Two way communication:

Make NO presumptions, but make KNOWING (and learning) your role

By Janelle (Nell) McMillan Sheridan (Sheri) Forster

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Nell Junior by Janelle McMillan

Hi Nell, Junior!

I am writing this letter to tell you that you might have had a couple of curve balls thrown at you in your short life. You have already managed and continue to kick those curve balls and battle through against the odds. You have been born with these extraordinary powers like determination, guts, fighting spirit and cheekiness.

You might be seen as being different to other human beings. No one wants to be normal anyway.

You have always challenged yourself in your short life, but unknown to you that you have already had a positive impact in the "World Normal" for change towards people with disabilities in the future and generations to come. Keep on advocating.

Life is a rollercoaster. You will experience highs and lows in life, but these experiences will shape you into the person that you will become, people will love you for that.

Communicating is a human right. Always remember that.

I have a voice and I am proud to use my voice.

It is my human right to choose how I communicate with people and the world.

People should respect the way that I chose to interact in world normal.

I don't want to talk to people through a communication device.

I am super capable of getting my messages across verbally. I will always speak my mind through how I chose.

Everyone loves to talk; this is the same for people with communication disabilities.

We might take a while to get our point across, but it is very important to be patient and understanding.

We don't want to be rushed or spoken over by people; it is very rude but easy to do. People should respect us and give time to listen to our voices.

It doesn't take much to be shown by people to wait & listen with their hearts as well as ears.

All kinds of communication are empowering & gives a sense of belonging to everyone.

Everyone has a voice to stand up & be heard.

People with all kinds of communication disabilities have ways & methods to get their messages across.

No one is perfect, so why are people with communication disabilities made to fit into the "World Normal" when very few people don't even try to listen to us.

Don't judge us from the outside because we are humans too. Our feelings are just as valid as people who are able to speak out loud and express themselves clearly.

We as people with communication disabilities have lots to say and contribute to "World Normal".

It is time to take notice, "World Normal" and start to change for the better. It will be a long road, but those small steps will lay the foundation for change to be created.

We have lived in two different worlds.

One of respect, acceptance and understanding when I am behind safe walls at home, but the other is filled with misunderstanding, judgment, disrespect, ignorance and sometimes downright rudeness out there in our community. I am fighting a war every day to get people to see who I really am and stop the discrimination, just because a large number of people want to stick their heads in the sand. Please keep fighting for the world to be changed for the better.

We are smart. I've been awarded an Order of Australia and I love raising money for charity. I have even published a children's book. See, look at what we have achieved so far. Go us.

Looking forward to meeting you again in the future. Good luck and goodbye,

Nell, Senior!

Communication



- Communication
 - Is central to all interactions
 - Is central to being supported by disability support workers.
- Communication includes
 - Understanding different types of communication
 - Expressing oneself with different people
 - For varying purposes
- Everybody's understanding and expressive communication is different – it also varies
 - Situations
 - Health
 - Stress



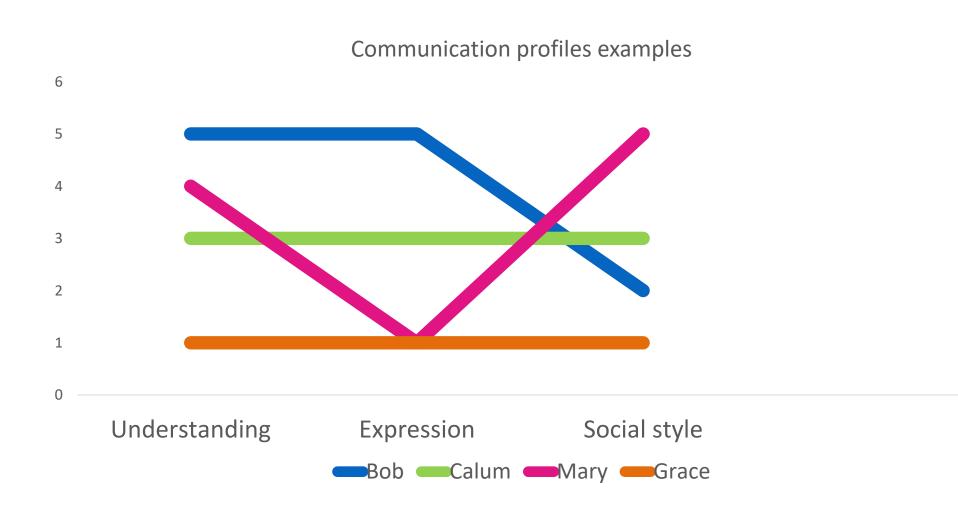
Don't make assumptions

- It is important that supporters do not make any presumptions about communication.
- It is important that they learn about each individual
 - Be curious
 - Observe
 - Ask
 - Reflect

