



Framing Sign Language as a Health Need in Canadian and International Policy

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Abstract

Although in Canada, hearing screening and early intervention are presented as a health need, we question whether young deaf and hard of hearing children's access to language is adequately supported by public health and children's services. The Ontario Infant Hearing Program has the stated mandate of supporting the language development of deaf and hard of hearing infants and young children. However, this program presents parents with early intervention service options involving either spoken or signed language, but not both together. This policy effectively restricts access to sign language learning for a majority of Ontario's deaf children. Consequently, some deaf children suffer language deprivation and its deleterious effects on cognition and emotional development. In support of our arguments, we refer to Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which Canada has signed and ratified. The CRPD supports recognition of deaf children's right to sign language as a health need because language deprivation occurs in many children who are not offered sign language, and this is a permanent impairment imposed on top of hearing loss. We conclude that in Canada, health services for deaf children do not align with accessibility and human rights legislation, thus creating a policy gap that leaves deaf children vulnerable to additional impairment.

Keywords Health policy · Sign language · Deaf children · Early intervention · United Nations Convention on the Rights of Persons with Disabilities

Significance

What is already known on this subject? In Canada, hearing screening and early intervention are presented as a health need, and public health and children's services have the stated mandate of supporting the language development of deaf and hard of hearing infants and young children. Language deprivation occurs in many children who are not offered sign language.

What this study adds? Health services present policy restrictions on sign language learning that leave deaf children vulnerable to additional impairment. The United

Nations Convention on the Rights of Persons with Disabilities supports recognition of deaf children's right to sign language as a health need.

Introduction

In Canada, publicly funded infant hearing screening and early intervention programs aim to support the language development of deaf and hard of hearing infants and young children (Ministry of Children, Community, and Social Services 2018). However, by upholding restrictions on American Sign Language (ASL) or Langue des signes québécoise (LSQ) services for children who receive a cochlear implant (Snoddon 2008), such programs have often failed to adequately support learning of a first language. The Ontario Ministry of Children, Community and Social Services' Infant Hearing Program (IHP) provides universal neonatal hearing screening in hospitals and community settings, audiology assessments, and habilitation and monitoring for babies born with or at risk for hearing loss (Hyde 2005). The

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2018 IHP service guidelines limit parents of deaf and hard of hearing children to a choice of language development services in either a natural sign language (ASL/LSQ) or spoken language, but not both together. In 2018, the guidelines explicitly stated, “IHP services are not designed to support development of a child’s bilingualism in spoken and signed language” (Ministry of Children and Youth Services 2018), and Ministry staff have confirmed these guidelines remain in effect (Martin, V., personal communication, September 24, 2019).

The failure to support ASL or LSQ for deaf children who are receiving spoken language services leaves many children at risk for language deprivation and a cascade of negative effects on their health and well being (Spellun and Kushalnagar 2018). This is because even with a cochlear implant, many children are not able to fully access spoken language. The 2018 policy outlined a regular assessment of children’s language development. Close monitoring could identify children who are at risk for language deprivation. However, government policy has dictated that a child receiving spoken language services does not have the option of also receiving ASL or LSQ services. Despite evidence supporting signed and spoken language bilingualism (e.g., Davidson et al. 2014; Priestley et al. 2017), parents would need to stop receiving spoken language services for their child in order to obtain the sign language support the child needs.

Sign Languages and Language Deprivation

Language deprivation occurs when there is a lack of access to language during the first five years of a child’s life (Hall et al. 2017). Language deprivation syndrome is characterized by language dysfluency, knowledge deficits, and disruptions in thinking, mood, and/or behavior; all of these characteristics have implications for a child’s long-term academic development. However, delayed first-language acquisition also has effects beyond altered neurological development that may impair the child’s ability to develop full proficiency and literacy in any language. Lack of access to language and communication in early childhood leaves deaf individuals at greater risk of physical, emotional, and sexual abuse and poor mental health, as well as poor health literacy and health outcomes in general (Humphries et al. 2019; Kushalnagar et al. 2018).

