

PEOPLE WITH INTELLECTUAL DISABILITIES AS LEADERS:
COLLABORATIVELY IDENTIFYING STRATEGIES FOR SUCCESS,
USING GRAPHIC FACILITATION

By

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Abstract

The newly ratified U.N. Convention on the Rights of Persons with Disabilities indicates that they will be increasingly included in all civic roles. However, while current policy and regulations often already require people with disabilities as participants in the leadership of organizations that support them, it continues to be difficult for them to gain authority. Their long, successful tradition of leadership in self advocacy groups and in some organizations has been barely examined from an ethnographic and appreciative perspective in terms of what works best for people with disabilities. This project's original research collected narratives of some people with intellectual disabilities about what has been satisfying and successful in leadership in their lives, in leading groups they belong to and in leadership roles in their communities. Concurrently, the effectiveness of graphic facilitation as one possible tool for understanding complex ideas in this population was tested. Graphic facilitation refers to the synchronous recording and visual interpretation of proceedings. Data was examined through a qualitative research process and findings were contextualized in terms of previous research. Graphic facilitation was deemed to be 100% effective and appears to bridge gaps in terms of literacy, cognition and learning modalities, while allowing a group to work effectively together on complex issues, such as, in this case, the changing face of leadership as defined by Parker Palmer and others. Surprisingly, findings were that these

particular participants were engaged in “taking action” and supported by peers in their community affiliations rather than within traditional self advocacy groups. Further, they did not proceed into leadership roles through scaffolded learning, but by strategically leveraging matrixes of opportunities and allies. This research may be an initial documentation of the leadership of people with intellectual disabilities in community affiliations, providing useful direction to organizations and those supported by them about leadership and accommodations, such as graphic facilitation.

“[N]o one could be called happy or free without participating, and having a share, in public power.”

Hannah Arendt, *On Revolution*

In Memory of Arnold Bennington

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¹ Those supported by LiveWorkPlay refer to themselves as members, and understand their roles as voting members who elect their Board of Directors and participate in directing the agency; where other people with disabilities call themselves "self advocates" I have used that term.

Introduction

I have long been fascinated by the question of how people with intellectual disabilities² move from the back of the room, assuming they have been invited in the first place, to take a place at the podium or at decision-making tables of participatory leaders. Often, afterwards, there are remarks about how impoverished the event would be without the presence of self advocate leaders. However, even such well-intentioned remarks assume the event was *enriched* by them, but still possible without them. While our service systems would not presume to make decisions about people of color for them, without them, or for people with physical disabilities, or for any other groups, many services and groups continue on course, and sometimes not out of patriarchal intent but because they are unsure about how best to incorporate self advocates. Self advocates are people who have been labeled as having an intellectual disability, who have learned how to speak up for themselves and can often assist others to do so as well. Historically, such individuals operate on their own and also as part of “self advocate

² People with intellectual disabilities have been called many things, however their main advocacy movement has been around the group, “People First,” which is an instruction to us; thus, “people with intellectual disabilities,” or the purposes of this project “people with disabilities” refers to those specified in the DSM-IV (American Psychiatric Association, 2000), in which “intellectual disability” indicates individuals who: a) are deemed to have a significantly sub-average intellectual level (less than 70 IQ); b) may be compromised in areas of communication, self-care, home living, social skills, use of community resources, self-direction, academic skills, work, leisure, health and safety; and, c) have been identified before age 18. Various factors related to theories of social construction and also the clarification of multiple intelligence theory make such labels increasingly less useful.

groups” such as People First or other groups, or as groups that advise agencies, organizations and government departments that support them. Increasingly, as we will see, self advocates are part of inclusive community groups.

Over the past decade in particular a growing recognition that people with intellectual disabilities must be involved in decision-making is reflected in law, government guidance, regulation and policy (Inclusion International) but not in practice. Robert F. Drake’s 1996 examination of the absence of people with disabilities in positions of authority evaluated systemic responses to concerns of exclusion stated about fifteen years earlier. Despite policy changes and leadership training programs, he found a continuing absence, motivated not least by the assumptions of those providing services to them:

Oh no, no, no, because for the simple reason they are mentally retarded. Our ‘consumers’ as you call them are not really capable of participating in the running of anything really I’m afraid. (1996 7)

Research since has not been particularly more hopeful about their inclusion as participating leaders (Frawley; Frawley and Bigby; Goble; Carter, Swedeen and Walter). For example, despite the proliferation of person-centered planning initiatives in schools, in which the person with the disability is to direct their supports, “only 12% were considered by school staff to have taken a leadership role during their own planning

meetings,” and although leadership is identified as one of five crucial areas determining adult outcomes, a 2001 survey of 1,180 special educators found that their students had almost no involvement in school leadership within student politics, sports, arts or extracurricular clubs, leading Carter et al to state that leadership is “perhaps the least explored and understood aspect of self-determination among individuals with disabilities” (57-8).

This work explores and explicates a social problem in that people with disabilities are often not included in leadership, or are included but not supported, or are included in ways that feel tokenistic (Hutton, Park, Park, Rider; Krebs; Stevens and Ibanez) while, concurrently, they have a long tradition of successful service as leaders within self advocacy and inclusive groups, which has been mostly unexamined, particularly through an ethnographic focus. Where they are successful, often one or more of several accommodations, such as graphic facilitation, has made effective participation possible.

What I imagined when I began this project was that I would elicit and clarify feedback from people with disabilities who are leaders in self advocacy and related groups about what worked best to support them. What surprised me, not least due to the serendipitous events of the day of the focus group, was that given the congruent support of an agency and staff members who are “community connectors,” there were no examples of themselves as leaders of segregated groups and many

examples of their participation as leaders in community and work based groups. An amazing group of leaders came together and willingly and proudly showed me parts of their lives and told me stories about their successes that were, for someone dedicated to social justice issues for more than a quarter century, inspiring. What I'd imagined as the end of a course of studies felt more like the beginning.

The *primary objective* of my research project was collecting and thematically organizing stories of some people with intellectual disabilities of successful and satisfying experiences of leadership in their lives, in groups they belonged to and as community citizens. I was also concerned with a *secondary objective*, to examine whether *graphic facilitation* is a useful accommodation for relatively complex discussions, in this case, the continuum of leadership as a changing practice.

