

Foundations for a good life

Rob and Virginia Lonsdale are the parents of two boys. After a youth spent living and working around the world, they are committed to investing in their local community and ensuring that Elijah, who has a disability, has the same opportunities as his brother Thomas.

In this article they explore how their family is consciously building a foundation for Elijah to be included in community. Virginia and Rob's understanding on how to make a good life for Elijah is underpinned by the theory of Social Role Valorisation (SRV) and conversations with local parent leaders, courses at CRU, and through some time spent with Queensland Parents for People with a Disability (QPPD).

VIRGINIA: In becoming a parent, I was hit with the overwhelming realisation that my own best interests now encompassed the best interests of our child. It was a stunning vista on the interconnectedness of our lives, but the ground below my feet also shuddered with the enormity of the responsibility.

This insight is particularly relevant for our child, Elijah, who could suffer or thrive for his dependency on us and our attitudes towards his ability to live in the world without being excluded, segregated or limited. For as certain as we are that there are many socially constructed impediments, parents also contribute to the size of their child's natural interaction with the world. Thus, we felt our enormous responsibility to listen and respond carefully to the question, 'in whose best interests?'. 'In whose best interests do these boundaries exist? In whose best interests are these activities undertaken?'

Our attitude about the absolute right for Elijah to belong just as anyone else does arises from this simple knowing – that Elijah is here on this Earth for his own reasons, that his life is of immense value, that he is whole and therefore complete and perfect as he is, and that he is loved, lovable and a lover of many things. Like me, his father and brother, he thrives on love, respect, attention, a bit of leeway, friendships, and a whole lot of fun. His inclusion may require, at times, a bit of imagination, planning, spontaneity or risk-taking, but if we can offer that, then I feel we are ethically obliged to do so - for the sake of love, empathy, and our dependency on each other. Moreover, Elijah's dependency on us, his parents, to build the foundations of a good life for him behoves us to think and plan about the causes that lead to a good life.

As parents, we discussed what we would like for Elijah:

- To develop friendships, joy, play and spontaneity.
- To use his strengths, assets and gifts.
- To explore his interests, potentials and choices.
- To have adaptations to help with difficulties.
- To be known and to be understood.
- To develop competence and independence.
- To develop into a decision-maker in his own life.
- To be educated, to continue learning, to have a job, to have a partner, to live in his own house, to get around town.

- To be HAPPY, SAFE, and find meaning in his life.

These are, essentially, the same aspirations we have for our older son, Thomas.

Mostly, a life is created out of many small acts that contribute to the whole. Our focus then is to nourish the conditions and causes that can grow into the life that exhibits the characteristics listed above.

In its regular habitual flow, life gives us many opportunities to make connections with community through our daily tasks and travels. We regularly visit our local library, supermarkets, and the video store. It is truly uplifting to go into our regular places and feel welcomed. It's an important value of mine to acknowledge the person who is serving me in a way that is friendly, open and inquisitive, and I am keen to develop that life-skill in my children also. We get to know one another by making small talk, giving a smile, having a joke and over time relationships develop. For example, before we pop into the library, I suggest how Elijah could say hello, hand over the card and ask to borrow a book. At the video store, Elijah says hello and asks for directions to his favourite DVDs. The supermarket, also, has been a place where we always see a friendly face and have a chat. I always make sure to use people's names and that people know Elijah's name. Elijah watches and he has learnt how to ask questions and find ways to talk with people. Elijah helps out at the tills, packing our groceries, and taking instructions from the person at the checkout. All the time he is learning useful social language and mores that make a community civil and an enjoyable, simple place to connect with each other. A place where we can experience belonging.

At the age of seven school is, of course, a regular place. Elijah has a natural ability to remember people's names and so he knows the groundsmen by name and most mornings we have a chat with them on the way to the classroom. He also knows the names of the office staff and teachers and he always says hello to the parents of his friends. This has helped him become well known in the school and there are people who look out for him; people who are happy to see him. His day starts off with many warm welcomes. What I can add to that natural ability is lots of encouragement.

