

# SRV in action

HONEST HOPE  
IN THE FACE OF  
VULNERABILITY

BEING ME

WHAT MIGHT SRV  
SAY ABOUT...  
'HELPFULNESS'

NOTHING SUCCEEDS  
LIKE THE APPEARANCE  
OF SUCCESS

## UNLOCKING POTENTIAL

*by Rebecca Murphy*

*Rebecca worked for 15 years in the area of community care and aged services before having two children. Her background and skills in advocating for clients helped to foster a firm belief in an inclusive and fulfilling life for Rohan, who lives with a disability. SRV training supported her awareness and values as well as developing her skills in how to aim for the typical and avoid the 'special'.*

*With limited access to services, and living in a regional area, Rebecca navigated many barriers and challenged people's perceptions to support Rohan's development. Rohan now attends mainstream school in Brisbane and loves the learning environment, and his friends.*

Born in beautiful regional Tasmania, Rohan was the adorable fourth member of the clan. With the realisation that Rohan's development was not progressing as that of his sisters or friends, we set out early on to ensure Rohan had every opportunity to reach his full potential and have a meaningful life.

Travis and I discussed our vision for Rohan and it was based more on what we didn't want for him.

And also our regular features:

- *Helpful Articles*
- *From the Inbox*
- *My Favourite SRV Concept*

# UNLOCKING POTENTIAL

Continued from the front cover

by Rebecca Murphy

We had known people deeply affected by having lived in institutional care and group homes and the lasting implications of that. I had also worked for over fifteen years in aged care and community care.

The other major influence was having attended an accredited Social Role Valorisation course with Jane Sherwin some years earlier. It made a huge impact on me at the time. The theory has been useful in navigating life for Rohan; it has underpinned a lot of our decisions around trying to ensure he is included and has an ordinary life like other boys his age.

Our experiences with early intervention therapies exposed us to the potential limitations and challenges Rohan may face throughout his life. He was denied access to some services because he was 'multiply impaired'. Having been given various labels, people did not see his potential or worth. We worked extremely hard to search for supports from outside our local area including interstate, in developing a home based program.

We moved to Queensland for work and schooling options for both our children. We believed that this would give Rohan greater opportunities for an education. After attending an amazing Early Childhood Development Program, we were strongly advised by staff, family, and friends, that special education was the only sensible option.

We enrolled Rohan into a special education school for Prep but realised straight away that it was not the right placement. They did not share our vision for Rohan, so we started home schooling. Our extended family members were not very supportive of this; they believed special education was the best place for him and that he would be looked after there. But we didn't want Rohan looked after, we wanted him to have an education. Rohan may have not been speaking but we knew and had a deep belief that he was intelligent and had so much potential.

After another extensive search we found a

mainstream school with a special education unit. We thought this would be a good balance between the specialist supports he needed and giving him access to a mainstream environment. The following year was our clan's hardest and tested our defences. Rohan was extremely vulnerable and was not yet able to verbally express himself.

We became aware that Rohan was being segregated and isolated from other students most of the time and not attending mainstream class. A lot of his time was being spent watching videos. He was becoming extremely unsettled, showing signs of emotional and physical distress. The school had assessed Rohan as being at a curriculum level below that of kindergarten. After many discussions, meetings and heartaches, we withdrew Rohan and started home schooling again.

Around this time Rohan started seeing an amazing speech therapist. She was opening up his access to communication through facilitated communication. Rohan had a breakthrough moment ... he could spell and had something to say!

Over the coming months we discovered that he was very good at maths and had great comprehension skills and had been able to read for some time. Rohan now attends a mainstream school, attends five days a week and is seen as a capable student. He achieves good grades at peer level (grade three), and does grade six spelling lists. The shift for Rohan has been enormous. In his own words, *'I feel valued at school because I have friends who like me. I am seen as capable and made to work hard which I don't like but it's good for me'*.

Last year Rohan wrote a story about himself that was put into the school newsletter for Disability Action Week; it is titled *Being Me*.

Rohan's story, *Being Me*, appears on the following page.

# BEING ME

by Rohan Murphy

EDITOR: We are thankful that Rebecca and Rohan have generously contributed their stories.

Rohan wrote this story on an iPad via an app called Notability using facilitated communication. Rebecca supported Rohan at the wrist to enable him to point to the letters with his finger.

Rohan uses facilitated communication at school using touch screen computers, and his iPad or a communication board to do his work. He is supported by his teachers and teacher aides. The teachers now assess him as now working at peer level.

The text below is presented as it was written by Rohan at the time, after only ten months of access to communication options. Both Rebecca and Rohan feel it gives more validity to the text to not edit.

Therefore, we have reproduced Rohan's story as he presented it. The experience of assistive technologies and facilitated conversation are both enabling in that they make communication via language possible and have restrictive elements of technological/human mediated communication. So, in the spirit of bridging this divide, we prefer to avoid technical expectations such as grammar and spelling.

*I was just an ordinary boy born into an ordinary family but that all changed when i turned 9months. I was given a diagnosis of 18q deletion syndrome and it has changed my life completely. I want to be ordinary and normal but that just isn't how it is panning out. Why does a diagnosis transform someones life? It is just a term for a medical abnormality but not a state of being.*

*I am a normal boy who likes roller coasters and swimming and playing with my sister. Not a thing that people stare at or tease. I want people to know i am intelligent and clever but my body has trouble being in control. I cant feed myself or dress without help but i know things most other 8 year olds dont. I want to be like other kids and go*

*to school and play soccer. Go to the football with dad. What does it take to make people see me for who i am.*

*I have been very lucky to have been given parents who see me how i am. They see my intelligence and abilities and know i can be someone great. I can be a valuable member of society and be a worthy citizen.*

*i am very sweet and gentle but my body is out of control and moves a lot. I cant stop it from swaying or hitting my head. I don't like it but i cant stop it. I try very hard at school and work to be in control but my brain gets in the way. I love my school friends. They see past my body movements and see me. I love my teachers who know i can do the work.*

*Please see me for who i am not my diagnosis. Its not a significant part of me just a barrier to where i want to go.*

Rohan's mother, Rebecca:

It certainly made people aware of Rohan's insights and depth of understanding. We are now focussing on developing his grammar skills!

When I asked him recently about what helped him in his life he replied:

*I love that you don't accept the limitations people put on me. I love how you include me in everything like going shopping karate music lessons and gymnastics. All that helped me be an individual that is loved. I think about how people don't always accept me but having a family who loves me gives me confidence I am a good person.*

*I wish others could have the life I do. I know I am in a good school a good family a good country. I hope to be a lawyer and represent people with a disability so they can have a good life too. I also want a good looking wife and a red Ferrari. Yes I deserve them.*

*Quotes on being yourself make it clear that the struggle to determine your own identity and live the life that is most real in your heart is an age-old fight. But just as others have risen to the challenge, you too can learn how to be yourself, standing tall and proud – Kye*