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Full Interview Transcript – Module 4

Why Words Matter- Presuming Competence

1 Can you tell us why it was important for you to write your book?

I wrote my book *An Unspoken Story* to tell my story of being Autistic. I did this as I thought that letting people know about my feelings and experiences of being non-speaking and Autistic was important. The reality of Autism is more important than a work of fiction. I want people out there to know that people who do not speak still matter in this world. I am also of the opinion that I am adding to the body of material about Autism and non-speaking Autism that researchers can tap into to, to really make a difference for all Autistics. I enjoyed writing my book, I hope people enjoy reading it. One of the points that I wished to make is that Autistics are as good as anyone else in this world. I hope I have made that point. My book is also aimed at changing the narrative about non-speaking persons with Autism. I think that they deserve a fair deal. By sharing the inner life of a non-speaker I have attempted to do that.

2 Why do words matter? How do we help people to understand how to get it right?

The words that we use to speak about Autism and Autistics who are non-speaking make a difference. There have been times when in my hearing a person has said something negative about me not realising that I understand language. Or they have made negative comments with an unthinking belief that it did not matter what they said about me as in their opinion I do not count as a person. These are the same people who don't believe that people with disabilities should be out in the community unless they observe all niceties of being in polite society. When I hear negative comments, it affects me deeply. It affects me so deeply that it is hard for me to even say it. We don't want to be around people who have negative attitudes towards us. It is necessary to educate so that positive words are used to speak about us. People have to use inclusive language in the community. There need to be anti discriminatory policies in place that are robust and can be enforced.

3 How has learning to use a communication tool changed your life?

Learning to use a communication tool has made all the difference to me. I started using a letter board as a teenager. I graduated to other tools. Some were low tech and others like the one I use most often now, an iPad pro with special software, are electronic. I would say that this brought about a major shift in the way I thought about myself and my environment. I have been able to describe this in my book. But let me say that using AAC brought order and self-regulation to my life. There was greater clarity in the way I connected to my environment. I would say that my relationship with my environment changed. There were other more concrete changes. Over the years, using AAC opened up opportunities for me that I did not have before. I now have the opportunity to present my work to you. I have found a way through my AAC to make and convey my decisions about how I wish to spend my day and eventually live my life. I think that having the ability to make decisions is powerful and positive. The ability to express my feelings has given me control over my life and I am a happier person because of it. I would like to add though that the assistive technology currently available to non-speakers leaves much to be desired. I am looking forward to a time when we have access to more efficient technologies.

4 What is the main thing you'd like people to know about being a non-speaking Autistic person?

Life for us non-speakers would be easier if we could make people understand a few things about us.

'People with Autism don't have feeling or empathy.' This is simply not true. Every Autistic person expresses their emotions differently. You can't generalise. I expressed my feelings through typing. I express my frustration through repetitive behaviours and throwing things.

Another misconception is people think I might hurt them.

So they try to stay away. I think people judge me by just looking at my outward behaviour. They use their pre conceived beliefs to judge me. It is important to educate the community to change the views people at large have about Autism and Autistics.

Every Autistic person expresses their emotion differently. I express my feelings through typing, through some ritualistic behaviours and a few acting out behaviours. Through my typed messages I have been able to let my support circle know that I experience the full range of feelings and my thought processes are coherent.



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I'm more interested in helping people to understand what it is like to be communication challenged. Lack of speech and behaviour difference do not mean lack of intelligence or feeling.

5 Can you explain how apraxia of speech affects you?

Apraxia of speech affects me with my communication skills and learning behaviour. I have trouble with controlling my willed movements. I might want to do something but may end of doing something else. This is hard. It also interferes with attention. Initiating an action is hard for me. For this reason, I tend to depend on others for initiation more than I would like. It is extremely limiting. There is a limited range of activities that I can undertake. For instance, I cant go out on my own. This is because apraxia also means that my communication is not independent and I can't exercise volition in the way needed. The motor issues that I face also will eventually take a toll on my health. Apraxia of speech is part of the over all difficulty with praxis that I face. It makes me a non-speaker.

6 What are the challenges of having complex communication needs?

People with complex communication will have difficulty in speaking. Speech is used to measure intelligence. To help them we need to use alternative forms of communication. This may include using sign language, visual board and other AAC tools. One needs to be patient and attentive because they will need more time to communicate. 'People who do not speak do not understand speech'- this misconception is common. However it does help to be patient and use clear, unambiguous speech as we do experience difficulties in sensory processing. This happens especially if you are a new acquaintance and or speaking to me in a community setting with a number of things going on around. People pose a question and we do not respond. Or they greet us and we don't respond to the greeting. This is seen as being indifferent or discourteous, deaf or having no capacity for understanding.. It is not the case. I am just as interested in social interaction as the next person. But it is hard to find a way of framing a response, even a wave of the hand.

I have described the challenges I face daily as a non-speaker in my book. The book takes readers into my world shows them what it's like to be a man who cannot speak and whose vision of the world is shaped by his communication challenges. One of the challenges of having complex communication needs is that our interaction with the people is greatly limited. Lack of expressive language can lead to loneliness. Over the years our lives become restricted we become more and

more isolated. Because it is hard to make friends and know people, it is hard to build relationships and have a social network.

It is frustrating not to be involved in conversations but to have to take everything away and put it down in writing.