Natural sign languages of deaf communities in Canada and around the world (in contrast to manually coded sign systems based on spoken languages) display the same levels of linguistic organization as spoken languages (Petitto 2005). Deaf and hearing children who acquire a sign language from birth reach the same linguistic milestones as hearing children acquiring a spoken language (Spencer 2004). However, in Canada few deaf and hard of hearing children learn a sign

language in early childhood, even though sign language is often the most accessible language for children with a hearing loss. When made available to deaf children, natural sign languages provide the neurolinguistic stimulation needed for healthy linguistic and cognitive development, thus preventing linguistic deprivation and its negative lifetime consequences (Humphries et al. 2019). Spoken language is available to deaf children in hearing families, but unlike sign language it cannot be acquired naturally or spontaneously, and sometimes it cannot be accessed adequately, even with a cochlear implant, intensive auditory-verbal therapy, and full immersion in a spoken-language environment (Spellun and Kushalnagar 2018).

The Canadian Pediatric Society (2011) reported that between 2001 and 2007, 91.8% of parents selected spoken language as the IHP interventional objective of choice for their child. In 2014–2015, the IHP reported that 30 out of 597 infants identified with permanent hearing impairment were in receipt of ASL services (at this time, no LSQ services were provided) (Snoddon 2016). However, deaf and hard of hearing children who receive only spoken-language intervention services are not assured of adequate language access, and long-term outcomes of these approaches are widely variable (Hall et al. 2017). As a consequence, a significant number of Canadian deaf children are at risk for language deprivation.

Hearing Screening and Early Intervention

Hearing screening is widely viewed as a health need. In Canada, services to enable and/or restore hearing and habilitation strategies toward auditory and spoken-language functions are listed and covered in all provinces’ health systems. The Ontario IHP is funded through Canada Health Transfer, a system of payments from the federal government to the provinces that supports the public health systems of the provinces and territories of Canada (Department of Finance Canada 2011). The IHP screens all newborns “to mitigate the impact of early childhood permanent hearing loss (PHL) on language development in young children,” due to the effects that delays in language development can have “on children’s functional behaviour and skills” (Ministry of Children and Youth Services 2018, pp. 5–6).

However, health care systems generally provide limited support for deaf and hard of hearing children’s learning of sign language. The IHP guidelines state “ASL/LSQ Consultants do not teach ASL/LSQ to families” (Ministry of Children and Youth Services 2018, p. 16), which suggests parents must seek and pay for this instruction elsewhere, while auditory-verbal therapy is covered free of charge to families under the IHP. The Canadian Pediatric Society’s (2011) Position Statement on universal newborn hearing screening, which was reaffirmed

in 2018, makes no mention of sign language, although it references “gestural communication” once. As the Position Statement asserts, “the development of spoken language is the primary objective of almost all English-based programs for hearing-impaired children.”

However, a growing number of researchers argue that the “predictable irreversible deficits in communication and psychosocial skills, cognition and literacy,” which the Canadian Paediatric Society (2011) cites as effects of lack of early intervention, are often due to lack of sign language access. Reliance on spoken-language strategies alone in early intervention does not ensure language development in many deaf children, and the addition of a sign language later in childhood does not prevent the lifelong cognitive effects of language deprivation (Humphries et al. 2012, 2014; Napoli et al. 2015; Spellun and Kushalnagar 2018). Although cochlear implant and auditory-verbal therapy programs with operational or explicit policy restrictions on sign language use are the standard of care in many countries that have implemented newborn hearing screening, success rates with respect to long-term language development are significantly variable (Humphries et al. 2014, 2019; Spellun and Kushalnagar 2018).