Graphic facilitation arose out of two movements. For one of the early Canadian practitioners, David Hasbury, it came out of learning about the Nicaragua Literacy Movement, educators like Paolo Friere who sought to teach and learn “with” students, and books on popular social justice based education for adults such as *Ah-Hah! A New Approach to Popular Education* (Hasbury). Concurrently, in California, David Sibbett sought ways of “creating the conditions for having conversations that matter” with working groups as a way of exploring new forms of leadership, “using large-scale visualization in real time for strategy, innovation, leadership and team development” (Grove). The International Forum for

Visual Practitioners now lists about 300 graphic recorders and facilitators working in fields ranging from NASA to social justice; the Graphic Facilitators' Facebook group has more than 1600 members working around the world.

With a small focus group in Ottawa, Ontario I examined these questions of leadership and the use of graphic facilitation as an accommodation.

Background

Interdisciplinary studies

The emancipatory agenda of self advocacy has not been well served by isolated disciplines, particularly given a medicalization focus privileging needs over social justice, allowing for a range of treatments ranging from exclusion to experimentation and even eugenics. Srikala Naraian writes that the “infusion of a humanities-based interdisciplinary disability studies within critiques of special education has offered scope for an increasingly sophisticated analysis of schooling systems that perpetuate flawed assumptions of dis/ability” and that interdisciplinary scholarship allows for a new “differential consciousness” (Naraian 2013 360). Conner et al have suggested that interdisciplinarity, by cultivating interfaces with fields formerly considered as separate such as multiculturalism, the humanities, social sciences, philosophy and cultural studies and simultaneously challenging research methodology

that “objectifies, marginalizes, and oppresses people with disabilities” is the very basis of disability studies (448-9).

Leadership concepts

An internet search on “leadership” + “disability” leads to hundreds of sites for supporting the leadership of those at the helm of organizations which support people with disabilities, but much less information about people with disabilities as leaders. Most of what exists, is written by others about people with disabilities, without them and not for them. For example, although “Beyond Tokenism: Partnering with People with Diverse Abilities On Consumer Advisory Boards ... Best Practice Guide,” incorporates some graphics and some plain language, however the document, written by people without disabilities, when tested for readability of the text on www.writingtester.com is rated at a Grade 11 reading level. The ethnographic investigation of the leadership qualities and capacities of people with intellectual disabilities provides a focused lens of access to the larger and somewhat fractious picture of inclusion. Continuing issues with social constructionism, particularly through the language and rhetoric of inclusion (Linton), the incapacity of systems to deal with self advocacy as potentially radicalizing (Goodley 2005), a lack of definition of “community” and “inclusion” themselves as key concepts (Cummins and Lau), and the conflation of disability – a state of extreme diversity – as itself a singular and othering construct (Shakespeare; Siebers 2011) have all created a careening state of

multiple visions in which, backed by little or problematic research involving them (Kitchen), governmental and agency programs rush headlong into a constant of imposed change which allows for little reflection. As Tim Stainton has said, it has been a “long and tortuous road of UK attempts to reform their guardianship and related laws” and this is equally true of other countries (294) – in most cases this constant of change, without clear and uncontested underpinnings of actual empowerment, has merely provided distraction to a burgeoning social justice movement with too few resources, and not necessarily been directed at what matters to this population.

Layered onto this is the changing conceptualisation of “leadership” as it incorporates community development, informed by such writers as Peter Block, John McKnight and Parker Palmer. However, these new definitions of leadership exist hand in hand with strong media personalities such as Donald Trump, demonstrating opposite qualities. There are continuing confusions for social service leaders around roles, practices and models of business and non-profit leadership (Drucker xv). For example, while Block would get rid of all board room tables and replace them with more inclusive communication circles, most non-profit and government organizations continue on course with board rooms, podiums and theater style seating. Dan Pallota has stated that they are incapacitated to be effective in either world, not least because of confusions around capitalism and conceptualizations of “charity”: “We

have two rulebooks — one for charity and one for the rest of the economic world. We blame capitalism for creating huge inequities in our society, and then we refuse to allow the “nonprofit” sector to use the tools of capitalism to rectify them” (Pallotta).

From a long list of readings in leadership I decided to use Parker Palmer’s work as a touchstone for my investigations. Palmer’s theory is that leadership has these five attributes:

An understanding that we are all in this together

An appreciation of the value of "otherness."

An ability to hold tension in life-giving ways.

A sense of personal voice and agency.

A capacity to create community. (172-3)

Palmer writes that we must address and come to terms with this idea of “otherness” to be true to “the invisible dynamics of the heart that are part of democracy’s infrastructure” (13).

Inclusion, self determination and leadership

Inclusion is problematized for several reasons. The primary confusion is of community as physical rather than social space in which one has a sense of belonging, somehow leading to a historical, unconsidered and even manic drive post-institutionalisation to access physical space as if it was what mattered. Cummins and Lau point out that while community presence “has no direct relationship with the number of times people go shopping or the frequency with which they

use community recreational facilities” most of the research about inclusion defines community as place, rather than as “community connectedness, of personal interdependency, and belonging” (151). This makes for difficult conversations. Alberta’s associate minister responsible for people with disabilities, Frank Oberle, recently cut some services, saying, “We spent just short of \$100 million on that [community inclusion] program last year and we get some of our lowest outcome scores on social inclusion” (CBC News Calgary). While interesting theoretical research has addressed this (Cummins and Lau; Verdonschot et al), it continues to be a confusing meeting of financial and agency agendas³, within which a wide range of states are all referred to as “inclusion” and can signify merely the opposite of institutionalization defined, as well, as a physical space - a building, rather than a system and state of social construction.