We acknowledge that perspectives vary across people with communication differences



A mix of understanding, expression, and social style

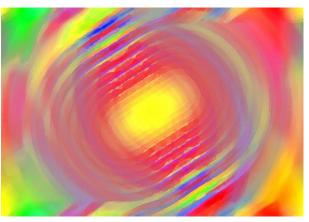




But communication success is about a fit

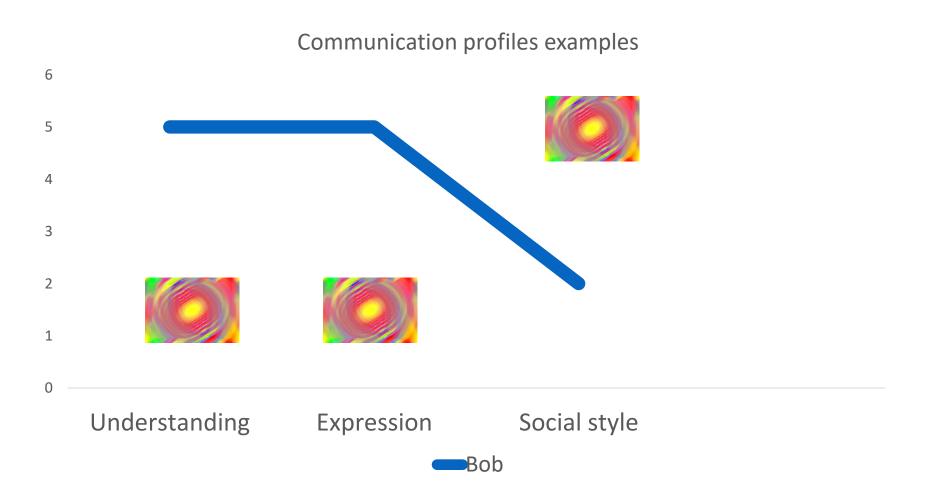
- Communication is always about a fit between two people:
 - expressing in a way that the other can understand and
 - understanding the way that an individual expresses themselves.
- Knowing about individual communication allows you to adjust your communication to support understanding and expression.













Hey, I'm Sitting Right Here! Anonymous

Look out I thought to myself, here we go again - I'd just been ignored by a tired waiter at a café who had come to take everyone's order. Whilst I may not have been able to communicate verbally, I am quite capable to express my preferred request from the menu and type my order with my communication device. Luckily, my mother was able to ascertain my complete frustration and feeling of absolute insult to right the wrong that had just occurred.

You see, when a person has difficulty communicating verbally, it is more often then not, presumed by those around that we are of limited intelligence without the ability to form thoughts of merit, ideas of justice or quite frankly, any suggestion of a humorous side. Whether it's within one's own family, the broader community, often even allied health professionals or people within education settings, there is very often a preconceived idea that a person with any degree of wanting within their communication must be of limited intelligence, an empty vessel who sits on the edge of human feelings and who won't be emotionally sensitive to being ignored or treated as though ideas and worth are not to be taken seriously.

Within my own life plenty of opportunities rely on people interacting with me on a personal level, through those people treating me in the exact manner they would treat any verbal person. Opposing interacting with me places my intelligence in a place of nonexistence, whereby presumption has already been made of my ability to understand others' opinions or thoughts, yet I can fully acknowledge what the conversation is about. Perhaps a more caring and respectful approach would be if people interacted with me as a human being who understands conversation, who has feelings and can be hurt and undermined as any verbal person could be made to feel if they were to experience the same thing.

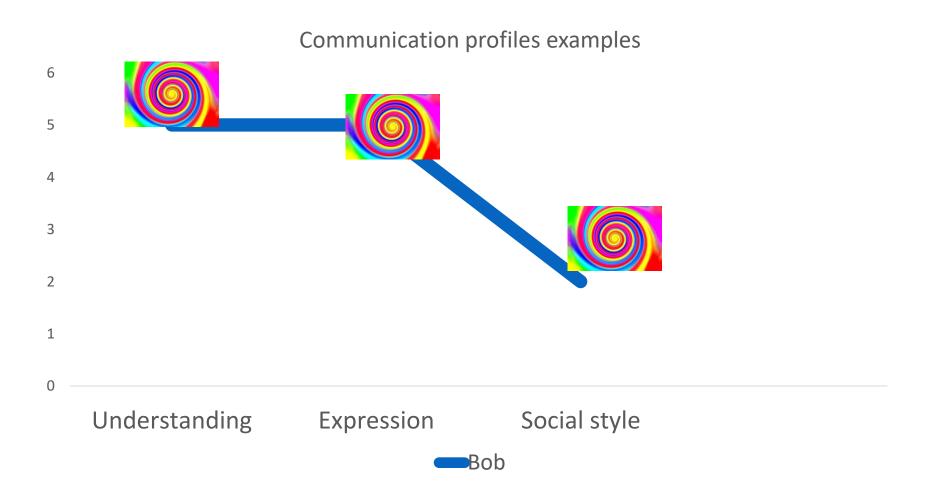
Perhaps a more respectful way to show overtures of initiating an approach to begin a conversation with a verbally challenged person, would be to look them straight in the eye, don't talk at or down to them and most importantly, don't presume they won't understand your conversation or that they won't wish to be included in the conversation. You may be very surprised how the interesting points of views others share may benefit the whole community and different perspectives can create engagement in challenging the so called normal ideals of some.

