



Living life to the max – how do we put
friendship on the menu -

Ten Steps to Social Connection



My life to the max -
Choice, Control, Friends.

A Vela Microboards Australia presentation

The Vela Community in WA - Who are we?

- Small group of families and supporters in Perth and the South West.
- Sons and daughters with complex needs and behaviours which could be seen as challenging
- Services haven't been able to cater for our needs
- Grass roots approach
- Links with international best practice and academic research - relationship with Curtin and Edith Cowan universities, AACL in Alberta and Vela and PLAN Canada.



How we work together.

- *The heart of Vela Microboards Australia is valuing and respectful relationships, through which we influence one another.*
- *Together we imagine, explore and dream.*
- *VMA people enact a principled and practical approach.*
- *Collectively, VMA members seek to build passion, commitment and energy, and to exert influence in positive ways.*
- *We push boundaries.*
- *We move beyond what we know and create links that really work.*
- *This is a collective work characterised by unity in difference and love.*

What is a microboard?

- 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.
- Microboards engage community members in supporting an individual by providing an enduring structure to maintain support throughout a person's life.
- 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.



My son Eli's microboard - 'Blazing Condor Soul Explosions' - first meeting in 2009



Blazing Condor's held the first Vela microboard AGM in Australia last year.

The principles supporting Microboards are not negotiable...

- ...and tricky! These help to guide us and make decision making easier:
- **Person-centred thinking:** focussing on who the person is in terms of their gifts, abilities, dreams and wishes.
- **Self-determination:** given the right support, people tend to make decisions which promote their positive development.
- **Reciprocal relationship:** the community needs to be in relationship with the person as much as they need relationship with the community.

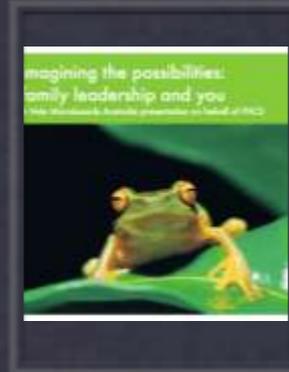
Vela: a community of learning and practice:



WORKSHOPS



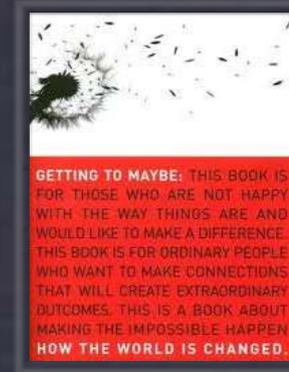
FAMILY MENTORING



CONSULTANCY TO FAMILIES AND ORGANISATIONS



WORK IN REGIONAL AREAS



RESEARCH AND REFLECTION



MICROBOARD FORMATION AND CONSOLIDATION



COLLABORATION



CONNECTING AND DREAMING TOGETHER



DEVELOPING GRASS ROOTS FAMILY VOICES



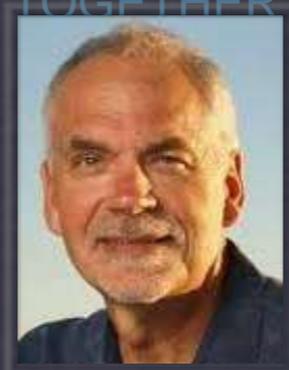
CHALLENGING BARRIERS TO INCLUSION



NARRATIVE PRACTICE



VOLUNTARY COMMUNITY EDUCATION



INTERNATIONAL CONNECTIONS FOR BEST PRACTICE



PERSON CENTRED PRACTICE



NON-VIOLENT COMMUNICATION PRACTICE

Why do we focus on reciprocal relationship?

- Firstly....Money can't buy love. There are many people with large amounts of funding who nonetheless have miserable lives.
- 'Love is that condition in which the happiness of another person is essential to your own' (Robert Heinlein)



Secondly...some practical realities.

- There isn't enough money, and isn't likely ever to be enough money, to pay for the support our loved ones need to be safe, happy and to fulfil their potential.

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- Even if we do choose group accommodation or agency based support, who makes sure the person is safe and happy, if not now then in 10, 20, 30 years time? Who makes decisions with/for them?

Eli's story

- Angelman syndrome with some features of autism
- Epilepsy
- Gross and fine motor challenges
- Uniquely verbal
- Sensory differences
- Significant ongoing behavioural challenges including hyperactive and destructive behaviours.
- When he was diagnosed we were told he would need 24/7 specialist care

And yet...Eli has been living in his own home for 2.5 years with all of his support at home freely given by his microboard members and friends.