This is not least because adults and the agencies and supports that serve them, are the products of an educational system which is even less clear on the inclusion of students with disabilities and has been even less challenged because of professional positioning. It continues to be the belief of many teachers that students with special needs should not be included in their classes, and that they do not have the capacity

³ For example, in the case of Alberta, the government is demanding more employment as “inclusion” for people with disabilities, as a rationale for cutting existing programs as unsuccessful, while at the same time reducing the budget of services for people with disabilities by \$42 million.

to educate them, thus leaving them to Special Education professionals who are seldom present, while, concurrently, typical students of such classrooms are frustrated by the othering of their friends (Naraian). This lack of clarity for adults is evident in research such as the Verdonshot et al meta-study of community participation in which the authors find that, in fact, “little is known about community participation of people with ID [intellectual disabilities]” other than they participate less than others in most community activities (303). A survey of members of the B.C. Teachers’ Federation encapsulates the difficulty in that while teachers see inclusion as generally positive for all parties, they do not have the resources or knowledge to support it:

Many respondents identified positive aspects of integrating students with special needs. The vast majority of comments focused on social benefits for students with special needs, for other students and teachers, and for schools as communities. The shift away from isolated, segregated settings towards inclusive settings was seen by many respondents as necessary and positive in philosophical terms, and a progressive step for the public education system, but not without problems in terms of implementation. (17)

An ongoing lack of resources, training and supports, identified and unaddressed over decades, led to teachers pointing out that such terms

as “flexibility’ and ‘de-targeting’ [have turned out] to be euphemisms for ‘cuts to services’” (11).

These ideas and ongoing tensions – well meaning people who believe in inclusion but do not have appropriate resources or opportunities to reflect on their own practices - carry over into the world of self determination and leadership within service providing agencies, as an institution is not just the building that houses people with disabilities, but the attitudes and workings of the people who run such systems. John McKnight has gone so far as to call traditional supports for people with ID “antidemocratic” (47) because they impede participation in decision-making most of us assume as a right.

Even within disability activist groups in terms of perceptions of people with intellectual disabilities there is an assumption of a lack of the capacities “of the ‘good’ citizen . . . [such as] rationality, autonomy and competence” (Erevelles 6) (whether citizens at large can be described as rational and competent seems to not be part of the discussion). Self advocate leader Tia Nelis speaks to this when she says other disability groups haven’t had “the ‘retarded’ word and . . . told they are not worth anything,” and recounts that a hero of the disability movement, Justin Dart, “didn't think people with cognitive disabilities could do a good meeting and be successful at organizing until he came to the national group.” However, afterwards, he said that, out of “many, many meetings, even with people who worked in the White House. . . [he] had never seen

a meeting more organized than when he came to the national self-advocacy meeting” (Nelis and Caldwell).

A pattern of two steps forward and one back runs throughout self-advocate leadership. It was a triumph for people with disabilities in British Columbia self-advocates when the constitution of Community Living B.C., a new crown corporation responsible for supports to people with developmental disabilities, “required board representation to include at least two self-advocates” (FamilyNet). “People with developmental disabilities and their families . . . actually want some input in designing the services,” said Minister Stan Hagen, in 2002 (Fowlie). However, in 2009, government amended the constitution to no longer require them, without warning or rationale. Within two years Community Living B.C. was deemed to be in crisis which Faith Bodnar, Executive Director of Inclusion B.C., believed was due to “a loss of the compass of human services and a loss of ensuring that we always have the people in the room for whom these decisions impact the most” (Fowlie).

For the most part, people with intellectual disabilities are simply, as Titchkosky has noted, rendered “invisible” through rather complicated sociological codes, even though they may be physically present. Tobin Seibers has suggested that these negotiations are so complicated that, “[d]isability defines the invisible center around which our contradictory ideology about human ability revolves” (273).

If inclusion is the point, and if organizations funded to support inclusion have such misgivings, how might the general community respond to the idea of a leader with a disability? The focus group's answers to this surprised me in several ways.

Accommodations and graphic facilitation

People with disabilities are successfully included by ensuring appropriate accommodations are in place, such as sidewalk ramping for people in wheelchairs, which allows them access, and, significantly, is also good for families with strollers and seniors with mobility issues. Similarly, graphic facilitation, the act of synchronously drawing the conversation or event proceedings as they occur, is a way to engage those with cognitive processing and literacy issues, but also works well for the estimated 65 - 86% of participants who are visual learners (Bradford). Participants refer to the graphic recordings to see that they were heard, that what is represented is what they meant, and to see how their ideas align with and build on the thinking of others. The graphic records the progression of the conversation and adds to effectiveness. Graphic facilitation has had a long history in self advocacy groups such as People First Canada / *Personnes d'abord du Canada* but there has been little research on its efficacy.

The Questions

Throughout my research project people with disabilities and those who support them were excited about my interest in how leadership

worked for them. There was a sense that the research addressed a need. The idea of leadership, of being heard itself, is often perceived as a fragile thing in circles of people with disabilities as while they have been successfully involved in leading different aspects of what affects them, these things have repeatedly been taken from them, often without notice or discussion, as if they've been temporarily conferred but not earned or rightfully theirs. They were excited about, first, the idea of recognition that they were leaders, and, second, about what might make their participation more meaningful and give them more leverage and, third, the possibility of increased presence and sustainability.

An ad hoc online group of self advocate leaders critiqued, challenged and changed my proposed research question in four significant ways. They defined and broadened my definition of leadership to include "leadership in your life" because they said self determination cannot be assumed. They asked me to focus on what was "successful and satisfying," rather than "success," and felt the way to do this was through stories, rather than through questions and answers. Concerned with plain language, they broke my questions down into bullets:

Question 1: *"Leadership means to take action. What are some stories about what has been satisfying or successful for you as a leader in:*

A. Your life

B. Groups you belong to

C. *Your community?*”

Interestingly, this feedback already called into question assumptions about leadership as a scaffolded (developmental) learning experience (Arnstein).

They also agreed that the usefulness of graphic facilitation was an important question, as they had found that accommodations such as graphic facilitation, which they felt strongly was part of “plain language,” were not reliably present:

Question 2: Did the graphic recording make things easier to understand? In what ways was graphic facilitation helpful?⁴

Methodology

Ethics review

Given my history in British Columbia as a self advocate advisor and consultant, I sought a group of people I had no previous or ongoing relationship with. The Ottawa service providing organization LiveWorkPlay agreed to host my focus group and to support my research project. My project received provisional approval from the ethics committee of Athabasca University as of June 11th, 2013. Final permission was granted to amendments on August 30th, 2013 and I met with the group on September 7th.

⁴ Graphic recording is the synchronous act of drawing pictures as a kind of note-taking; graphic facilitation is often identified as the facilitator or co-facilitator’s use of a mix of synchronous and pre-determined graphics to further the meeting or learning and is more rare. The two terms are used somewhat interchangeably.