Provider Knowledge Gaps

When an infant is identified through IHP neonatal screening as having a hearing issue, the family is referred to an audiologist for additional testing (Ministry of Children and Youth Services 2018). The audiologist is responsible for providing information about intervention strategies and language development support. As a health care professional, an audiologist is governed by the Regulated Health Professions Act of 1991. Despite this principal role in working with families with newly identified deaf and hard of hearing infants, an audiologist providing services under the IHP is not required to have knowledge of or about sign language (College of Audiologists and Speech-Language Pathologists of Ontario 2014). The same is true of family support workers, who work with audiologists in counseling families regarding language development service options. The family support workers are either registered nurses or social workers. Families with deaf children cannot receive adequate information when information providers lack expertise in sign language and do not recognize its value. This knowledge gap effectively restricts the option to receive sign language services.

Article 25 of the Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights treaty that sets standards for how countries should meet the

rights of disabled people. Article 25(b) of the CRPD, which focuses on health, includes the requirement that parties shall “Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.” Article 25 must be read alongside the full text of the CRPD, which gives prominence to sign language in terms of legal recognition and accessibility, educational, and cultural rights.

In the case of deaf children who are not offered sign language and for whom spoken language supports for age-appropriate spoken-language outcomes are not wholly successful, language deprivation is a further impairment imposed on top of hearing loss that has lifelong effects (Humphries et al. 2012). Language deprivation in early childhood leads to significant health disparities and knowledge gaps in preventive health for deaf individuals (Kushalnagar et al. 2018). Furthermore, language deprivation leaves deaf individuals at greater risk for abuse, exploitation, and reduced access to care, leading to greater risk of injury and death. This was seen in the 2013 death of Dylan Lachance, a 16 year-old, language-deprived deaf Indigenous adolescent from Saskatchewan who, while in custody, was unable to communicate with staff responsible for his care and subsequently died of sepsis (Pacholik 2016).

As a signatory to and ratifier of the CRPD, Canada must report to the CRPD committee regarding implementation of the Convention (United Nations 2014). In addition, Canada has ratified the CRPD Optional Protocol, which enables individual citizens to submit complaints to the CRPD Committee if the Convention is violated and once domestic remedies have been exhausted at the national level (Council of Canadians with Disabilities 2017). In its first report to the CRPD Committee, Canada stated that the Convention is implemented through the Canadian Charter of Right and Freedoms in addition to other federal, provincial, and territorial human rights laws. As a publicly funded government program, the Ontario IHP falls under the remit of the Charter, Section 15 which guarantees equal rights for persons with disabilities. If a Charter challenge, which has been proposed elsewhere fails, an appeal to the CRPD Committee may be possible (Paul and Snoddon 2017).

Policy Recommendations

Because cochlear implants do not provide adequate language input for some children, researchers now recommend a bimodal bilingual approach where early intervention programs facilitate access to both spoken and sign language (Humphries et al. 2019). This position is supported by growing public awareness and acceptance of sign languages, such

as ASL and LSQ, as natural languages and by research findings that show normal language development and executive function are supported by language access, rather than auditory access (Hall et al. 2018). A bimodal bilingual approach ensures deaf children have optimal access to language and can reach developmental milestones when a cochlear implant provides only partial benefit (Humphries et al. 2012). This approach is in keeping with Article 25 of the CRPD and with Canadian human rights legislation.

Conclusion

Given the lack of expertise and the polarity of service options available to families, we argue that the Infant Hearing Program fails to recognize that natural sign language has a role in optimizing brain development and preventing language deprivation and therefore should be considered a health need. We urge Canadian governments and other ratifiers of the United Nations Convention on the Rights of Persons with Disabilities to commit to its implementation and pay heed to how Article 25 can ensure sign language programming in early childhood. Due to the uneven outcomes of deaf children with only cochlear implants and auditory-verbal therapy, ensuring that all deaf and hard of hearing children and their families can learn sign language in early childhood is a pragmatic strategy to protect children from language deprivation. At the same time, it will demonstrate the value of this international human rights treaty and how it can be used to protect deaf and hard of hearing children in Canada and around the world.

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