The principles of getting relationships right

Narissa Niesler (nee Wilson) is a leader, designer, manager and someone who is passionately focused and committed to inclusive communities for people with disabilities. For the past decade professionally, Narissa has led highly productive teams within the IT sector and founded a small web and graphic design business.

Narissa is based on the Sunshine Coast, has recently married and is a passionate foodie. She advocates and manages her own supports and services which she has been self-managing since 2009. Narissa spoke about the concept of right relationship and drew from her own experiences of managing her own team of support and the lessons she has learned.

For our four month wedding anniversary, my husband Steve and I received a surprise gift from my niece Isabelle. She had drawn us a picture of the characters Anna and Kristof from the movie Frozen because the characters "are in love, just like Aunty Rissa and Uncle Steve". This picture, and the lovely message that goes with it, demonstrates that in her world, relationships and love are freely chosen for all. In her world she doesn't see me in my wheelchair, as being any different. She just sees me.

Relationship is defined as "*the way in which two or more people or things are connected, or the state of being connected*". There are so many layers to my web of networks that it helps me to have filters for what each relationship is and how it sits within my life.

For me, there are two types of relationships that exist; personal and functional. My personal relationships are with people I have chosen to be a part of my life in a valued way because I like that person and have built trust with them over a period of time. These are people such as my husband, family, friends and members of my community.

My functional relationships exist to serve a specific purpose. They are generally relationships that have parameters and a certain element of order and structure to them. I have functional relationships in my professional life, such as those within my business, but in this article I am focussing on the relationships with my host providers and support workers.

Relationships are, by their nature, quite personal and carried close to our hearts. For me, the concept of right relationships within my supports and services are those that are valued and empowered. So when I was first asked to explore the topic of right relationships, it challenged me because it all seems like such common sense. It is how healthy relationships should be.

I have been fortunate to have parents that really paved the way for right relationships in my life. I did not really think about my family's principles when I was growing up, but looking back I can see they were really quite intentional and have shaped who I am now. These are principles such as respect, honesty, freedom, teamwork, exploration, sharing and celebration. For me, these principles are the foundation of a right relationship.

Even with the best of intentions, relationships can be messy and like all things in life they change and take different forms over time. I have had functional relationships grow into personal ones; albeit with a lot of intentional nurturing and sometimes stepping around some of those grey areas. On the flip side, I have had a personal relationship grow into a functional one which led to upheaval in my life.

At the age of 17 I moved out of home with no paid support. I lived with friends in a share house and it was these friends who informally met my support needs. This meant that at this point in my life these personal relationships, which made up 90% of my relationships, were fulfilling the functional role of meeting my day to day physiological and safety needs. As these personal relationships slowly morphed into functional ones they broke down and I was suddenly left in a vulnerable situation. As the friendships came to an end, so did my supports and living arrangements.

It was at this point I started building a more sustainable and secure future for myself, eventually securing paid supports. With the introduction of support staff in my life, I really had to start taking the lead with the relationships in my life and being very clear and intentional with them. I had to learn how to compromise, negotiate, influence and manage my interests so I could continue to live an independent life.

Up until this point my parents still assisted with negotiating my functional relationships. I don't think there is ever a point where family step down but this was definitely a time where I had to step up. I needed them to hand over the unspoken authority so I could become ultimately responsible for creating and maintaining these important relationships. I had to focus on my vision of inclusion and share this with the people that were about to come into my life in a very functional way.

I definitely did not get it right in the beginning and it took a lot of trial and error to get where I am today. There were lots sleepless nights, tears, phone calls to mum and moments of doubt questioning why I was putting myself through this. I asked myself, 'is living independently really worth it or should I just succumb to the institutionalised pressure and go to that group home?'

After two years of receiving support from a traditional service provider there was fractured trust and angst surrounding the delivery of my supports: we had a different vision of my future. After searching for a service who matched my DNA, I found them! They embrace my constantly changing goalposts and collaborate with me on creative approaches that ensure my supports and services are delivered in ways that uphold my vision.

My service works with me like any good mentor. They get excited by my hopes and dreams, they share the successes, they challenge me in ways which keep pushing me forward and I know they have my back.

What facilitates the creative approaches to my supports with my service is; we share the same values and vision. Their service values and visions walk side-by-side with my core values and vision for my life. There is a common understanding that service delivery doesn't have to be perfect because life isn't perfect but we do what's best at that given point in time.

There is a common understanding that we all do what we can to ensure the sustainability of my vision. The collaboration is clear because both the service and I know what is expected of each of our responsibilities surrounding the business of my supports. Because the expectations are clear service systems are not an imposition and keep my vision at the heart of service delivery.

When I first moved out of home and I had little formal support, only 10% of my relationships were functional. Whilst now up to 70%, the functional relationships in my life service a very specific purpose, with order and structure that I influence.

These functional relationships have a real impact on my quality of life, so when my biggest asset is not operating in line with my vision, breaks or moves on, I can get emotional, upset and frustrated. The best version of me does not shine through and my basic physiological and safety needs are not met and therefore

during this time I become more vulnerable. It is at these times the safeguards I have developed come in to play and I can rely on my plans B, C and D.

Self-managing supports and services is definitely always a work in progress and every day I endeavour to improve how I operate and manage them. Over the years, I have become more skilled at recognising functional and personal relationships and the role they play in my life and this helps me to address issues that arise in a more timely and specific manner.

Some strategies over the years that have helped me to achieve respectful functional relationships are to:

- **Be clear about the purpose of the functional relationship – both at its conception and as it continues over time**. I make sure I keep my personal relationships and life sacred. One simple strategy of not merging the two worlds is to not add anybody to my Facebook that I have a present functional relationship with. When that relationship is no longer a functional one it may become a personal one, but that is a choice I make depending on my relationship with them.
- **Review my functional relationships.** Have honest discussions and make plans to move forward from the stuff that is not working anymore. This could be applied to any context whether it is the big picture stuff with my service or the day-to-day stuff with my support team.
- **Trust my safeguards.** They are there for a reason and can alert me to things I might otherwise dismiss. My safeguards are everywhere, intentionally. They are the people in my inner circle such as my husband and family. People in my broader circle who are safeguards in my community, such as the neighbours on the corner who I wave to on my walk, the friendly faces at my local shop, people at the local coffee shop or the ladies at yoga. However, don't forget the most important safeguards, the ones I choose, my friends.
- **Ensure I employ the right people.** By employing and engaging with people who are the right fit for my vision, it saves me a lot of time and energy in the future.
- **Invest in the people who support my vision.** Sharing a meal with those I am close with is a core value of mine. I have a gathering every 6 to 8 weeks with all my supporters -paid and unpaid - where we gather, share a meal and communicate. We don't talk about the nitty-gritty of my supports. We look at team building philosophies, reflect, strategise and align ourselves with the common goal – my vision.

My mum has always said that it is up to us to educate those I work with on how I want my supports and services to be, so it is important that we operate from a very honest and open platform. It is equally important that the people I work with are willing and open to learn about, and get on board with, my vision and align with its DNA. If things are not working out then I need to speak up and work with and educate those people.

As we aim for greater levels of empowerment for people with disabilities the concept of right relationships goes to the heart of this issue. I have seen how respectful and functional relationships help develop greater personal fulfilment, belong and have assisted in my own self-actualisation. Ten years ago if I didn't refuse the suggestion of a group home, take the leap to invest in my future and build the right functional relationships, then Isabelle's picture of her Aunty and Uncle would look very different.