Group composition and recruitment

LiveWorkPlay used social media and word of mouth to invite interested people to inquire about the research study. I asked LiveWorkPlay to find a cross-section of people with differing levels of experience of leadership and ways of communicating. Self selected participants were then approached by a LiveWorkPlay representative who used my prepared script to describe the project. The group was comprised of adults with intellectual disabilities who are recipients of ODSP (Ontario's Disability Support Program), meaning that an approved professional assessed them as having a "substantial . . . mental impairment that is continuous or recurrent, and is expected to last a year or more," resulting in restrictions to the person's ability to "work; take care of him or herself, or; take part in community life" (Ontario Ministry of Community and Social Services).

As the focus group date drew closer, participants realized that my project resonated with LiveWorkPlay's annual theme, which for 2013 was to work in alignment with Inclusion International's "supported decision making" campaign, reflecting "the right to make decisions and have control in one's life" as described in the United Nations Convention on the Rights of People with Disabilities (Inclusion International). It was interesting that, like my local advisors, the Ottawa group immediately connected self determination and "leadership in your lives, groups you are part of and in your community." Perhaps because of this, more

participants came forward and I was asked to expand the group to “about ten.” The Athabasca University ethics committee allowed this amendment to methodological changes that better fit the culture of LiveWorkPlay.

Collaborative Research: last minute changes

Just prior to my arrival participants asked for one last change, which was that I graphically record stories of their lives before asking my research questions. This resonated with the Vancouver self advocates’ sense of using a narrative approach and also with a leadership training “hotseat” model from Australia. Tanya Moore has written about her experience of being asked to participate and to “resist the temptation to prepare a presentation but instead, allow the session to take it’s own course [and] . . . not to attempt to ‘rescue’ . . . any silences but instead, to allow the space for reflection and the gathering of thoughts” (Moore). She writes that such innovations in communication are “a dynamic way [for participants] to take on new information whilst getting used to being in control of discussions with professionals.” Eleven people confirmed that they wanted to tell stories, hear about the research project one final time, and then would decide whether to stay on for the research questions. In both participatory action research (Chevalier and Buckles) and Inclusive Research (Walmsley and Johnson) participants actively co-construct the research agenda and given my topic of leadership, making these small changes seem a good way to engage in self determination

practices with a population with a problematic history of research (Kitchin). In the end, their freely told stories provided great examples of leadership concepts.

Procedure

Only some members of the group had met each other before, so telling stories was also a way to introduce themselves. As they spoke I intruded only to ask for clarification. When it became evident that they wanted to convey ideas about leadership in these stories, I stopped to ask them to define leadership with me, and then to sign the final agreement to participate in the research project and be recorded. As each told a story, I asked what their favourite color was and drew pictures of their experiences as they spoke, to give them a sense of the process of graphic facilitation.

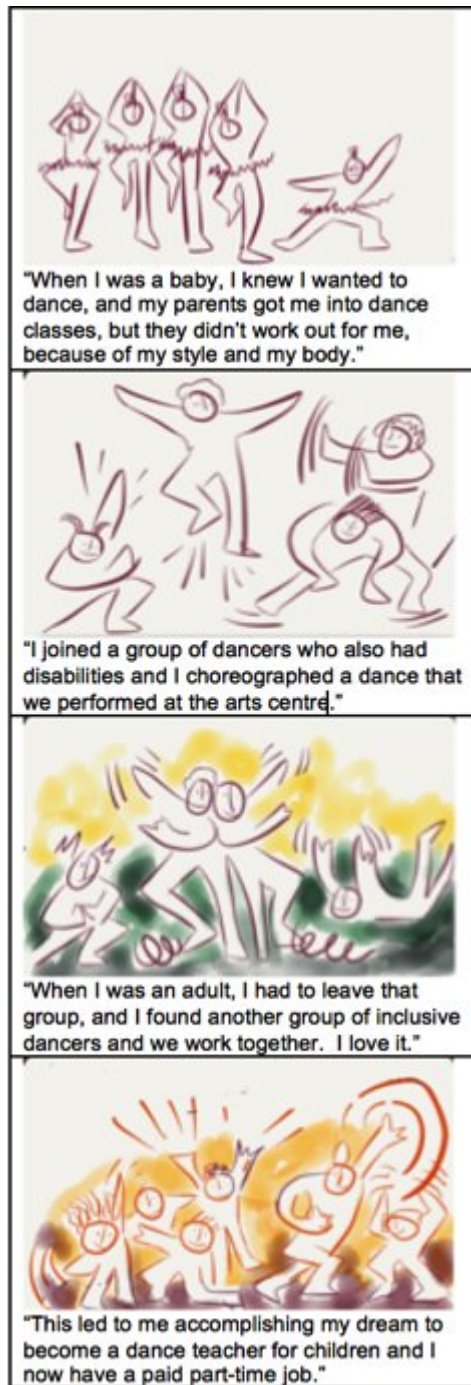
Everyone enjoyed the story telling and remarked that they learned a great deal from each other's successes; all eleven participants decided to proceed to the more structured research questions for which I had pre-created a template for a large graphic chart within which to organize their ideas. As their stories were good examples for our discussion the rest of the dialogue went quickly. When there was a sense that we had a complete picture of their successful and satisfying leadership experiences, we discussed whether graphic facilitation had been a helpful accommodation.

Data collection was in the form of an audio recording transcribed by me later, graphics and brief notes taken on the graphic chart, as well as handwritten post interview notes about body language, emphasis and movement that I wanted to capture. During the recording I photographed individual “story graphics” as well as the large graphic recording. Member checking was automatic as the focus group participants could see what I was drawing and writing and several changes were made as requested as they ensured I recorded what they wanted to say.

Later, interview transcripts and graphics were coded for anonymity and organized into categories, then color coded thematically. I decided to focus on the top three themes in terms of frequency and vehemence and then sought quotes that best represented these interests of the group, changing their natural language as little as possible to keep their voices intact. Most changes were to make sentences easier to scan or amalgamate repeated statements, or reflecting body or facial language that conveyed intention (in square brackets, []) or group responses (braces, {}).

As I analyzed my findings I continually returned to the original transcript and my notes from later that day and also listened again to the recordings several times to be certain that I was not editorializing or emphasizing beyond the group’s indication.