- We don't get any funding for paid support at home for Eli.
- We do get Community Living Funding which pays the rent - not framed up as 'payment for hours'.
- He typically has 4 - 5 housemates, who to date have been friends and their partners/friends and who provide the 24/7 support he needs.
- Attractive - Eli has no shortage of people wanting to move in or to be part of his household.



Eli and Joe
outside their home



Eli's friend and microboard member Coral
stays at Eli's place most weekends with
her husband Jason so that housemate Joe
can play footy and go to Church

The rest of Eli's life...

(and some of Joe's life too)



Eli and Joe just completed a unit in drama at Edith Cowan University



Eli plays the drums in inclusive community music movement 'Catch Music'



His own business "Merger of Minds" which hires out technology and supports other 'uniquely verbal' people to access technology



The only thing Eli loves more than trains is train crossings!



Eli and Coral watching Joe play footy!

How did we get to this place where Eli has so much freely given support?

- He was included in school, but excluded from out of school socialising
- I had to stop resenting that and understand that other people just didn't know how to include Eli
- We had a circle of friends night with pizza and coke, and asked them what they wanted their relationship with Eli to look like
- This changed the dynamic with his friends and they started being more proactive.
- Eli's house soon became 'the place to be' and it still is.

Creating a home took about 3 years of intentional work.

- It began when Vela began, and we were 'forced' to invite friends to stay with Eli for a weekend.
- We continued to experiment - having friends stay over, taking them on holiday with us.
- Two friends of Eli's moved in with us for a while
- We thought about what would make Eli easier to live with...house design, behaviour patterns, skills...
- Joe lived with us for 6 months before we moved out



We were anxious when we asked Eli's friends to stay with him for the weekend - but look what we came home to! (note - we asked three friends, not one...)



Family holidays became possible for the first time when we asked Eli's friends to come with us

Everyone needs a home, and community

- The ironic lesson four of Eli's friends sadly taught us.



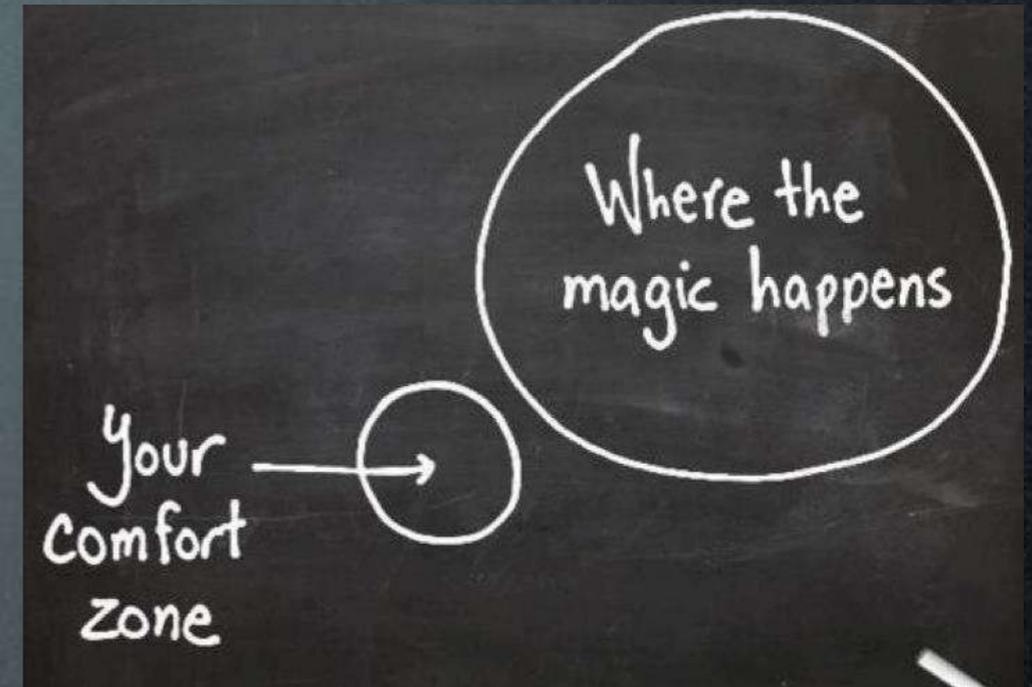
Our home has become a bit of a 'village' in the suburbs

- Two houses next to each other with adjoining back yards
- 8- 10 people at dinner weekdays, and 14 - 16 weekends
- We haven't had to 'roster' home support shifts for Eli (or our other charges) ever - there just always seem to be lots of people around who know him well enough to look out for him.