7 Can you tell us a time where you felt very misunderstood?

There have been times when I have felt frustrated at being misunderstood. My apraxia causes me trouble in conveying my intention or feeling. I have a couple of words that I use but I don't always use them to say what I wish to say because I think that I use stereotyped motor patterns in speech as in everything else. There are times when I am trying hard to work but my body movements or body language convey that I don't want to work or want to do something else. This probably happens when the work I am doing is making a heavy demand on me and I am trying to cope. Due to a brain body disconnect I often act in ways that do not reflect my state of mind at that time or my feelings/thoughts/intentions. I have asked my support circle to go with what I type and not with my body movements. What I convey in my writing/typing is more consistent with my intentions. When I am in a social setting where I need to be around people, I go away on my own for a long walk. This gives people the idea that I don't enjoy their company or like being alone. But I think that it is more that I am overstimulated and need to regulate.

8 In what ways would you like people to adapt their communication style with you?

There are things that neurotypical people can do that would make an interaction easier. I want people to know that I love to be able to social. I want them to give me time to prepare and understand the environment I am going to be placed in. In preparing for a meeting, the more I know of what to expect the more likely I will be able to manage my communication with my AAC device. People are puzzled or put off by the amount of walking and pacing I do. They themselves probably have to prepare for this meeting. I am attending quite closely when I move around and this is something that people have trouble with. Even when I am face-to-face with a person, he or she will assume that they have got my attention only when I look at them. This is not the case. Even when I look at an object or a face, I have to glance sideways. In a new environment, my anxiety is in keeping with the unfamiliarity of the environment. The more familiar I become, the more regulated and productive I am. This is not typical attending behaviour. If people were made aware of this beforehand, things go better. I also need to walk around to figure out what to say. I want people to not judge me by my actions. When I am typing, I take a lot of breaks not only to compose my thoughts but to relieve the stress on my joints and



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muscles. The communication partner and my conversation partners have to be able to stay with me through this.

I would like to put this to you and get your views on this. I can see that it places a lot of limits on what can be achieved and how much people can have to do with me, or people like me.

9 How do you think we can change the narrative so that people presume competence regardless of an individual's situation?

The narrative around non-speakers need to change to being more positive. Clearly in Autism that there are many things that we don't know very much about. This is accepted. We don't have tests that are designed for Autistics with all their sensory and motor issues. We still don't know the causation. There is no treatment for the core features of Autism. How does one decide that we are not intelligent. Please give us a break. Positive words give rise to positive beliefs.

10 In what ways do you see the world needs to change to accept difference?

Changes in the world need to take place to bring acceptance of difference. Soldiering for change is about efforts to be seen as an equal to normal people. I hope in future there is more opportunities to work as Autistic individual. I wish to be able to go out independently and wish to enjoy outings by myself. I wish to be able to live independently. I want society to give me equal opportunities to live my life. I feel now as an Autistic, and we are going well to be treated inclusive. But we need to do better. That's it. Funding red tapes get in the way of getting what we need at the time we need it. I think that services that are meant to take care of us need more understanding of Autism. I would be glad to have work that is right for me.

11 How has writing helped you express your feelings?

Writing has helped me to express my feelings. Writing has helped me more than I can say. For non-speaking person writing is the main tool to communicate. My decision to tell the world about my experience of being Autistic was the best decision I made. Writing has given me a voice and has opened up doors to make a difference not only to my life but I hope to the lives and experience of other non-speaking individuals. My frustrations, low mood and insecurities have found expression so that I can now receive support and share these with others in my circle. I am able to say that I enjoy holidays with friends, scenic outdoor places, company and good food. Writing has also helped me to access counselling and this has been helpful. I enjoy my sessions with the groups I am involved with. It has



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allowed me to have purpose in my life. To educate myself and the community about what we are living with and what can make a difference to us.

12 What makes a good support worker for someone with complex communication needs?

People with complex communication needs benefit from having a worker who has certain skills. I would say rapport between the communicator/non-speaker and worker is important. It takes time to build rapport. For this reason I don't like short term workers and prefer to have a stable group of workers with me. Dependability and trust are good qualities to work towards in a partnership such as this. I would like to think that the worker is a person who will take responsibility for his actions and act with initiative. I am often dysregulated and experience ups and downs. There are days when I have difficulty engaging with the program. For this reason, stability in the worker is important as he/she needs to offset my ups and downs. A worker who understands Autism and is curious about it is a good worker to have.

13 How do you socialise as a non-speaking person?

As a non-speaker, I will say that socialising is an important aspect of what I want from life. In mainstream settings, in the community in general my socialisation is limited to passive participation. I am an observer. In smaller group settings, it is more active. But people have to give us their time and hear us when we use our AAC device.

I use email to write about my life to my circle of supports. I go out on train and get to city. I have a website and blog to share my experience. I use images to express myself. I go to circle of supports meeting. I like going to cafes. I think people need to be happy and be accepting of differences. I think one should not judge me by what they see. I think we should be seen as different but not quite a lot.

Being able to write has meant that my circle is more aware that I like to socialise. I like being around people and listen to conversation. Now that my circle knows that I enjoy these pastimes, my being passive, mobile or even acting out has not prevented them from helping me to access more groups, friendships and activities. When I participate by conversing with the help of my iPad, given the adaptations in the environment needed, I have to be in a small and supportive group. This is a limitation of my Autism. I also participate in several purposive groups and have enlarged my circle by doing this. I try to exchange emails with people in my circle. I take part in online groups with others who have complex communication. I would like to set up an online friendship group for people who like me who use a speech



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generating device. We have a network of families with a family member who has a disability which is active and we meet at least once a month.