Stories



Smith and Sparkes have said that “exploring narrative is potentially useful for the insights it can give into the active, self-shaping qualities of human thought and the power of stories to create and refashion selves and identities in their multiple guises and different contexts” (18). A focus on telling stories also, in terms of accommodations, levels the playing field and equalizes participants: we all have stories. An example of one of the stories told, with re-created drawings, follows:

“My story begins when I was little
– I am okay to stand up and talk [stands]
– basically when my story begins I was little; I was into, really into, dance and my parents signed me up for community

dance classes - like typical ballet classes – and I, and I... it didn't quite work out because – because it... I didn't fit. Um, ah, ack... um... [having difficulty talking]. It was hard and difficult. I had to follow the exact timing and rhythm and

the exact timing... and it actually didn't quite work out for my body and for my style and that was really really hard on me and I actually really wanted to express my feelings and my emotions but in that... typical setting it didn't work out as... as I hoped it would.

“After that I went to an all women all girls dance group for people with disabilities and they talk about social issues and I loved it and I actually choreographed a dance . . . about my deepest feelings about having a disability and it was very fun because I got to express all these emotions that I had at the time.

“When you become an adult you have to leave the company. I was really sad because I really didn't want to leave but I found another dance company – which I'm in right now - it's an integrated and mixed ability company and organization and it's really fun. It works with integrated dance. It is like being part of a family; I am part of that family and it really helps me with freedom, with me being a dancer and performer and a motivational speaker.

“And I teach – I have a part-time job - I have a paid job teaching dance on Saturday mornings to kids, so that's really fun, and I really enjoy it.”

This identification of a leadership goal followed by a sustained search for opportunity, with the support of allies, was typical of participant experiences.

Each person shared experiences of leadership, with some overlapping content. There were three common themes:

- Relational leadership: 8 of 11 participants' stories involved leadership in their workplace teams while 7 of 11 participants discussed leadership in groups they were part of (for example, being on a small committee organizing a women's leadership retreat). These leadership stories involved community allies.
- Formal and informal learning: 6 of 11 participants talked about a drive to pursue formal or informal adult education, which required leadership to access or to prioritize in their lives.
- The role of staff and support agencies was interwoven through their stories.

Participants also brought up a number of lesser, secondary themes such as social media, popular media, disability history and negotiation within relationships.

An overarching narrative for participants was that of relationships which supported their goals and / or required them to take accountability (leadership) for ongoing negotiations which were often complex, prolonged, and, perhaps even therapeutic, given successive deaths, delayed grief and difficult situations. One participant, for

example, had negotiated the death of one parent, the chronic illness of another, a move to a new city and then the re-marriage of her parent, who then passed away and left her with the step-parent, who re-married (?) again and she then went to live with her step-grandparent, got married herself, and continued to negotiate with her husband and friends, and with classmates in a professional level college program. In telling these stories she was calm, reflective, positive and organized in her thoughts, sustaining a clear vision of her future.

Participants assisted and encouraged each other, and were assertive and careful communicators. During a discussion of work related leadership, for example, a participant began to talk about seeing people with significant challenges in public, and wrestling with the idea of “how well off” she was in comparison, and I stopped drawing to listen. When she was done I started to bring the group back to the topic of work, but another participant stopped me to make me realize that the speaker’s subject had actually been rising to the need to be a leader to support those who could not articulate for themselves. I saw the speaker was nodding in agreement, feeling heard. I added to the drawing to reflect this and she responded very positively and seemed to feel able to speak more. The group then built on this idea about taking responsibility as leaders and “role models” for those with fewer opportunities. Goodley also observed such alertness to subtle communication from peers in his study of self advocate leadership interactions (2000 161).

Primary themes

Relational leadership

Participants voluntarily mentioned 121 different community affiliations, averaging approximately 11 affiliations per person, with some overlap. Groups they were part of ranged from LiveWorkPlay, Citizen Advocacy, H'Art of Ottawa, an arts program for people with intellectual disabilities, work teams, sports, arts, recreation and educational groups. Affiliations were diverse and individualized to each person's interest. Some groups were segregated, or because of their disability they were the assumptive recipient of a volunteer's assistance, while in other groups they were the volunteers, assisting others. In still others, they said that, "No one knows I have a disability." It was obvious that the relationships formed in these affiliations were of primary importance. Notably, no one mentioned participation in traditional self advocacy groups.

In many of the focus group's stories of leadership I was reminded of American self advocate leader Chester Finn, who stated that the priority was to be a visible presence as, "you can't teach people, if you're not there, if you're not out in the community. If they don't see you, they don't know that you can do things . . ." (Finn). Independence and growth within their networks often evolved through being supported to take roles as part of participatory relational leadership teams, often at the insistence of their group leaders (Christens). This joining together of

friends, learning, social life (online and in person) and work relationships, led to independence, pride and also safeguards:

“Sometimes life can be a journey, and you have challenges ahead and stuff you need work on, you notice people are ahead of you, and yes you have stuff you need to work on and yes it can be hard – yes it’s hard – but it can be fun. You get to live life to the fullest – you have supports you need. You have people who help you and support you no matter what, you have friends, you have... y’know, partners...”

“And phone numbers!”

“Yes□- and Facebook.”

“Yes, social networking!”

“It’s fun and really social. And you get to live life.”

“And you know you aren’t alone.”

“No, you are not alone, if you get lost and or you are at a crossroads people will come and get you and guide you.”

“Basically if you are in trouble, people will help you.”

Participants built networks of preferred supports in community at work and with others who shared their interests, which included their peers:

“If I had not had Down Syndrome I would not have met you all – I want to say thank you. I am part of a community I love.”

“This [community/life] is cool, that’s all I can say.”

These narratives resonated with a very different energy than the victim messaging which is often part of media representation. For example, the focus on singularity of this participant telling a story about a person with a disability who had a helper dog:

“I said to the guy wow you have an amazing life right now – you got this dog and – and that’s – that’s *magic*, right there, *one of a kind*.”

Workplace managers and peers insisted they participate in team decision-making as equals, as well as in after work activities, which led to friendships. One, having unsuccessfully tried various jobs, repeatedly went to his favourite store department when distressed. The department manager asked him why he was spending “way too much time” there and when he said he had lost another job, she hired him on the spot. Eight years later, at the time of the focus group, he felt strongly about being an equal team member:

“I take leadership at my work, I am a leader at my job . . . I have a good leading team, and friendships...”

