

Erin and Maggie

- Erin needed emotional support to take the risk
- What if Maggie were rejected...?
- Check out Erin's website/friendship resources:
- <http://www.sheldonhickey.com>



Erin and Ellen Walker, Vela community member, near Erin's home in Kingston, Ontario.

How Erin learned to **support** (not **hinder**) Maggie's friendships by becoming aware of her beliefs.

She said...	I heard...	I thought....	She meant...	I should...
"Maggie is my best friend!"	"I don't object to being around Maggie. I will think I like her until I get to know her well enough to know she drools and wets her bed."	"That's so cute and delusional. How can they be friends when they can't talk?"	"Maggie is my best friend!"	Invite her over to play.
"I want Maggie to come play at my house!"	"I have this fantasy that Maggie could play at my house."	"That's so cute and delusional. She doesn't know that Maggie would break her toys and need her diaper changed."	"I want Maggie to come play at my house!"	Accept her invitation to go play.
"That's so gross, Maggie!"	"I don't like Maggie anymore since Maggie did something gross."	"I knew this would happen."	"That's so gross, Maggie! You do gross things just like every other six year old does."	Accept that Maggie does gross things and needs friends to call her on it.

Take a moment to reflect on your level of belief.

- Be continually self aware of your level of disbelief
- **and**
- Choose to behave as though you have a strong belief in friendship anyway.



Vela mum and dad Jenny and Leighton made 'YES!' t-shirts to inspire themselves and others to take the risk of believing in a more socially connected future for their son.

2: Gather the support you need.

- This is often hard work
- Risky
- Confronting
- We need a solid foundation of support to see it through



The WA Vela mums and Catalyst Susan Stanford attending the Jack Pearpoint/John O'Brien workshops

Being there with each other

- Protects us from harm
- Makes us strong
- Gives us access to more networks and connections
- Shared intelligence



Vela families in WA are available to each other to share learning, ideas, support and celebration.

If the community out there doesn't feel safe, then...

- Create your own!
- We do have each other
- Once we have a small community with each other, let it grow.



My son Eli is known and loved by the other Vela parents, and I know their sons and daughters too.

3: The reciprocity principle

- The community needs our kids as much as our kids need the community.
- The benefits to others can be profound. Being friends with Eli has assisted the recovery of two friends who had mental health issues, and has created more social inclusion for others.
- Five of Eli's friends from school chose to become support workers or EAs because they found being in relationship with Eli added such meaning and value to their lives.



Remember to look at the quality of the relationship.

- Not 'right person' but 'right relationship'
- Relationships have their own energy and are different with each different person.
- They can be nurtured and developed.
- Just as we do for our family members, remember to look for the unique contributions others make.



4: Listen to the person - what support do they need in order to be a friend?

- 'But...the person shows no interest in friends'.
- Go back to (1) - belief.
- Think about what the challenge might be.
- Sometimes people have been so excluded that they need a very safe social environment to get their self esteem back, or that they just haven't had the opportunity to learn to be socially connected - we use the Vela community to provide this experience of unconditional inclusion.
- For some young adults it might take a year or two for them to get their social confidence.

5. Build a community of interconnectedness and support

- Robust long term social connection is more likely if we build **groups** of relationships, not a series of individual and isolated relationships
- Begin with an awareness that **everyone** needs support - not just how do others support the person, but...
- How can the person support others in their lives? What contribution could they make?



Build up your repertoire of socially interactive, easily inclusive group activities.

- For people with complex needs, buddy them up with another player or make sure you have a good communication partner to help them join in.
- Explore modified ways of joining in.



Our crew like playing the game 'Apples to Apples'



The annual Vela picnic models way of including diverse people in games by the beach.

It can be awkward to invite just one person over...

- This puts a lot of pressure on the person, their friend as well as on the parent
- Ask two or more over, and the pressure eases.
- Stress isn't conducive to social connection.
- Give the person time and space to join in if they feel ready.
- It might take a few goes before they decide to participate.



It can be much easier with more than one

- Lets go back to the idea that relationships are based on emotion.
- In a healthy relationship, a good 'vibe' is often generated.
- This can take the pressure of the person, and lift the quality of connection.
- We seek to create a group of friends, a gang, a club, which has its own culture and energy, and which naturally extends itself.
- For people with high levels of support needs, a group of people providing the support is much more sustainable than just one person.



6. Communication

VMA believe that everyone communicates, and that everyone has a right to engage in and develop communication, regardless of their label or challenge.