Thinking about my own life I am fortunate to have, least not, but most importantly a loving family who have always engaged with me, who have never dismissed my intelligence and who value my opinions and worth. It has allowed me to weather the callous reactions from some others who have at times shown disregard in their dealings with me. To be able to communicate with others waving on my sense of humour and giving looks of approval in my vital sense of justice, gives me worthwhile emotions and their acknowledgement of my value is immeasurable.

So please, to anyone who may be reading this – take the time to walk in others' shoes and you may find a world opens up that is full of surprise and interest. Stop looking down but out and connect with that person who might appear different, but who underneath may be just like you. What a happier world might be created if everyone could be included to share their gifts in everyday life for everyone.

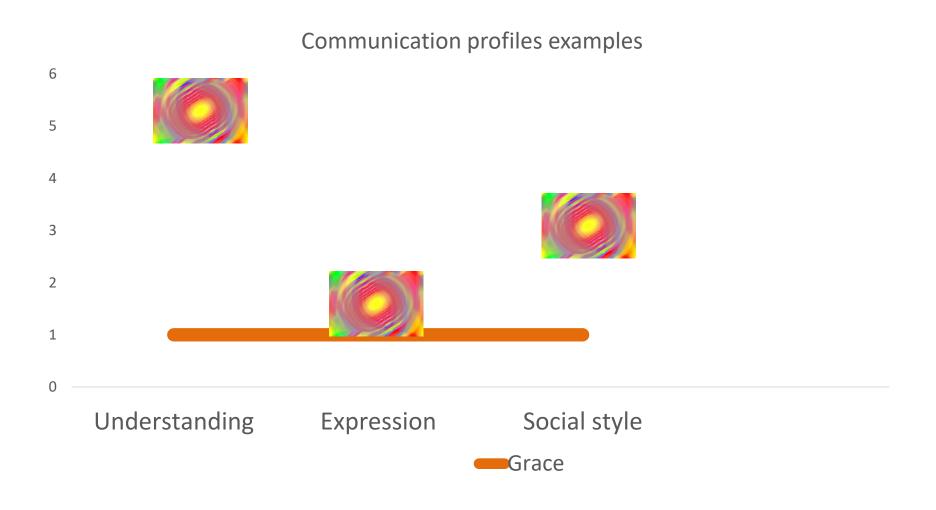


Communication fit for Bob





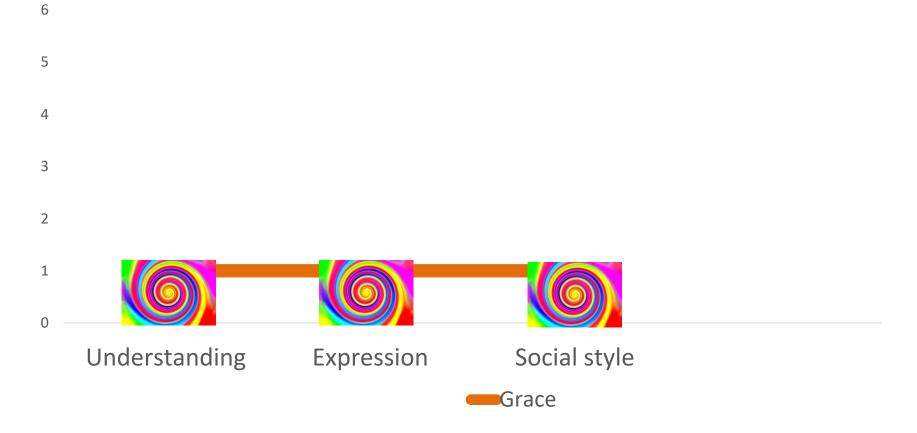
A miss fit for Mary





A fit for Mary

Communication profiles examples





Anonymous... from Can We Share a Word

....I have even at times found it helpful to use AAC myself when my stress has become so overwhelming that speech has become difficult. I certainly have become confident in requesting that official information be communicated with me in writing rather than by telephone, to help with my auditory processing issues, and I can now understand that this is a valid request. It is both interesting and frustrating that while many people with communication challenges face discrimination because people assume that lack of speech equates to lack of understanding, people like myself struggle because of the assumption that a good speaking ability means good understanding. Oh for a world where we can ask individuals what they need instead of assuming that we already know!...