A pattern of success at work after challenges in finding the right situation, leading to social belonging and confidence was apparent:

“I have friends and everything [at work], I didn’t have many friends in high school and all that, I have more of a social life, more than in high school.”

“The staff treat me very well. I sometimes go out with them and we do barbecues or play paintball or go for pizza. I have more friends now that I started there. Sometimes we’ll do stuff individually – we go to movies or they play videogames at my place.”

“I collect friends [through work related activities] and we go out Friday nights and on the weekend we go out and goof around and do stuff...”

This expanding social network and sense of belonging at work led to increasing self-determination. Parker Palmer has written that,

What does all this [relationships at work] have to do with “healing the heart of democracy”? The workplace where we spend so many hours of our lives is one of the prepolitical spaces where our habits of the heart get formed or deformed. It is a human-scale setting where questions arise about our capacity for mutual respect and trust, open listening and courageous speaking, and individual and collective resolve to work for the common good. The way we answer those questions in the workplace often spills over into the larger society, for better or worse. (162)

An example, which speaks to this came from one participant who, after many trials finally found a job he liked and passed his probation, then to everyone’s surprise immediately negotiated to work fewer days. He wanted to volunteer at a mission soup kitchen, partly to “give back” to

others, to investigate a spiritual environment, and to learn new kitchen skills. His success at work made him confident enough to think ahead to his next goal, and make plans to expand his skills, and his employer was supportive of his goals and changed the schedule for him.

Participants had gone on to live independently after finding a stable place within a work team:

“I learn everything at my job and then I go home and I’m oh my god - I am independent – there’s more than meets the eye. I learn new things every day I learn new things every day of my life□- not just in schools – in real life.

“I can do whatever I want to do that makes me happy, and I’m on my own – I’ve been living on my own now for 2 years. It’s been great. I make my own plans. I’ve come a long way. I’m proud of me. I’m proud of what I’ve done.”

Participants had examples of how co-workers and employers had assisted them, often very successfully. One, after being laid off, possibly because of problems at work, went directly to the top person in the organization, far above his worksite supervisor, to ask for advice. The “head honcho” stopped work to meet with him and suggested he volunteer in places he’d previously been successful, to demonstrate his abilities to potential future employers. Following this advice he was later ready when a paid worker quit, to take a position based on demonstrated skills:

“Yeah it’s hard - so yeah it was hard. I can’t impress a panel of people – just by talking to them – what am I supposed to say? {Other members; yes, yes, that’s true} I got this job by volunteering instead of trying to impress people in a short period of time. I had many job interviews before - nothing else panned out.”

While this was excellent advice, it was different from traditional job coaching and he was excited when other participants shared their stories about different ways they found jobs. When another participant said, “I was trying to figure out what I wanted to do with my life and all that and my mom was recognizing that some people who lived on our street were neighbours *and* employers, and one of the dads was working at the university and he said would you like a job would you like to work with me and I said sure,” the first participant was very excited as he seemed to have assumed his experience was perhaps even odd and that he may have done something wrong.

Notably, at least some of the participants would be challenging to include on a decision making team. However, it appeared that committed employers and work-mates were concerned to include those with more significant challenges in ways that made them feel part of a team making decisions that compelled action.

Participants agreed they liked it when they were missed when they took days off – one talked about returning from her holiday to have her

colleagues say, “We didn’t know what to do without you.” This did not surprise them and there was a general nodding “yes,” a general certainty, which made me think of David Pitonyak’s comment, “Caring about someone is not the same thing as taking care of someone. You can’t make people care about one another but the good news is that happens all the time” (4). They were cared about and knew it.

When I asked what supports made such leadership possible, the list was entirely relational: parents, step-parents, grandparents, siblings, other family members; friends; room-mates; neighbors; employers; co-workers and co-volunteers. Interestingly, supports from different parts of their lives were described with the same language and metaphors. Variations of, “They have my back; I couldn’t ask for more - they support me,” were used to describe family, employers and agency staff. Support of an agency focused on their choices and decisions was also perceived as relational, in that they were “like a family.”

Other supportive relationships included fellow congregation members, at least two of whom had become active supporters and allies, those who shared a passion for certain activities (dance, sports, art, cooking, games) and those who volunteered with them, acting within a prescribed role but, at times, transcending those roles and/or becoming friends.

Lifelong Learning

Participants told many stories of informal and formal learning situations in which they demonstrated leadership by “catching up” now that they had what they considered better opportunities for learning. Almost all participant stories about school were problematic. As in other research with this population, many were bullied (Williams 21; NIID). One said schools had “no programs” that interested her and no interest in finding out how she learned best (she indicated the graphic facilitation) so in effect she was simply unable to pursue her interests for twelve years. Her language differentiated school from learning. She said, “Learning is a hard thing to do” and then, “Going to school is a hard thing to do too.” From her current perspective as a successful adult learner, she looked back to summarize her experience of school: “That was very bizarre.” Another participant told a very moving story about being in an inclusive high school English class where they were reading a book that used the word “retarded.” Though on weekends she was a speaker for a campaign against the “R” word, she did not want to draw attention to herself so did not object, but it bothered her that no one else said anything. Things became even more challenging when the school decided to put on a play based on the book and although she had been actively involved in theater, she made an excuse to not be part of the play. Given that she was an accomplished public speaker, she was asked to help encourage the student assembly to come. At that point she finally said, “You do not want me to do tell them what I think – trust

me!” After they had talked, the school teacher decided that he did want her to share her thoughts, that they had made a mistake and it was a learning opportunity for the school. It was evident that she didn’t consider this to be her issue – the error belonged to people who should know better.

