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**Subject: Human rights Council resolution 37/20 “Rights of the Child”**

Pratidhwani West Bengal, located in West Bengal, India welcomes the decision of the Human Rights Council to focus its next annual full-day meeting on the theme “Empowering children with disabilities for the enjoyment of their human rights, including through inclusive education.” As a federation of parent groups, we would like to take this opportunity to highlight a few key issues regarding children who are deaf or hard of hearing from a parent perspective.

1. To ensure access to inclusive education for children with hearing loss, early identification followed by access to appropriate services and support that promote language and communication are critical to the optimising educational and psychosocial outcomes of the child who is deaf or hard of hearing. But there is enormous disparity around the world. A child born with a severe hearing loss in Australia will be diagnosed before 1 month of age; receive free audiological services and devices until 26 years of age; access free early intervention services through the National Disability Insurance Scheme and attend mainstream schooling with appropriate support. Whereas a child with the same level of hearing loss born in India will not be identified until way past two years of age.

**Recommendation:**

* That India as a nation implements universal newborn hearing screening programs to identify infants with permanent congenital hearing loss in letter and spirit.
* That access to early intervention programs that promote acquisition of age-appropriate language –whether spoken or signed be universal across the country irrespective of geographic, socio, economic situation of families.
* That children and families are provided with the services and support they require to meet the communication, education and psychosocial needs of the child who is deaf or hard of hearing.
1. Laws and policies in India intended to ensure inclusion of children with disabilities in the general education system and transition from segregated t inclusive setting.

**Recommendation**:

* That India is a signatory to UNCRPD and has framed a new Disability Law RPWD - Rights of Persons With Disabilities Act 2016. It needs to be ensured that rules are framed within stipulated time in all the states as its implementation is subject to state rules.
* That large scale awareness and sensitisation on the law and its implementation needs to be made at every level. Law enforcement agencies in association with government departments and civil society organisations need to percolate the information from government departments, public bodies, down to common people that disability rights are human rights and they have to be ensured. It is not a matter of charity or development but is a matter of right which cannot be denied.
1. a) Empowerment of children is possible when early identification and early intervention has been made possible supported by preschool education which would provide the foundations for equitable education for children who are deaf or hard of hearing. Equitable education means the child has access to the same quality of education as their hearing peers in an environment that best suits the child and family.

b) Cost of assistive devices is an important issue in the process of early intervention. The high costs of hearing aids often make it beyond the means of average parents and government hearing aids often fail to meet the needs of children who are deaf or hard of hearing.

c) Empowerment of children also means empowerment of parents and families. Unless families are empowered the child will not live in an empowering environment and will not feel included and will not belong to the school or community.

d) A study undertaken by NISHD (National Institute for the Speech and Hearing Disabled) published in their annual report for the year 2017-2018 on learning outcome of children with cochlear implant suggested that 1) the children and their parents should be encouraged to attend therapy regularly 2) the parents need to be empowered to teach their children at home.

 **Recommendation:**

* That universal appropriate and quality early intervention programmes is made available for children with deafness. The early intervention would build foundation for learning which will pave a path for children with disabilities to be empowered and be aware of their rights and responsibilities.
* Cost of assistive devices should be regulated so as to make it affordable and accessible for common people and the information should be widely circulated.
* That focus has to be on language development of deaf children during preschool age. Lack of adequate language acquisition affect building of concepts and education for children who are deaf or hard of hearing.
* That early intervention has to be a process of empowerment of parents too along with children. Parents must be educated and sensitised to the needs and potential of their children so as to play the right parental role and facilitate empowerment of children with disabilities. Motivation and willingness of parents is directly proportionate to the development of deaf children.
1. Discriminations are faced by children in inclusive school settings. A growing child spends considerable time every day at school during the formative years. The school experience has a significant impact on a child’s personality and helps shape a young mind. But the school environment, syllabus, evaluation system often subject a student with disability to discrimination owing to its non-inclusive and inflexible approach. This affects educational, social and emotional outcome of a child who is deaf or a hard of hearing. An appropriate inclusive environment promotes values of equity, culture of compatibility reducing tendencies of bullying, teaching every student to respect one another and learn from each other. Sign language needs to be promoted as an alternative language for students with deafness.

**Recommendation :**

* That children who are deaf or hard of hearing have the right to quality and equitable education in a regular setting. The regular setting has to be equipped to meet the specific needs of students with different disabilities or diversities.
* That schools should design and undertake disability sensitivity training programme for students, teachers, parents and non teaching staff members. Parents of children who are deaf or hard of hearing and deaf role models could form an integral part of such programmes.
* That syllabus should be inclusive catering to the specific needs of students who are deaf or hard of hearing. The teaching mechanism should be inclusive so as to meet the particular needs of students who are deaf or hard of hearing.
* That the evaluation system in schools should be disability sensitive and empowered to evaluate the learning outcomes in the students rather than examining their abilities in comparison to their non-disabled peers.
* That official status should be given to ISL - Indian Sign Language and introduce measures to support students with deafness extensively across the length and breadth of the country.
1. A well-adjusted, successful child who is deaf or hard of hearing is the product of a well-adjusted, successfully supported family. The well-being of children who are deaf and hard of hearing and their families depends upon the availability of high quality formal and informal support imbedded in the systems that support them.

Recommendation:

* 1. That systemic family support programs that emphasise parent-to-parent contact needs to be established.
	2. That parent perspective need to be acknowledged and incorporated into the development and monitoring of systems that serve them.
	3. That rights of the child who is deaf or hard of hearing depends on the availability of quality support to their family that is implemented as a result of incorporating the perspective of parents in policy creation and implementation of the systems that support them.
1. Data is an important tool to measure progress and its lack of availability indicates that work is yet to be done in those areas. Desegregated data on inclusive education at national or state level is not readily available in India.

Yet from the little data obtained, it is evident that 71% of population with disabilities live in rural India. 10-15% urban population with disabilities complete graduation and 5% at the rural level attain graduation. The total percentage of graduates with disabilities is about 8%.

54% of the disabled children with multiple disabilities never attended educational institutions. Also, 50% of the children with mental illness never attended educational institution. (Source: <http://mospi.nic.in/sites/default/files/publication_reports/Disabled_persons_in_India_2016.pdf> Page 25-29)

**Conclusion:**

In order to make inclusive education a reality across India, Universal Newborn Hearing Screening followed by early identification, early intervention and preschool education for children who are deaf or hard of hearing, while empowering parents as equal partners in the process is inevitable. Acceptance of disability as a human diversity among cross sections of society is important for inclusion of disability in mainstream education and society and towards building a society that is free of discriminations.