

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

The Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPODHH) 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.”

A survey of parents undertaken by the European Association of Families with Deaf and Hard of Hearing Children (FEPEDA) in 2013 found that the greatest concern of the 1190 parent respondents was the quality of education provided to their children who were deaf or hard of hearing. 56 percent of the respondents disagreed that their children received the same level of education as their hearing peers. This figure rose to 65 percent of respondents disagreeing that their children had equal opportunities to further education<sup>1</sup>.

As a community of parent groups around the world, 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. Research evidence is unequivocal that early identification of hearing loss followed by access to appropriate services and support that promote language and communication are critical to optimise educational and psychosocial outcomes of children who are deaf or hard of hearing. But there is enormous disparity around the world. A child born with a permanent hearing loss in Australia will be diagnosed before 1 month of age; receive free audiological services and hearing devices until 26 years of age; access free early intervention services through the National Disability Insurance Scheme; and have the option to attend mainstream schooling with expert support. Even in relatively affluent countries in the developing world such as South Africa and India, there is no free universal newborn screening and no access to early intervention services.

**Recommendations:** That countries throughout the world undertake to honour the rights of the child who is deaf or hard of hearing by:

- implementing universal newborn hearing screening to identify infants with permanent congenital hearing loss as recommended by the World Health Organization (2010)<sup>2</sup> and the Joint Committee on Infant Hearing (2007)<sup>3</sup> and be available regardless of a family’s ability to pay.

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<sup>1</sup> Tuokko, A. & Hakanpää, N. (2013). Vertaileva kyselytutkimus kuulovammaisten lasten tilanteesta Euroopassa vuosina 2000 ja 2012. Retrieved from <http://www.theseus.fi/handle/10024/61374>

<sup>2</sup> World Health Organisation. (2010). Newborn and infant hearing screening: Current issues and guiding principles for action. Outcome of a who informal consultation held at who headquarters, Geneva, Switzerland, 09–10 November 2009. Retrieved from [http://www.who.int/blindness/publications/Newborn\\_and\\_Infant\\_Hearing\\_Screening\\_Report.pdf](http://www.who.int/blindness/publications/Newborn_and_Infant_Hearing_Screening_Report.pdf)

<sup>3</sup> Joint Committee on Infant Hearing. (2007). Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, 120, 898-921. doi:10.1542/peds.2007-2333

- providing access to early intervention programs that promote the acquisition of age-appropriate language –whether spoken or signed – and in the case of children who are deaf with intellectual disabilities, access to augmented or alternative communication to assist language development.
  - providing the child and family with the services and support required to meet the communication, education and psychosocial needs of the child who is deaf or hard of hearing.<sup>4</sup>
2. Early identification, diagnosis, and intervention provides the foundations for equitable education for children who are deaf or hard of hearing. Equitable education means every child has access to the same quality and level of education as their peers with typical hearing in an environment that best suits the child and family. For example, in the United States the Individuals with Disabilities Education Act (IDEA) requires teams to review the unique circumstances for an individual child so the educational placement will be most conducive to his or her communication access needs. That may be in a school for the deaf—where all students use American Sign Language—or it might be in the typical neighbourhood classroom because the child has a cochlear implant and is listening and speaking. Inclusion in a general classroom setting can be the most isolating environment for some children who are deaf or hard of hearing who may not have developed adequate listening and spoken language skills or where sign language support is not extended. Regardless of language or modality, an argument for inclusion in a mainstream classroom based on socialisation and non-segregation is not justified if it results in a child’s less than adequate access to communication and learning opportunities.

**Recommendation:** That children who are deaf or hard of hearing have the right to quality and equitable education in a setting that suits the unique communication needs of the individual child and promotes the best access to quality education to fulfil their potential.

3. Policies and laws are meaningless when they are not implemented. Many of the countries of our member organisations are signatories to the Convention on the Rights of Persons with Disabilities (CRPD) and The Convention on the Rights of the Child but implementation is slow or piecemeal with few changes evident for children and their families.

