

What Does it Really Take to Live my Life to the Max?

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My son, Eli, celebrated his recent 21st birthday recently. More than 100 people of all ages gathered at a local pub to celebrate the joyful life this young man has had, as well as his magnificence in the face of sometimes grueling challenges. Most of these people were Eli's friends - people who were there because they have a real relationship with him. It was one of the most joyful nights of my life and I could not help remembering what we were told by the doctor when Eli was diagnosed with Angelman syndrome 18 years ago - that he would never walk, talk or be able to do anything independently, and that a typical life was out of the question as he faced a life of 24/7 care.

The predictions that doctor made all those years ago have mainly come true - except for the typical life part. Eli may be 'uniquely verbal' (the term we prefer to 'nonverbal'), he may need support with pretty much every aspect of his life and he may have behaviours which could be seen as very challenging most days, but he also has a close group of friends who love him and take him to the footy, to live gigs and to parties where he is known for his love of Jim Beam and coke and a crazy night dancing to ACDC.

He has just finished a semester studying drama at university where he has been successfully included not just in terms of his learning, but also socially, and he has his own business 'Merger of Minds' which hires out technology to other young people who need support to access technology. He is an experienced presenter and co-facilitates presentations at universities and to the general public using whatever his communication device of choice is at the time and his gregarious sense of humour.

Eli has been living independently for nearly three years with no formal funding for the support he needs at home which is provided by the four friends he lives with, and by his microboard members most weekends.

It is this microboard that we believe has been fundamental to the making of Eli's 'typical life'. In fact, for our family, we believe that none of this would have come about without the community of learning and practice that is Vela Microboards Australia (VMA). We were founding members of this organization, along with a small group of families who have all worked together since 2007 to create the outcomes described by our vision statement 'My life to the max - choice, control, friends'.

Microboards are an innovative concept started in the mid 1980s by David and Faye Wetherow in Manitoba when they successfully designed a process around a young man leaving an institution. Microboards engage community members in supporting an individual by providing an enduring structure to maintain the support throughout a person's life.

Microboards have most notably been developed as a sustainable model in British Columbia, where they are still growing in strength after 25 years. There are over 700 microboards in BC currently, with examples emerging in many states in the US as well as in other countries.

A microboard is formed when a small group of friends and family gather around a single individual to form an incorporated association for the benefit of that individual. Depending on a person's particular needs, a microboard's role can include assisting with coordinating support services, finding and keeping employment, meeting a person's social needs and managing living arrangements and funding.

Whilst microboards in Western Australia don't yet have access to direct funding, the intent of government is that this is one of the capacities they will have in the future. In the meantime, government funding for microboards needs to be brokered through services. In most cases these services work with microboards on

a shared management model to develop a simulated experience of direct funding which has worked well in terms of offering a greater degree of flexibility and control.

People often assume that the incorporation process is mainly to create a transparent and accountable vehicle for managing funds or sometimes for raising money. As a charitable organisation, some microboards establish their own small business activity to augment or create funding. Whilst having an incorporated body to deal with financial management is an appealing aspect of the model, it doesn't represent the full story. Many microboards in British Columbia, for example, receive no funding at all, but still manage to create good outcomes as a result of relationship based work.

The group of pioneer families who started Vela Microboards Australia five years ago all have sons and daughters with very complex needs. Most of our sons and daughters have started from a position of profound social isolation and a lack of quality educational opportunities, and as for most parents, we have all had wounds which needed acknowledgement and some support to heal. One of the realisations we have had is that whilst at the outset we thought we were just going to create microboards, what we have actually been tackling additionally is a number of other distinct tasks which are pre-requisites to having a Microboard.

We like to remind people, for example, of the wise words of the Beatles song - 'money can't buy me love', and that it is too easy to forget that it is loving relationships which give us all real quality, security and meaning in our lives. We think there is something about microboard members having made a legal commitment to supporting the person to experience a full life which creates a more robust level of sustainability - mature microboards tend to function independently of external support or facilitation for very long periods of time, depending on only occasional support from the parent organisation. It is our hope that we can create a similar resilience in Western Australia, and to date the most effective work of our microboards has had little to do with managing funds and much more to do with building relationships, having fun, dreaming big and creating a strong and expansive network of people committed to social change.

We'd like to finish this discussion by sharing two of the many building blocks we have identified as being essential for the foundation of a Microboard. Whilst flexibility and control of our funding is an essential part of this process, it certainly isn't the only part of the answer, and we have found that it can in fact make little difference if other understandings and processes aren't in place.

1. Expanded possibility thinking

We've become aware of the importance of 'expanded possibility thinking', which really means that we as parents need to stretch the limits of our beliefs about what is possible. Our decision making is profoundly impacted by how we think, as we can easily shut down opportunities because of our disbelief, or fears of being hurt or rejected. Moving past years of chronic exhaustion, social isolation and perpetual grief to a state where we can believe that a person who can't walk or talk can have a paid job and a terrific group of mates, to taking the complex steps needed to make that happen, requires expansive thinking.

The shift in how we think about what's possible in our own, and our family member's life, has lead us to explore our engagement with collective support, both freely given and paid, which can help meet our family member's needs, including their need to self-determine. As a community we do intentional work such as workshops, mentoring, coaching and retreats to explore the ways in which parents can be supported to dream beyond what they currently believe is possible.

2. Building collective capacity

Another common question is what is it really like to invite people in to our lives - what are the challenges? Well, it isn't easy, and the challenges are many - but the results make it worth the effort. We use the image of 'constellation' to describe the complex relationships we notice and build around our loved ones. We've discovered that really we are in the business of building individual communities who provide support and attend to the needs of all of their members - this is the essence of their sustainability.

On the other hand, recruiting and managing paid teams has its own challenges and Vela Microboards Australia have most recently engaged a business coach who has worked with us to build highly individualised and successful recruitment processes. We have been delighted with the results of that - the majority of people we now recruit have no disability sector experience, so that we can create an expectation of high level outcomes much faster, as well as not having to untrain people exposed to out of date thinking.

Our reflection on the question of building collective capacity is that the disability sector and families generally lack awareness of just how complex this task can be, and of the level of energy and investment of resources initially needed to establish what is really a small business structure.

We look forward to the introduction of direct funding! However, our learning is that this is just the beginning of the journey. Families need each other and need to be connecting with each other as we create new ways of doing and being. We need support to think big and to let go of the wounds of the past. We need help in learning how to welcome others from the community into the lives of our sons and daughters, and the community needs help to find its way in. We need support to learn business practice too because the responsibilities of being an employer are way more complex than many of us realise - and they can change daily as new legislation is introduced. We have a responsibility to future parents to make sure that we do this very well indeed, so that direct and individualised funding can be a choice well into the future.

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(For a detailed explanation of the thinking and history behind microboards, see <http://www.communityworks.info/articles/microboard.htm>).