 Nell and Sheri will share about ways they and other people they know communicate... from people with excellent understanding of spoken speech to people who do not understand speech but understand touch or the gaze of someone sitting close to them.

 We will share stories of when the communication fit is poor and what that feels like, and stories of when fantastic interaction is possible when the fit is good.

The communication fit between Luke and his mum SBSK



The communication fit between Matty and his dad SBSK





You Don't Need Words To Connect With A Human Spirit! By Janelle

I love you, being imperfect.

Life with you.

We don't need words.

Learning to read you like a book and between the lines.

You have taught me kindness and practice patients to be a better person.

I just love doing life with you.

Embrace holding your hands and rubbing them in the slightest of the day and night.

Watching your chest raise and fall, when you are calm and relaxed.

Embrace the facial expressions without the words dominating the conversations.

Your smiles bright up the room like a sunrise.

You have learnt to tell people when you have something wrong.

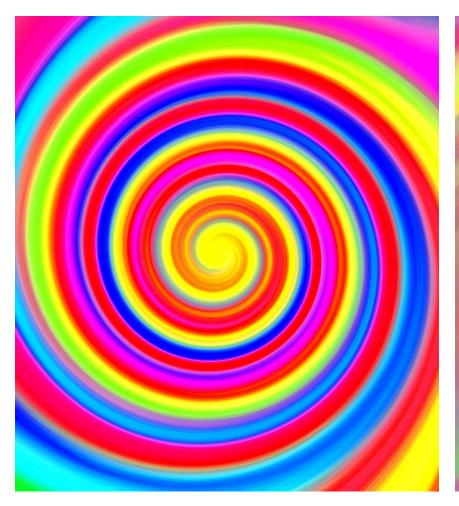
It is an honour to call you, my son.

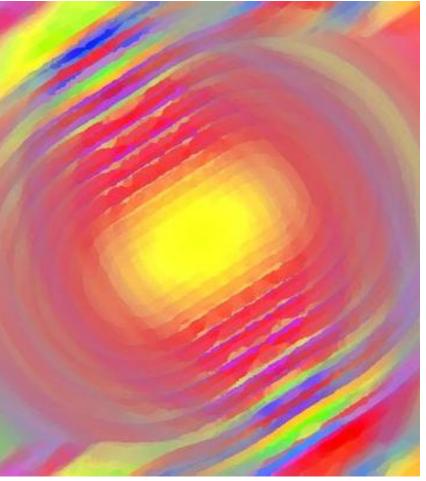
You have taught important lessons to people who have come into contact with you.

Thank you, my son for being here on earth.



All about the fit of two people: you make the difference







How do you need to be in order to be with the person you support?

And... how might you need to be if you are supporting someone community with other people...



Expression of Choice ... to Be Rude or Not by Janelle McMillan

To Anyone Who Wants to Know,

I would like to share with you how I felt in a recent incident to show that it is ok for people with a communication disability to stand up for themselves.

I am sharing my point of view about what happened with my support person when they supported me to a clinical appointment. There were three people involved: me, my support person, and the clinic receptionist.

"What is the next thing for her to have done?" the receptionist directed to my support worker.

"You can talk to me and not my support worker please", I told the receptionist in Nellspeak, a voice not understandable to unfamiliar people.

But rather than a relay of my message, my support spoke over me with an answer of her own.

I was upset how my support person disrespected me, because their job was meant to be being my voice, as I can't be understood by most of the people in the community. I had a message for the receptionist. It was not rude. I was standing up for myself as it was my appointment. The receptionist should have been speaking to me and not to my support person.

I felt that my support person had broken my trust because they refused to tell the receptionist what I said, because they felt that it wasn't warranted - but they are my voice.

I felt that no-one has the right to pick or choose what is appropriate to translate for me, because I am my own person who has a mind of my own. I have a right to freedom of speech just like everyone else.

A support person should not have the power to decide what they are going to translate for me - they are gagging me, because they won't say my words. I don't need their permission to express myself as I am an adult.

I have the right to use the language that I chose, and to be able to swear just like verbal people.

It is going to be hard to work with someone if they are going to put their own judgement on what I should be saying to people.

I think that people should put themselves in my shoes and to see how would they feel?

What do you think?

Takeaway points



Don't assume anybody can NOT communicate



Consider what it might feel like for you if you had differences in communication and needed supporters to adjust their communication style



Think about YOUR ROLE to support communication between a person and others in everyday life



Respect!

Equal Rights!

Be Understanding!



No Belittling!

Be Willing To Liste

Put yourself in the shoes of a pers with complex communication nee





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Everybody's understanding and expressive communication is different.

It is important that supporters do not make any presumptions about communication. It is important that they learn about each individual.

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