For me, there are many times in life where we can step up to the plate and become bigger, wiser, kinder, better people than we would otherwise know or believe ourselves to be. It can be such a simple step to adapt, be flexible, be positive, and see the humour in whatever is happening right now. Imagination, fun and risk-taking are often frowned upon in our drive for an efficient society, but the question raises itself, 'in whose best interests?' We believe a good-life is always the life SUITED TO THE PERSON, so whatever is a good fit for Elijah will be our guide.

Rob: Early on in Elijah's childhood we reflected on what could contribute to growing a good life for our little boy. As parents, we thought it was important for him to have lots of fun, make friends, and learn the skills to communicate with a variety of people. And, as such, we have been looking to nourish these things in Elijah's everyday life in the most regular and ordinary ways.

From the age of 2, I took Elijah every week to Scouts with his older brother, Thomas. At first it was to give his mother a break and to let Elijah do something with Thomas, but I soon realised that Scouts would provide Elijah with a great community. All the older kids and their parents got to know him. He would play and engage with everyone, dishing out high fives, having fun, showing off whatever he had just mastered. They saw his journey learning to walk and he mastered his first step up to the Den, to the cheers of everyone. Elijah helped me give a talk on Key Word Signing to the group, teaching everyone a bunch of signs. The Scout Leader, Possum, who still knows how to sign 'Chocolate', always had a Freddo frog for him.

When Elijah started at school, the connections he had already made paid off. The kids from Scouts were scattered throughout the years and classes, so walking around in the first term I would often hear "Elijah!" as someone called

out to him. The friends they were walking with, not wanting to be left out of this special relationship, would get to know Elijah too. He was so happy to see people and engage with them that any 'disability' tag from being 'that kid who looks different' was quickly replaced by a name – "It's Elijah!" Last year Elijah was old enough to join Scouts. It was never a question of 'if' he would join, but 'when'.

In addition to birthday parties, Virginia and I decided that we would also have an end of year party to bring Elijah's friends from school together. We choose games that Elijah can take part in and all the usual party stuff. It's an easy way for Elijah to strengthen friendships and for us to get to know the parents. Everyone loves a party!

We have also started an inaugural vegetable growing competition with our neighbours' children. We all grow pumpkins, cucumbers, lettuces and other produce. We take photos and share our progress and then the plan is to have a 'best produce' party and cook-off, sharing all our delicious food. In doing this, we all become more familiar with each other and find a way to enjoy each other's company, along with all the skills we learn from growing our own food.

Expecting Elijah to communicate politely and to develop communication skills has been something we have encouraged from an early age. We started with signing, then an electronic communication-voice device, then speech, and now reading. Books have played a large role in helping Elijah. Reading is a valued skill, so we aimed to build on Elijah's good memory by focusing on sight words from an early age and as an added bonus it gave him something to WOW his teachers with. We filmed him for the school interview and showed his high-speed word recognition to the teachers, highlighting what a capable learner he was.

Book-reading is rewarded in school with certificates for students who have read 50 books and 100 books. We targeted this to get him on stage and have his name announced to the school assembly. He now proudly displays two Silver and two Gold reading awards on his wall, next to the Premier's 2016 Reading Challenge award. We have always encouraged him to help us around the house with cleaning, sorting laundry, cooking or gardening, which he is keen to do. We have made photo books for him to take to school and share his home activities, which his friends always love to read. We try to show him being independent to reinforce his ability in his friends' minds. We practise reading these so that Elijah can read them to his friends at school. This puts him at the centre, making use of his reading skills.

Overall, I believe that our role as parents is to help lay a solid foundation for Elijah's future. The skills for communicating and being a friend, and the network within the community that we help him build will support him throughout his life and allow him to grow and thrive. What I know for sure is that we as parents have to lead the way, by having the courage to set the highest possible expectations and, with an unwavering optimism, let our kids give it a go.