Has it been hard?

- Of course it has.
- There have been painful parts which broke our hearts, and parts so awesome it makes us full of joy. And then there are all the normal bits in between.
- Would we rather be doing this than struggling through caring for Eli ourselves well past the point where he or we wanted that?
- Absolutely.
- There is work which drains us of our energy, and there is work which lifts us up and leaves us feeling ready for more. This is work which inspires us.

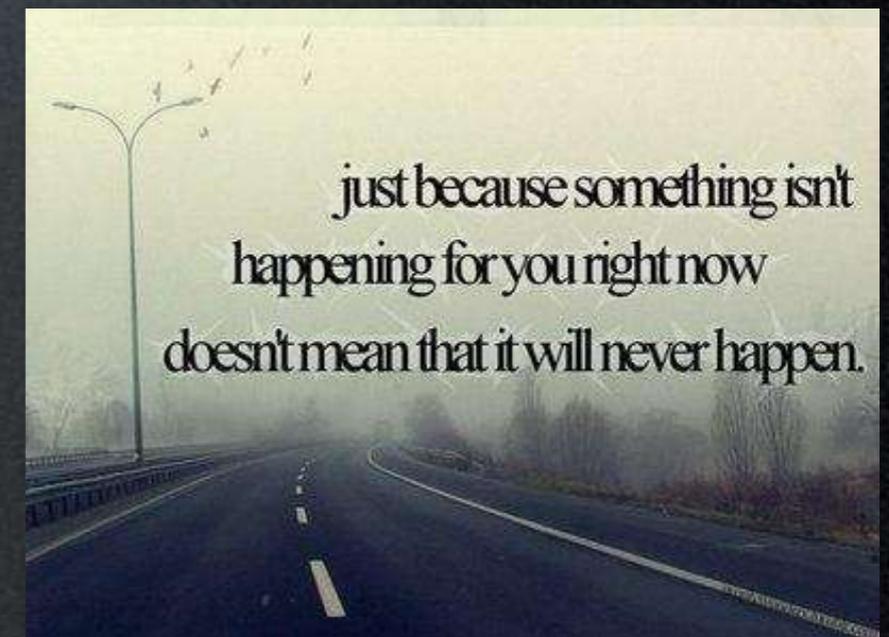
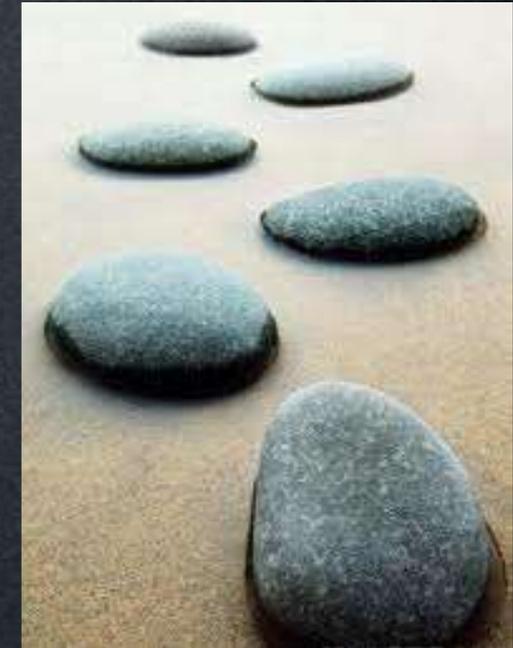




- We're not suggesting our lives as a model for everyone!
- The learning is - our solution wasn't 'on the menu'
- When we look at the challenge of sustainable, good lives for our loved ones with disability...
- ...maybe the most robust solutions come from attending to **everyone's** wellbeing.

How do we do this?

- Ten Steps to Social Connectedness...
- Being included and making friends at school did make it easier for Eli - but it is still possible for socially isolated adults to make friends.
- What would it take for real friendship to be on the menu?



1. Believe it is possible

- Research shows it is almost impossible for us humans to make decisions which will lead to different outcomes if those outcomes don't match how we have felt in the past and feel now.
- If you have felt that friendship isn't possible in the past, you will continue to make decisions which stop it from happening.

Two examples:

- Eli's prac teacher - my lack of belief resulted in a closed door
- Liam - by now wiser, a door opened wide

