

Who do we listen to?

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People all over the world have appropriately, been mourning the recent death of Professor Stephen Hawking. While Prof Hawking was regarded as all the more brilliant for his achievements due to his determination to overcome the barriers his disabilities posed, he was associated with the scientific community rather than the disability community. He may not have considered himself a leading light and role model within the disability community, but he was indeed for many people with communication support needs. There are very few people who have overcome the barriers that significant speech loss creates, to go on and achieve such greatness.

It was no doubt due to his scientific brilliance, that Prof Hawking had access to the greatest “like minds” and expertise in the area of communication technology. As his physical limitations became greater each decade, commensurate effort was put into ensuring that he had the most sophisticated communication devices available. This ensured that as much as possible, his ideas, research and societal inclusion were supported to the greatest degree.

We cannot but reflect on the barriers a person today who has speech loss similar to Prof Hawking, faces in Victoria when relying on government services to ensure they reach their full employment, personal and community potential.

Under the National Disability Insurance Scheme (NDIS), many people are being denied access to a means to communicate, despite clinical and evidence-based assessments being provided to the relevant decision makers. The rationale for the declining of applications is often not provided, and when provided, often has no rationale. Examples received from NDIS staff include the claim that communication assistive technology is seen as a duplicate of supports, or “double dipping”, as apparently you cannot have your physical support needs met and technology to communicate. Another reason given is that the provision of technology may prevent the person from using or developing speech (despite expert opinion negating such a view). One man was refused the relevant technology because the current app on his tablet was deemed to be “meeting his needs”. This was despite the fact that the man was not using the app as it utilised an American female voice only. Apparently, access to a quality synthesised voice of your own gender in order to retain dignity was not a strong enough rationale for the NDIA.

There is no right in Victorian schools to communication devices, or training in the utilisation of those devices. There is no expectation or right that a child with communication needs will leave school with a communication method.

Not every person who has a disability preventing them from easily communicating will become a Prof Hawking. However the right to communicate is enshrined as a human right in international law, and is integral to a person’s inclusion in our society. It is our responsibility to make it happen.