



Raising Stuttering Awareness on December 3rd, The International Day of People with Disabilities 2020

The International Day of Disability (IDPWD) is today, December 3rd 2020. The day, which is celebrated each year, represents the value of the global community diversity; learning to understand the experiences of people with disabilities (PWD), optimism towards the future - a world where a person is not characterized by their abilities and finally - action of individuals and organizations to show their support and take on a commitment to create a world characterised by equal human rights for all (United Nations, 2020). In addition, IDPWD 2020 focuses on hidden disability and the effects of COVID-19 on PWD.

Stuttering and disability

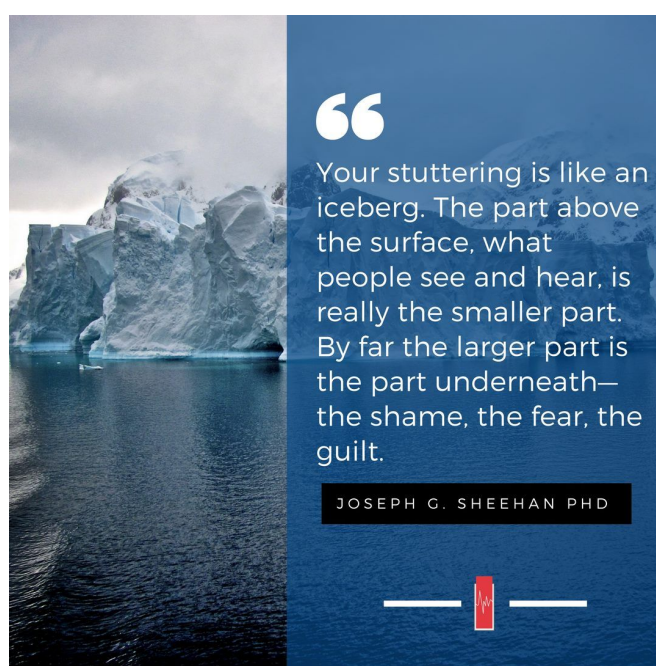
What has this got to do with stuttering, you may ask? Well, stuttering can be defined as a disability. Disability has been defined in different ways throughout history and different models have been put forth to explain these definitions. According to the medical model of disability, stuttering would be defined as a speech *disorder* that needs to be "cured" or "fixed" by professionals, such as speech and language pathologists and therapists (Retief & Letšosa, 2018). The social model defines disability as happening at the intersection of personal impairments and an inaccessible environment. People who stutter (PWS) have limited and often no real access to certain types of communication technology, such as automatic answering services, Google assistant, Siri and the like, which are becoming more widespread in the digital world of today (Wheeler, 2020). These services have as of yet, limited ability to understand or "read" dysfluencies in speech, creating barriers for PWS.



Building on inherent human dignity, *The human rights model of disability* defines disability as a natural part of human diversity that should be respected and supported (Lawson & Beckett, 2020). Assuming that PWD have the same rights as everyone else in society, the model puts the responsibility on the shoulders of decision makers, institutions, corporations and organizations to ensure that impairment is not used as an excuse for denying or restricting people's rights. While technological advances take time, according to the human rights model of disability, PWS can request that communication services, requiring the input of speech, be made available and accessible to all, regardless of severity of stuttering.

