

## A sustainable community for my son

*In this contribution **Sally Richards** describes the key elements of the family-governed structure which she and two other families set up to support their sons to live a good life in the community. Sally believes that no single person in a family is more important than any other. Hence her struggle has been and continues to be not only for her third son, Jackson, who has a profound intellectual disability, but for herself, her husband and her other three sons. She is a teacher, writer and advocate and represents families on various government and nongovernment reference groups and has presented at conferences, workshops and forums*

My twenty-year-old son, Jackson, is a young man with the potential for a great future. He is a thrill seeker, a music lover and a car enthusiast; he has enormous stamina and perseverance, rides pillion on a 750cc BMW motorbike and enjoys bush walking and boiling a billy. Everyone who really knows him loves him. He also happens to have very high support needs; he needs one-on-one supervision and assistance all his waking hours. Without caring people with vision to support him to lead a good life, the typical future he can look forward to is one diminished in real and valuable roles and adventures.

He has so much to offer. However, we live in a society that often refuses to acknowledge the contribution he can make; a society which does not, to any large extent, value or respect people like Jackson. He is seen as 'other', a lesser kind of human who can contribute little and is not entitled to the support he needs for his life to be rich in people and experiences.

As Robert Theobald says in Anne Deveson's book Resilience (2003):

*Increasingly it seems to me that we need to rebuild at much smaller levels of neighbourhood, and develop the kind of face-to-face interactions where groups are small enough to make connections at very personal levels. It's that old adage: 'It takes a village to raise a child' – and we've lost our villages. We need to allow people to talk through a growing feeling that society needs to be more compassionate, and to take better care of the children we bring into the world.*

Jackson needs to be part of a community that will grow around him and with him as he matures. However, unless we do some structural work on his community, he risks living always on the edge of life. His community needs assistance, encouragement and support to include him fairly and squarely in its midst. To provide these vital incentives, I have developed, over the past five years, four supporting structures which are interconnected. Each of the four structures: family governance, planning, a circle of support and a small business is vital to the overall sustainability of Jackson's place in his community.

The initial impetus came from a Community Resource Unit conference several years ago where I heard Michael Kendrick speak about family governance and where I established a friendship with two other mothers who were also from Canberra. We had not been friends before but realised very quickly that we were like-minded and that we held the same values about the importance of our sons having a real, not a token life. We were three women who could use a common vehicle, family governance, to reach individual solutions for our families. So, in 2005 I invited them to join with me in establishing a family-governed project which we called Getting a Life.

Getting a Life provides the first building block of Jackson's community. He and the other two young men are at the centre of the project. The families and the coordinator form a circle around them; a hosting agency, which is philosophically aligned with the group and understands its very important but back-seat role, is to one side; and a funding body sits underneath.

As a family-governed group we, the families, have the autonomy to make decisions about the people we serve (our sons), the emotional support of the other families, the practical support of our coordinator, the guidance of the hosting agency, and the financial support of the funding body. These elements of the project are interdependent and each sustains and supports the others.

The second ingredient of Jackson's community is a broad life plan. Jackson's plan evolved some years ago but I have used PATH (Planning Alternative Tomorrows with Hope) to record it. PATH is a highly visual, person-centred planning tool which, with the assistance of a facilitator and grapher (drawer), uses very simple drawings and words to represent a person's goals and the eight steps leading there. The result is a colourful, visually attractive record of the person's hopes and potential achievements at some time in the future – this could be anywhere from twelve months to five or ten years hence.

It is important to articulate goals as this encourages and assists us to think about the kind of life Jackson wants, the steps and stages necessary to achieve that life, what's blocking him from having that life and who and what can assist us to realise his dreams. The PATH is flexible and changes often. It represents his life at any one point and needs to adapt as his circumstances, achievements, needs and goals change.

The third sustaining element of Jackson's overall life plan is his circle of support. It is also the most difficult part of the whole equation. Many people struggle with circles and so do I. Circles can be relatively straightforward to establish but are notoriously difficult to sustain.

A circle of support must be made up of individuals who have the common goal of wanting to make a real difference in the life of the person the circle supports. I have invited a variety of people in the past. At different times my own friends, family members, Jackson's support workers and other interested people have all been involved. We talk about Jackson, what is happening in his life, what is good about that, what is not so good and how we can make it better. It is a fun, interesting, brain-storming event which always has food, laughter and, often, champagne.

The most recent development in the creation of Jackson's community is the establishment of a small business. This is a PO Box mail pick-up and delivery business and it is still in its fledgling days. Jackson's support worker will also be the driver of the van. The aim of the business is to give Jackson a valued role and meaningful employment doing something he enjoys. It will also give him the opportunity to meet many small business owners and for them to know him. I believe that he will form relationships and friendships as a result of being a paid employee doing a real job in the real business world.

In creating all of this, I have discovered something rather amazing. When people see a person striving to create something and when they see commitment, energy and determination, many are drawn in and want to be part of the creation. If they are invited to be part of Jackson's community they are likely to accept and, once there, to stay – at least for a while. This is not a result I would ever have anticipated but it is a powerful force which helps to sustain my energy and which helps to sustain Jack's life plan.

So creating and sustaining Jackson's community is a many-layered and many-faceted enterprise. Some parts, like family governance and his business, are comprised of many smaller pieces which all join to make up the whole - much like a jigsaw puzzle. These in themselves, along with the circle of support and the PATH, are sections of the bigger picture: Jackson's sustainable community.

It is not easy - but then life wasn't meant to be, as a former Australian Prime Minister once said. However, it is exciting and rewarding and offers the potential of a real, interesting and valued life for Jackson supported by the community we have created for him.