Leadership Through the Lifespan:
TASH 2018, Portland
Laurel Charnetski, B.A., PDP
Liz Etmanski
Barb Goode
Aaron Johannes, PhD

What we’ll talk about

– Laurel fostering school experiences of leadership as inclusion
– Aaron and Barb: talking to self advocates about their adult experiences of leadership
– New research on self advocates leading in families, prior to school entry
– Liz will document our conversation

• Are there questions people hope we’ll answer?

Inclusive Research

– Term from England / Australia. In Canada “collaborative” research, in US sometimes “action oriented research.”
– Social constructionist research (Taos Institute)
– How we do inclusive research
  – Advisory committee
  – Research question
  – Self advocate co-facilitation
  – Processes developed in collaborative
  – Data collection
  – Synthesis

• Ethics
Inclusive Research
- 5 years of meeting with small groups and individuals around the question of leadership
- Documenting stories and conversations with graphics
- Now looking at memories of pre-school entry leadership within families
- Other new research project on the role of a small church in a contemporary community

Barb and Aaron 1:10
• Barb’s lifelong question: Why don’t I feel like a leader?
• Curiosity of self advocate supporters: why have we worked so hard but not made much forward movement?
• Defining leadership? What is it?
  - ...
  - ...
  - ...

Barb and Aaron 1:10
• Barb’s lifelong question: Why don’t I feel like a leader?
• Curiosity of self advocate supporters: why have we worked so hard but not made much forward movement?
• Defining leadership? What is it?
  - Self direction / self determination
  - Through the lifespan
  - A continuum that includes participatory decision-making
  - Life, groups, citizenship
Pre-school stories of family leadership

I asked him, “What was I like when I was a baby?” He said, “I don’t know. You were like any other baby. The only thing about you was you crawled. Instead of walking, you crawled.” But the story he tells me is I crawled until I got bored. That is how he tells me. He said, “You didn’t worry about whether you could walk or not getting around here playing with all the rest of the kids, because you crawled to cause trouble.” I said, “I did?” He said, “Yeah, you caused trouble.” Because I would be doing something and know that I wasn’t supposed to be doing it. He said, “Then you would crawl to get away from people. You became the queen of crawlers. Then when you finally got bored you started walking.” That is how he tells me.


Stories of school life

- Often assumptions about abilities and limitations
- Separate streams of education meant limited opportunities
- Family involvement increased opportunities
- Some singular teachers focused on inclusion and leadership opportunities
- Often in education outside grade school

Leadership in schools

Moving from integration to leading the learning

Laurel Charnetski, Inclusion Support Teacher, Surrey Schools
charnetski_l@ surreyschools.ca
Do something because you are told to.

I do things because I choose to.

I share what I am good at and I am a leader.

---

**Engagement**

I do things because I choose to.

- Have a clear way to make choices and say what is important to you.
- Share what you love to do and feel you are good at doing.

---

**Caleb’s Story of Engagement**

Caleb is:
- Communicating what he needs and wants.
- Sharing his strengths and what is important to him.

Our role as a family member/friend/support:
- Listen to what is being communicated!
- If it is not clear, help develop a communication method that is.
- Respect and honor choice.
- Always be looking for strength-based opportunities.

---
Empowerment
I share what I am good at and I am a leader.

Leading the learning
• Be an active part of my school and home community.
• Teach others what I know.

Mentorship
• Be a “big buddy” to someone and give them support and cheer them on as they learn something you know how to do.
• Help others to learn how to be a leader and let them have a turn to lead.

Theo’s Story of Empowerment

Theo is:
• Communicating what he needs and wants.
• Sharing his strengths and what is important to him.
• Learning to lead and is starting to teach his classmates.

Our role as a family member/friend/support:
• Listen to what is being communicated.
• If it is not clear, help develop a communication method that is.
• Respect and honor choice.
Michael’s story of empowerment

Michael is:
• Leading the learning and teaching younger students new skills.
• Being a mentor to support and welcome others to lead too.

Our role as a family member/friend/support:
• Make and hold space for leadership to happen.
• Get out of the way!

Leadership in adults with disabilities
Aaron and Liz
• Unsuspected complexity and occurrence
• Subverted in ways that leadership in other minority groups has not been
• Tools like the Clarity Model (Karsten’s collected tools for youth leadership) unexplored, so lots of uncertainty over who made what decision, how.
• Hoped for some tips so that people could be supported to be more authentic, included leaders but realized that they had already been, and then these experiences were disrupted, devalued and forgotten
  – Often involved allies, often with good intentions
3 QUESTIONS

1) At your table, discuss: What is a good story about a leader you know?

Traditional leadership: person at the front of the room

Doing your own shopping
Conference

Tips to support leadership

- 2 self advocates on a board or committee
- Individualised supports to prepare and debrief
- Building in more time, front-loading
- Continuing to support someone with a disability over a career in leadership, based on their past successes
- Constantly, honestly debriefing (Karsten’s models)

Embedded small scale R & D
www.spectrumsociety.org
lessons learned = changes
Some Resources

- http://www.beyondtokenism.com

Some Resources

- Aaron’s dissertation and related materials: https://imagineacircle.com/2017/12/19/dissertation-what-works/
- Laurel: Student Profile (TASH conference site)
Barb Goode on the Eve Case
https://cic.arts.ubc.ca/the-eve-decision-1986/

Contact

- Aaron, Barb and Liz re. research:
  imagineacircle@gmail.com
- Laurel:
  charnetski_l@surreyschools.ca