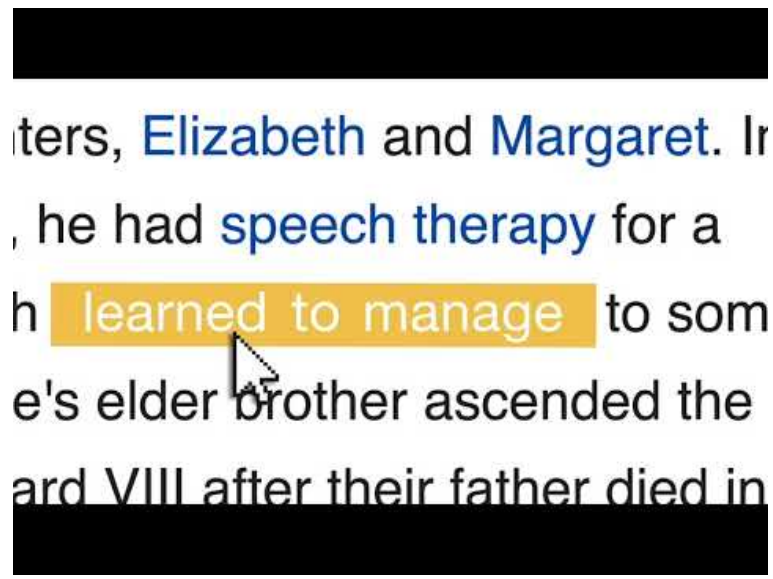
Stuttering, a hidden disability

In the United Nations Convention of the Rights of PWD, CRPD, Persons with disabilities "include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." (United Nations General Assembly, 2007). This can include stuttering/stammering, which can have "substantial adverse effects on a person's ability to carry out normal day-to-day communication activities" (United Kingdom Office For Disability Issues, 2010). Through avoiding daily speaking situations, such as phone conversations or video conference calls for example, avoiding using certain words by speaking less or swithing words in order to maintain fluency. If we assume that stuttering is a disability, it is in many ways hidden. Contrasting to a wheelchair user for example, stuttering is not apparent to others until the PWS speaks. Even then, PWS can use different methods of avoidance and fluency shaping. Perhaps the iceberg is particularly relevant when explaining the hidden side of stuttering. The thoughts and feelings around stuttering are often described as being hidden below the water, at the root of the iceberg.



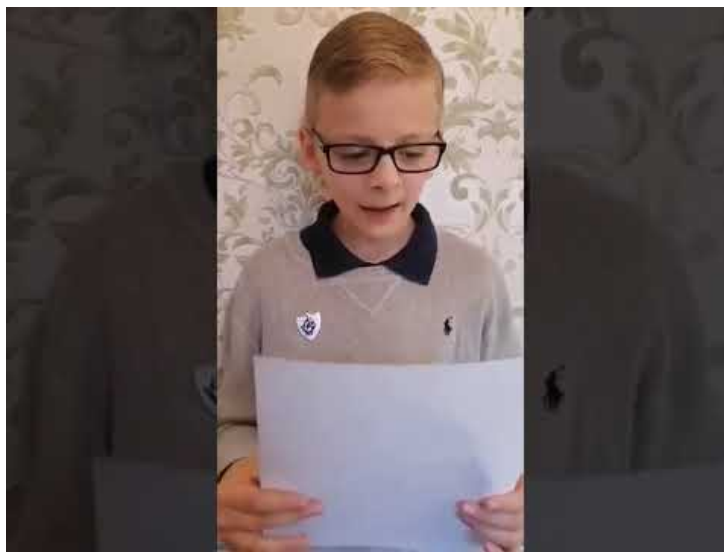
Speaking about Stuttering

While not everyone feels comfortable being open and upfront about their stuttering, I believe it is important that we encourage a discussion around stuttering and the challenges PWS face around the world. If PWS feel similarly around stuttering below the surface, on a global level, could it be that this is caused by our environment? Stamma, the British Stuttering Association has worked with Wikipedia to change the language around stuttering. They also launched a media campaign this fall about the words used to describe stuttering, criticising the usage of negative terms such as "defect" and "suffering from stammering/stuttering" and offering the more neutral terms: "trait" and "has a stutter".



ters, Elizabeth and Margaret. In , he had speech therapy for a h learned to manage to som e's elder brother ascended the ard VIII after their father died in

This is in line with the human rights model of disability, defining disability as a natural part of human diversity that should be respected and supported. Too often, PWS get pigeonholed, but PWS come in all shapes and sizes. Perhaps we can take the opportunity today, to share our unique experience with the world and define our own stuttering ourselves. Sam, chair of the World Stuttering Network Youth Committee, recently wrote two poems about stuttering at 10 years old, with the second one reframing the often negative discussion around stammering/stuttering (Stamma, 2020). He has explained that he doesn't suffer from stammering, on the contrary, he "rocks his stammering."



Pandemic Challenges and Opportunities Surrounding Stuttering

With the pandemic affecting us all in one way or another, disrupting normal life and in some cases leading to feelings of isolation, powerlessness, worry and even depression, there has perhaps never been a more important time than right now, to bring our experiences as PWS to the surface. Many have lost their jobs or have had to work remotely, often with the expectation to do more tele- and videoconferences. Speech therapy and stuttering self-help might be less available on site as well. While the increased flexibility might be working out for some, it can pose a challenge to others, who might participate less in different speaking related activities as a result. Face masks can provide a hindrance to effective communication, where the listener can't see our mouth, while others might find it a relief not to need to put the stuttering on public display.



What is your experience during and after the pandemic? Where does your iceberg come from? Would you like to change it? How can we as a world stuttering community build an inclusive environment where PWS feel seen and heard during the pandemic?

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