**Recommendations:** That all countries

- sign and ratify the UNCRPD convention and protocol.<sup>5</sup>
- are held accountable through the UNCRPD reporting guidelines and supported by additional inquiries by the UN Committee through the Optional Protocol to the

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<sup>4</sup> Moeller, M. P., Carr, G., Seaver, L., Stredler Brown, A., & Holzinger, D. (2013). Best practices in family centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, 18, 429-445. doi:10.1093/deafed/ent034

<sup>5</sup> United Nations. (2017). CRPD and optional protocol signatures and ratification. Retrieved from <http://www.un.org/disabilities/documents/maps/enablemap.jpg>

Convention on the Rights of Persons with Disabilities – see 2016 UK inquiry.<sup>6</sup>

4. When parents/children choose to use signed language, their choices need to be recognised and supported to ensure optimum educational *and* emotional outcomes for children who are deaf or hard of hearing. Signed languages are not afforded equal status to spoken language in many countries.

**Recommendation:** That all countries

- incorporate the CRPD into national legislation.
- give legal status to signed languages. Introduce measures to support and promote Deaf culture and native sign languages, ensuring full implementation of Articles 21 and 30.<sup>7</sup>

5. A growing child spends considerable time every day at school during formative years. The school experience has a significant impact on a child's personality and helps shape a young mind. The school environment, syllabus and curriculum play an important role in the educational, social and emotional outcome of a child who is deaf or a hard of hearing. An appropriate inclusive environment promotes culture of compatibility reducing tendencies of bullying, teaching every student to respect one another and learn from each other in an environment of equality and equity.

**Recommendations:** That all schools

- design and undertake disability sensitivity training programs for students, teachers, parents and non-teaching support staff. Parents of children who are deaf or hard of hearing and deaf role models form an integral part in the design and presentation of such programs.
  - ensure the syllabus is flexible - catering to the specific needs of students who are deaf or hard of hearing.
  - promote teaching strategies that are inclusive so as to meet the particular needs of students who are deaf or hard of hearing.
  - utilise an evaluation system that is disability sensitive and empowered to evaluate the learning outcomes in the students rather than examining their abilities in comparison to their hearing peers.
6. 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 the whole family. The Global Coalition of Parents of Deaf and Hard of Hearing Children (GPODHH) Position Statement and Recommendations for Family Support in the Development of Newborn Hearing

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<sup>6</sup> United Nations. (2016). Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention.

<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/InquiryProcedure.aspx>

<sup>7</sup> British Deaf Association. (2017). *Alternative Report – United Kingdom. Implementation of the United Nations Conventions on the Rights of Persons with Disabilities*. Retrieved from London, UK: <https://bdapullzone-u3iu3cc8pz6o.netdna-ssl.com/wp-content/uploads/2017/07/BDA-Alternative-Report-UK-Implementation-of-the-UNCRPD-February-2017.pdf>

Screening Systems (NHS)/Early Hearing Detection and Intervention Systems (EHDI) Worldwide (June 2010)<sup>8</sup> outlines the importance of systems to:

- provide systemic family support programs that emphasise parent-to-parent contact; and
- acknowledge and incorporate the parent perspective into the development and monitoring of systems that serve them.

These principles have been highlighted in the best practices in family-centered early intervention for children who are deaf or hard of hearing: an international consensus statement published in 2013<sup>4</sup>. These principles apply beyond the early years.

#### **Recommendation:**

- That the rights of the child who is deaf or hard of hearing depends on the availability of quality support to their family in accordance with the international consensus statement on best practices in early intervention for children who are deaf or hard of hearing.
- That the perspectives of parents are incorporated, through meaningful consultations, into the development and monitoring of programs and systems that support them and their child who is deaf or hard of hearing.

#### **Conclusion**

In order to make global inclusive education a reality for children who are deaf and hard of hearing, universal newborn hearing screening followed by early identification, diagnosis, and early intervention and empowering parents as equal partners in the process is essential. Ensuring accommodations that suit the child and family are paramount to success. Acceptance of disability as a human diversity in society is important for inclusion of disability in mainstream education. The principles of universal design for learning should guide the development of the curriculum to accommodate the education and socioemotional needs of all children.

#### **About GPODHH**

The Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPODHH) is an international collaboration of parent groups dedicated to promoting improved systemic protocols and practices which encourage informed choice and the empowerment of families with a deaf or hard of hearing child throughout the world.

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<sup>8</sup> Global Coalition of Parents of Deaf and Hard of Hearing Children (GPOD). (2010). *Position statement and recommendations for family support in the development of newborn hearing screening systems (NHS)/early hearing detection and intervention systems (EHDI) worldwide*. (2010). Retrieved from <http://www.gpodhh.org/position-statement-2010>