I was reminded of stories of schools and adult education that are a theme in the transcripts of self advocate oral histories at Berkeley, in which Betty Williams discusses meeting a friend from Special Education at a night school course:

One thing I remember, we were talking about being back there in the dungeon [Williams says all special education classes are in the darkest rooms, furthest away from the centre of things so she calls them dungeons]. We ran into each in a reading class after we were adults, and she is like, “You are taking reading too?” I am like, “Yeah, I am taking reading too.” She said, “You know, why didn’t they teach us this stuff in school?” Now, we know we could have learned, but they just didn’t take the time with us when we were in school. They didn’t have or they didn’t want to take the time to teach us in school, and some of us could have learned and had a better life. Education is so important even for people with disabilities. (Williams)

Three participants attended college or university, and two worked on campuses, which seemed also to indicate a learning environment. Participants quizzed me on universities I'd studied at in an informed way. One talked about college diplomas leading to bachelor degrees and then to masters and PhD degrees:

“Having education is very important to our lives. It's like graduating from high school or college or getting your masters degree – I like having education – it's very important to us, to learn, and study for it. It's very important to have advice [support to navigate educational institutions and expectations] - any program you go into you have to work really hard.”

One participant, after negotiating her way into college, found herself unprepared for expectations placed on her. This was mistaken for inability, but in fact her experience of special education had simply not prepared her for the expectation of “keeping up.” Her supports assisted her to negotiate another chance and she was proud that she had been able to stay on top of things since.

At this point there was an interesting misunderstanding in that when someone was talking about “educational programs,” another participant thought they meant television programs:

“I look at programs – I have the same thing, I watch television – ‘Switched at Birth’ [a program about two babies

accidentally switched at birth, one of whom is deaf, and their families seek and find resolution and support] - don't get me wrong – that's a different kind of education than school and there are different educations.”

This sense of informal multi-modal learning through experience, television, film and the internet, in all parts of their communities, was important and pursued reflectively:

“Learning is a process – whatever happens, okay that was today, tomorrow is another day. I'll be learning another new thing – I didn't learn it today but I'll learn it tomorrow. I guess I will learn about that tomorrow. That was today – I learned something and tomorrow I will learn something new.”

Informal learning was a conscious act: “I am educating myself – all my life – wherever I am.” Often learning happened with friends, or was later processed through discussion. Two participants had been to a “Star Wars Identities” exhibition which incorporated a “quest” based on the question, “How did Luke and Anakin, who share similar genes and grew up on the same planet, become such different people?” and are there implications for one's own identity? (Canadian Aviation and Space Museum). He and his friend had obviously spent some time reflecting quite deeply on these ideas.

Unlike most other studies of leadership among people with disabilities, participants did not discuss themselves as members of self advocacy groups, although many had attended related events. However, they discussed historical and global disability issues in an informed way, learned through video, film and other media:

“People with disabilities – in other countries – they can’t get away from the past. I’m not going to say the R word – I’m just not going to say it – but back in the day they couldn’t get away from it – it was a *vendetta*.”

“They were institutionalized. It made me mad; it made me angry. It is really hard – mind blowing – it was really, really sad, it was really sad.”

“Some of them [people in institutions] were just shy [had not learned to speak up for themselves].”

In particular they had a significant sense of current and historic role models from popular media, discussed at length, as they shared film and television references: Helen Keller in *The Miracle Worker*, the work of deaf actress Marlee Matin, Becky from the television series “Glee,” and Chris Burke, both actors with Down Syndrome, and a model with autism from a reality show contest, of whom one participant said, “I only watched it when she was on, but she had what I have.” A male participant who obviously did not have Down Syndrome said of Becky, “She is like me.” An episode of “Glee” discussed at length was one in which Becky wants

to go to the prom, and one of the most popular boys in school says, “I will take you.” This reflected some of their experiences. However, when I asked if they felt that they were “like Becky,” and was that why they watched the show, a couple were vehement, “I am more like Rachel” (the show’s lead). It was as if, in terms of understanding history, sociology, and interpersonal dynamics, they did so by personalizing media and historic role models.

All of these ideas – contextualizing through what is known, using current learning as a bridge to further learning, and learning with others, are part of transformative learning practices for adult learners as outlined by Mezirow:

Their goal is to become autonomous, responsible thinkers. Often, adult learners’ immediate focus is on practical, short-term objectives—to be able to qualify for a driver’s license, get a job or promotion, or teach a child to read. It is crucial to recognize that learning needs must be defined so as to recognize both short-term objectives and long-term goals. The learner’s immediate objectives may be described in terms of subject matter mastery, attainment of specific competencies, or other job-related objectives, but his or her goal is to become a socially responsible autonomous thinker.

(8)

Focus group participants were also more knowledgeable about their own learning modalities than has been my experience of training staff who support people with disabilities. One referred to herself as a “visual and kinesthetic learner,” while others said they were visual learners, and spoke knowledgably about optimal conditions for learning (intolerance of distractions, working in groups, learning under pressure, etc.). Many were aware that their best learning was experiential and prioritised finding opportunities to learn.

Supports for self determination and leadership

While it was not clear if all participants were served by LiveWorkPlay, it was clear that those who were felt this was an organization that they participated in as leaders, setting the direction and having a sense of quality control. Unlike a previous study of self advocate oral histories (Johannes 2011) and Drake’s overall work (Drake 1992, 1994, 1996), in which support agencies are perceived to be repressive and isolating, members spoke fondly and appreciatively of paid staff in their lives as having widened their circles of supports:

“I love being associated with LiveWorkPlay – because of the [holiday] trips, but I also love the AGMS. Even after being bullied [during high school] I gradually moved on – I love people. Sometimes random people will come up and shake my hand and say “Who are you?” and I love it. {Everyone

laughs in agreement; A.G.M.s are popular.} I love it. I love shaking hands.”

Some members told stories about how they were able to trust their relationships with LiveWorkPlay representatives more than previous experiences: “People talk to me and they say oh I’ll do this – and they don’t [whereas LiveWorkPlay follows through].”

LiveWorkPlay was identified by members as having become like family, after “turning my life around.” One participant was frustrated with a relationship and another suggested that instead of repeatedly trying to resolve things in the same way, with the same person, she might talk to her staff about new options. The participant immediately relaxed back into her chair and smiled:

“That’s the decisions [choices] I love – he works with me, he helps me a lot. What I love about LiveWorkPlay is that it’s almost like having a brother – I lived with my family, and I did have a brother and he died; he’s up in heaven and I’m still thinking of him but [names staff] is like having a brother. I am the only child in the family now so I am very grateful for him for coming into my life...”

Participants engaged me in a knowledgeable discussion about the agency I am a Director of and whether we supported group homes and congregate day programs, or individualized services. One said, “We don’t have day programs,” and another answered, “But we used to – now we

are out in the community, we're not just going somewhere for the day to do stuff we are doing stuff that matters to our lives. We are living our lives." Another responded, "We're not just in a building, it's not about the building."