Communication Bill of Rights

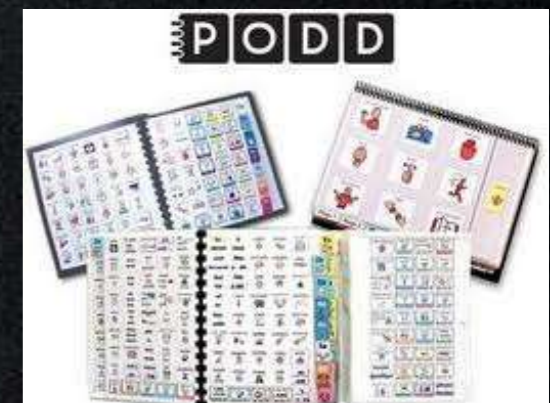
The Communication Bill of Rights consists of 18 panels, each with a title and an illustration:

- to be given real choices**: A stick figure points to three colored blocks (blue, green, red).
- to say no, refuse and reject choices**: A stick figure with a sad face and hands held up in a 'stop' gesture.
- to ask for what I want**: A stick figure points to a red block.
- to share my feelings**: Four faces showing different emotions: sad, angry, happy, and neutral.
- to be heard and responded to (even if the answer is no)**: Two stick figures talking, with speech bubbles containing the word 'talk'.
- to ask for and get attention and interaction**: A face with a dotted line extending from its mouth.
- to have and use my speech system all the time**: A stick figure holding a tablet with a clock icon below it.
- to be taught how to communicate**: Two stick figures looking at a tablet, with a greenboard showing 'ABC' in the background.
- ask and know about my schedule and world**: A 'SCHEDULE' list:
 1. bus
 2. reading
 3. math
 4. lunch
 5. recess
- I have the right:**: A central panel showing three diverse people walking together, one holding a tablet.
- to have my speech system in working order and to have a back up**: An open folder containing a grid of communication icons.
- to be a full and equal member of my community**: Three people sitting at desks in a classroom setting.
- to be treated with respect and dignity**: Two stick figures shaking hands.
- to be spoken with, not about**: Two stick figures talking, with speech bubbles containing the word 'talk'.
- to be communicated with in a sensitive manner**: A yellow duck.

From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). for meeting the communication needs of persons with severe disabilities. *Asha*, 34(Suppl. 7), 2-3. adapted by K. A.

Communication is the foundation of relationship

- We have spent a lot of time researching and exploring best communication practice for people with complex communication needs
- Take the time to learn and document the person's 'uniquely verbal' language
- For people with complex communication needs - check out the work of Gayle Porter at the Cerebral Palsy Education Centre in Melbourne, or Jane Farrall from Jane Farrall consulting.
- This is an area of dire and urgent need.
- Vela have just been awarded a grant by the Disability Services Commission in WA to facilitate the creation of two Masters levels units in communication for learning and relationship for people with CCN at Edith Cowan University in Perth.



7. Trust and allow relationships which are unique to emerge.

- The interactions might look different, especially when the person is (for example) on the autistic spectrum.
- The story of how Eli learned to connect through Thomas.
- Start with a blank slate, and learn to observe, not the gaps, but the fleeting moments of interest or connection. It might start with a super fast and covert glance...but if nurtured might end up being a profound connection.
- We need to make sure that people are getting positive feedback if they have a go at connecting - both the person with disability and those they are connecting with.

8. Paid supports: New professional roles - the Social Catalyst

- PLAN Canada started with paid friendship facilitators
- This can be tricky work
- Mum and Dad aren't always the best people to do this, especially when young people hit their teens and beyond.
- We created the 'Social Catalyst' or 'Fun Manager' role - we enrol outgoing, socially intelligent people who are able to connect others and foster friendships.
- If you have paid supports, think about what it would take to recreate their role so that it supports social connection.



Being silly, having fun, getting close...the challenges of nurturing the (often tricky!) world of young adult social cultures.

Our Social Catalysts get people together, spot new connections who might want to be friends, organise social gatherings at home and in the community and generally can't help generating fun!

They also negotiate the tricky world of young adult parties and cultures.

One of the reasons social inclusion drops off some time during high school is because the other young people don't know what it is ok to include friends with disabilities in.

Sometimes some frank conversations need to be had.

For example... 'are we allowed to talk about sex in front of Eli?' ...



Happiness and fun are attractive



9. Make reflection part of your process

- With a group
- What worked?
- What didn't?
- What do we need to do differently?

10. Connect with us!

- 'Like' Vela Microboards Australia
- Our new website will be going live soon - details will be on FB.
- We run interactive workshops via Skype/videoconference to support groups of families to create social connections.

