

# The technology that gave Stephen Hawking a voice should be accessible to all who need it

March 16 2018, by Bronwyn Hemsley



Acclaimed British theoretical physicist, cosmologist and author Stephen Hawking passed away peacefully at his home in Cambridge aged 76. Credit: Intel Corporation

Stephen Hawking was one of the most prominent people in history to use



a high-tech communication aid known as <u>augmentative and alternative</u> <u>communication (AAC)</u>.

His death comes in the year of the 70th Anniversary of the Declaration of Human Rights. Over the course of his adult life, Hawking came to represent the epitome of what effective <u>communication</u> with AAC systems really means: gaining access to the human right of communication enshrined in <u>Article 19 of the Universal Declaration of</u> <u>Human Rights</u>.

Today, many Australians who need AAC <u>still lack access to the</u> <u>technology</u> and the support they need to use it. It's time for that to change.

### How augmentative and alternative communication works

To most people who can speak, AAC systems are a bit of a mystery – it's not always clear how the person using it is controlling the system. Indeed, people's fascination with how a speech device works often overtakes their attention to what the person is actually saying.

AAC includes sign and gesture systems, communication boards, speechgenerating devices, mobile phones with apps, and even emojis and <u>social</u> <u>media</u>. Ultimately it works not only through the interaction of the user with their device, but also through their interactions with communication partners.

Some types of AAC don't involve technology at all, but use the person's body, such as sign or gesture systems. Some AAC systems are <u>non-</u><u>electronic</u>, like communication boards, books, or wallets for people to point to or look at letters, words or phrases to communicate. Other types



of AAC are known as "high-tech", in that they involve <u>electronic</u> <u>systems and computer-based technologies</u> to both store and retrieve words for communication.

Apart from the time taken to compose a message, it can take hours to program what could be spoken using a communication aid – and many more to ensure that the desired words can be found just in time for communication.

Hawking <u>used a switch to control software on a computer</u> that enabled him to talk. This kind of switch allows users to scan through options shown on the screen until they reach the letter, word or message to select for the device to "speak".

## **Realising the potential of people with communication disability**

Hawking did not tend to use his platform in relation to disability, but when he did his words were significant. In writing the <u>foreword to the</u> <u>World Report on Disability in 2011</u>, he highlighted the importance of people with disability having access to the equipment that they need, saying: "...we have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of people with disabilities. "

A patron of the Motor Neurone Disease Association, Hawking inspired millions of people around the world with the condition. His lifetime achievement as a person who uses AAC was recognised by the International Society for Augmentative and Alternative Communication.

RIP <u>#StevenHawking</u>. I was inspired by his longevity with <u>#MND #ALS</u> and how he just got on with life regardless of his



condition. <a href="mailto:pic.twitter.com/IbmuYGOEqt">pic.twitter.com/IbmuYGOEqt</a>

- eyegazeartist (@sarahezekiel) March 14, 2018

Although he hoped to be remembered more for his science than for his popular appearances on The Simpsons, his character delivered a vital line on communication rights and the need for AAC with a firm directive: "Silence. I don't need anyone to talk for me except this voice box."

His call to "look up at the stars", should further compel AAC users and communication technologists to work together and <u>reach for the stars</u> in finding solutions for people who cannot rely on speech to communicate.

#### People who use AAC need to have a say in the design process

Hawking's fame attracted the world's best and brightest to work with him to solve problems around the use of communication technologies. But AAC systems still don't stop people from "<u>slipping through the</u> <u>timestream</u>" of conversation. Communication using AAC systems is slow and effortful.

It can be hard to make a comment in a conversation – by the time the person has got the attention of other speakers and composed their message, the conversation has moved on, and the message is delivered "out of time". It's a puzzle to find systems that improve the timing and flow of talk, to match each user's communication needs.

Even as communication tech advanced and Hawking's distinct voice <u>got</u> an <u>upgrade</u>, he chose to keep his "<u>robotic drawl</u>". Like the famous film critic <u>Roger Ebert before him</u>, he had the final say on his own vocal identity.



Hawking's empowered story highlights the importance of designers not allowing ableist notions of an acceptable voice to restrict an AAC user's self-expression. His stance also reflects the importance of people who use AAC co-designing AAC systems that reflect their own <u>identity</u>.

#### Making AAC accessible to all

Hawking knew his privileges in having access to the equipment and <u>the</u> <u>social supports he needed</u> to participate. Unfortunately, many people in Australia who need AAC <u>lack access</u> not only to the funds they need for the technology, but also to the professionals, such as speech pathologists, who know how to design and teach people how to use communication systems.

The Australian Bureau of Statistics <u>estimates</u> that as many as 1.2 million Australians have a communication disability. With roughly a quarter of all people with <u>cerebral palsy</u> or autism spectrum disorders being <u>unable</u> to rely on speech to communicate, it is vital that more is done to improve access to AAC worldwide.

Like all <u>people</u> who use AAC, Stephen Hawking was unique. It's time to make communication systems like the one he used available for all who need it, so that they too can have their chance to shine.

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