Kingdom of Great Britain and Northern Ireland families often struggle to draft, implement and uphold their Education, Health and Care Plans and neurotypical youth often have very little understanding of the challenges and difficulties faced by their neurodiverse peers.
- (4) For employment and vocational skills training opportunities to be enhanced for neurodiverse individuals. Both in terms of providing neurodiverse individuals with alternative routes to finding and obtaining employment such as the allowance of audio and video recorded job applications or CVs, performance of the role interviews, etc... but also ensuring that employers mandatorily provide and uphold the most recent best practice guidance on inclusive workspaces.

Our proposals are supported by Heba Hagrass' report entitled A/79/179 in which she recommends to States to ensure the meaningful inclusion and participation of persons with disabilities in the follow-up and review processes of the 2030 Agenda:

'[...] (a) Establish accessible and inclusive tools, including digital platforms, to inform and raise awareness about national policies and actions to achieve the 2030 Agenda and related consultative and review processes, such as voluntary national reviews;

[...]

- (d) Provide details in voluntary national reviews about how different stakeholders, and persons with disabilities specifically, were consulted and incorporate their observations and recommendations, for example as annexes. Outline the impact of policies and measures taken to achieve the Goals for persons with disabilities;
- (e) Ensure that persons with disabilities are represented in all bodies tasked to monitor and review the implementation of the Goals, such as sustainable development councils, advisory committees and monitoring boards;
- (f) Allocate independent funding to increase and strengthen the capacity of organizations of persons with disabilities to contribute and participate in the Goals review and follow-up processes at all levels, in particular organizations at the grass-roots level and representing those at particular risk of being marginalized;

[...]

(i) Foster partnerships between States, international organizations and organizations of persons with disabilities to leverage expertise and resources for disability-inclusive implementation of the Goals;

(j) Ensure that persons with disabilities, as well as other groups at risk of being left behind, and civil society are meaningfully and systematically consulted and their opinions duly weighted in the negotiations of resolutions and outcome documents concerning sustainable development [...]'

The Special Rapporteur also recommends that the United Nations system:

- '[...] (a) Speed up efforts to implement the United Nations Disability Inclusion Strategy, in particular within United Nations country teams, with a focus on increased and systematic consultations with organizations of persons with disabilities, including in processes related to the development and reviews of the common country analyses and cooperation frameworks;
- (b) Step up efforts to ensure that all consultation mechanisms related to the Sustainable Development Goals and sustainable development are disability inclusive and accessible, including by providing the possibility of online participation to foster the inclusion of diverse voices, such as women and girls, young people, older persons and other disadvantaged groups of persons with disabilities;

[...]

The Special Rapporteur [also] recommends that international, national and private donors and foundations support capacity-building initiatives for organizations of persons with disabilities to engage effectively in the review and follow-up processes of the 2030 Agenda at all levels. This can include training on advocacy, compliance with the Convention, policy analysis, data interpretation, inclusive budgeting and monitoring and evaluation techniques [...]'

The SHRG and its affiliate organisations are well-versed in all of the aforementioned and would be delighted to assist the UN HRC and other relevant stakeholders in developing this further.