

To Be or Not to Be (Me)

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We are all aware of the negatives associated with stuttering, including teasing, discrimination and stereotyping of people who stutter (PWS). Our ability to communicate is core to being human, hence difficulties with self-expression are experienced as deeply personal and can impact significantly on identity.

As parents, your sense of self is intertwined with your child's identity. If you have a child who stutters, you will have experienced emotions and thoughts such as worry for your child as he starts school, or guilt, often felt by parents who stutter. It's highly likely that you and your son or daughter want the [stuttering](#) to "just go away". Speech pathologists recommend early intervention because research shows that it gives families the best chance of 'success'. [But what is success?](#)

Taking a very limited, simplistic view, an individual is either 'disabled' or 'non-disabled', 'normal' or 'not normal'. All people with disabilities are made conscious of this, however PWS in particular may be more affected as they stutter on some occasions and not on others, and may constantly feel pressured to "succeed" by not stuttering. Therefore, concepts of 'rehabilitation', 'success' and 'normality' may equal efforts to "*not be*" something or someone.

Recently, researchers investigated the interplay between identity and disability in adults who stutter and the internal conflict commonly recorded in their experiences. The authors demonstrate that throughout the history of intervention approaches to stuttering, many continue to – explicitly or not – promote fluency, ie. by eliminating or reducing stuttering. It seems the obvious goal. But have you ever considered the implications of a relentless focus on "stopping" a stutter or "not stuttering"?

In modern 'Western' societies, we are often judged on our performance, whether as employees or parents. Efficiency, immediacy and competitiveness – areas potentially influenced by stuttering – are highly prized, drawing attention away from the equally important efforts required to understand and integrate difference.

The way society views physical disability is changing: we're building accessible tram stops, an Australian girl with Down Syndrome has become a professional adult model, and we're using more inclusive labels to describe individuals with disabilities (eg. "differently abled"). Wearing glasses technically indicates vision disability, however it's so common that we are unlikely to perceive it this way. Perspectives on stuttering however have been more resistant to change.

Unlike many other impairments, stuttering results in dysfunctional communication. When communication between two or more people breaks down, the burden falls to both the speaker and listener. It is typical to blame the speaker, however all involved experience the defectiveness of the failed exchange. The listener is unable to fulfil her obligations and role, and feels awkward as she faces the opposite of control, immediacy and perfection – ideals esteemed by society. In a world where things are expected to work instantly and "right", the uncertain, tense gaps in conversations with PWS may feel agonising. Consequently, the powerful collective desire to "fix" the problem is strongly linked to emotions.

For many, the separation of stuttering from negative ideas about impairment to seeing it as a different form of speaking is difficult. However, as parents of [children who stutter](#), you can help yourself, your child and your network:

- Commit to following your speech pathologist’s instructions for home practice, but don’t focus on your child’s speech all day. Children who feel nagged will resent you and will resist therapy sessions!
- Maintain a balance of activities that your child enjoys. We tend to perform better when we are interested in a task.
- Provide positive feedback in areas unrelated to fluency, eg. “You’re such a great listener,” or “You run really fast!”. Let him know that fluency isn’t everything and that he has lots of other great characteristics.
- Find a group of families with children who stutter. It’s support for your child and you!
- Read picture books about children who stutter. We all want to relate to book/film/toy characters to feel a sense of understanding and belonging. Try <https://www.mnsu.edu/comdis/kuster/kids/kidsbooks.html>

References

To be or not to be: Stuttering and the human costs of being “un-disabled”

Watermeyer, B. & Kathard, H. International Journal of Speech-Language Pathology, 2016; 18(1): 11-19.



Image from: <http://www.metroparent.com/daily/health-fitness/speech-therapy/stuttering-in-children-what-parents-should-know/>

[Call Box Hill Speech Pathology Clinic on 9899 5494](#) if you have any concerns that your child may be stuttering.

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