

April 26, 2016

Brief to the Standing Committee on Justice and Human Rights

C-14

Communication Accommodations and Supports for People with Communication Disabilities

Communication Disabilities Access Canada (CDAC), is a national, non-profit organization that promotes accessibility and human rights for over 450,000 people in Canada who have speech and language disabilities due to disabilities such as cerebral palsy; autism spectrum disorder; fetal alcohol syndrome; cognitive delay and Down Syndrome, traumatic brain injury; aphasia after a stroke; dementia; Amyotrophic Lateral Sclerosis; Parkinson's Disease; Huntington's Disease, and Multiple Sclerosis. A person with a communication disability may have speech that is slurred or difficult to understand, or they may have little or no speech and communicate by pointing to letters, symbols, pictures or using a communication device. Some communication disabilities, such as aphasia after a stroke, impact on a person's ability to understand and process what others are saying but do not affect their cognitive ability to make decisions. The incidence of speech and language disabilities increases with age and includes people with pre-existing and age-related disabilities as well as communication challenges related to typical aging, such as hearing and vision loss; reduced comprehension of complex sentences and word finding difficulties.

Effective communication is essential for all patients facing end-of-life decisions. Successful communication is a two-way process in which messages are correctly and unambiguously understood by both the patient and the medical practitioner. This includes getting and understanding information about one's diagnosis, prognosis, treatment, and palliative options, weighing up information to reach a decision, communicating that decision and the reasons for the decision. These are complex communication issues for anyone and further compounded for people who have compromised speech and language abilities due to disabilities that affect their ability to understand spoken and written language; retain options; appreciate consequences to options; ask questions; give opinions, and communicate a decision. However, with appropriate communication accommodations and supports, many people with speech and language disabilities can make and communicate informed decisions.

There is ample evidence to demonstrate that many people with speech and language disabilities experience significant barriers when interacting with medical practitioners about their healthcare and specifically within informed consent situations. Unlike people who are Deaf and who may require sign language interpreters, or people who require oral translators, there are currently no protocols or directives in place to ensure that people with speech and language disabilities are provided with appropriate communication accommodations and supports.

People with speech and language disabilities report that healthcare professionals often overlook and misunderstand their wishes. They are very anxious about the lack of safeguards in C-14 because they report that medical practitioners often:

- Do not know how to make spoken or written information accessible to them
- Do not understand what they are communicating when they use ways other than speech to convey their messages
- Assume their speech and language disability is a cognitive disability
- Underestimate their capacity to make their own decisions and end-of-life directives
- Defer to family members and personal support staff to communicate on their behalf
- Rely on untrained people to assist with their communication where an arms-length, neutral, qualified professional communication assistant is required
- Under-value the quality of their life and their need for healthcare interventions

CDAC is asking for stronger safeguards for people with communication disabilities. These safeguards must include a directive to medical practitioners to engage a communication professional to assess the patient and to provide any required accommodations and supports. We are proposing the following amendments to C-14 to ensure that people can effectively communicate about medically assisted death:

Safeguards

If there is any question about the communication process as identified by the medical practitioner or the patient, then a neutral, independent professional with expertise in the patient’s communication needs, must be engaged in order to assess the required communication accommodations and/or to provide direct communication support. Communication accommodations and supports are required if the patient has challenges understanding information provided to them, retaining and weighing-up the consequences of options as part of the decision-making process and accurately and authentically communicating their decision. Communication accommodations include picture or letter boards, speech-output devices, or communication support from a sign language interpreter, Deafblind intervenor, speech language pathologist, language translator, or cultural interpreter.

Unable to sign § 241.2 (4)

Add “under the person’s direction”

If the person requesting medical assistance in dying is unable to sign and date the request, another person — who is at least 18 years of age and who understands the nature of the request for medical assistance in dying — may do so in the person’s presence and *under their direction* on their behalf.

Please contact us for more information at admin@cdacanada.com