Members had a clear sense of the supportive but not paternalistic role of staff:

"It's a great big world out there sometimes you need guidance, other people who help you make decisions – you ask them for help – you're still in charge. Ask people for their input."

When asked how participants knew staff would support their choices and decisions (leadership in their lives), rather than direct them, they said:

"They help us with challenges and you learn it... through [repeated] experience [of having one's leadership and autonomy supported through various situations]."

"It is hard [to tell them you have made a choice], but you have to do it – it gets easier, or it doesn't. You have to do it many times and then you see if it's easier – it's hard for me but I get by... I do okay speaking up."

"If I didn't want to do something, I'd say no thank you and we would do research, we'd research it together."

Interestingly, members saw this support as part of a chain of community reciprocity: “I like getting help from other people, I like having people to ask. And I like volunteering – I like helping other people.”

Discussion

Comparative data

In Steve McNally’s survey of forty self advocate groups central themes of self determination were “to be taken seriously and listened to,” advocating for equal opportunities, and support to speak up for oneself. In order of frequency after these general goals were finding jobs, having friends, finding different housing options, transportation and money. However, a great deal of those groups’ focus was on negotiating with service providers as to “how the centre is run,” staffing issues (“How we want staff to help us”) and ideas like being part of a self advocate evaluation team for such centres. This is telling given that more than half of the self advocate groups were started by agencies (an improvement from a 1993 study which cited a little more than 9% of groups had been started by people with disabilities) and 67.9% of the groups met on agency premises, while another 11.3% met in funders’ offices, leaving only some 22.6% to meet in their own homes or independent spaces (McNally). It is of such groups, hosted and run by agencies as a “program,” that Canadian self advocate leader Peter Park is thinking when he says that after thirty years of involvement he wants to get a t-shirt that says “Self-advocates are tokens.” The opportunity in

this Ottawa focus group may well be to understand leadership issues for people not embattled by their supports, although that was not my expectation.

In Joe Caldwell's 2009 study of the participation of people with intellectual disabilities on advisory boards and committees, five themes emerged: individualized supports, financial supports for accommodations, coordination and communication, leadership development, and values and outcomes (Caldwell 2009). In this focus group, participants were already involved in individualized supports, so this was not an issue, and almost all were engaged in paid work so neither were finances a topic. Most of the similar concerns of the focus group around coordination, communication, values and outcomes had been addressed in community settings, sometimes with staff facilitation and other times through repeated evidence-based learning.

In Powers et al's study of "Leadership by People with Disabilities in Self-Determination Systems," the authors' concern is finding out why people with disabilities are not involved in leadership at agencies concerned to provide self determination based services. The agencies reported these difficulties:

- difficulty recruiting ethnically and culturally diverse staff members and participants,
- language and communication barriers,

- difficulty providing supports to individuals and a lack of support providers,
- lack of leadership opportunities and difficulty recruiting individuals for leadership roles,
- limited knowledge of leadership training approaches or resources,
- lack of funding,
- lack of transportation,
- difficulty assessing individual support needs and providing accommodations, and
- administrative or policy barriers (e.g. hiring constraints). (Powers et al 127)

What's of interest is how many of these were not concerns for those in the community (employers, co-workers, co-volunteers, other group participants) as they included focus group participants in leadership within worksites and other affiliations.

In a 2010 paper, "Leadership development of individuals with developmental disabilities in the self-advocacy movement," Caldwell identified four themes for his participants: disability oppression and resistance; environmental supports and relationships; leadership skills; and advanced leadership opportunities (2010). Caldwell's assumption in this paper is that self advocate leaders are found in self advocate groups (this would have been my assumption as well) and, indeed, a concern for

him is ongoing funding so that self advocate groups can provide what he calls a “pathway to leadership.”

While not a great deal of literature on the leadership of people with intellectual disabilities exists, at least some of this research project’s themes are common. However, it might be necessary to sort out the leadership priorities from within what are in effect segregated groups from these participants who lead from within community groups as equals.

Goodley’s paper, “Empowerment, self-advocacy and resilience,” suggests overarching themes of resilience but also a rupture in understanding between the services intending to support self advocate leadership, and the political dynamic as “[p]erson-centred planning’, ‘service consultation’ and ‘user empowerment’ are all terms that reveal a non-conflict position in relation to services and empowerment . . . [and] an assumption that all is well with the status quo so long as people with learning difficulties are consulted about and participate in shifts in policy, provision and practice.” However, he states, telling people with disabilities what their issues are and what will serve them best is a way of ignoring the radicalizing “more critical view of society and its understandings of people with learning difficulties” that is the opportunity of self advocate leadership (2005 341).

The complicating factor for people with intellectual disabilities is not their learning challenges or inability to lead but the social

construction of their roles and their ensuing marginalization, within an ill defined continuum of “community” participation expounded as rhetoric in social services. Their place within this continuum of leadership depends on where they live, who they are supported by, the governmental trend of the moment, their family and cultural background and in general the state of welcome that exists in their supports and the communities they are part of. While one person with a constellation of factors construed as disability might be working at paid employment, surrounded by friends and family, married, a homeowner and a member of the church board, another with the same etiology and diagnosis might be attending a sheltered workshop surrounded only by other people with disabilities, living in a group home with five others, allowed to make few choices for whatever reasons (policy, accreditation, safety, etc.), not “allowed” to have a relationship and told that there are not enough resources to attend their family’s church, much less sit on the church board. When such disparities are examined, social constructionism becomes apparent. If governments, and agencies, are authentically concerned to work for “inclusion” what does it mean that both situations cost the same in terms of funding (the latter example may actually cost more because of staffing)? Yet their respective supports will insist, usually unchallenged in any meaningful way, that this is the best they can do, or that this is what people want.

What becomes apparent in these stories is that people with intellectual disabilities not only survive awful life experiences and social devaluation in various situations but somehow still come to thrive as leaders in their communities, demonstrating valued qualities in our culture. Their stories are of how, as Parker says, quoting Thomas Merton, “We don’t need to adjust to the world. We can adjust the world,” or, as self advocates restated my question in plain language, “Leadership means to take action” and should be of interest to the larger communities they are part of. These stories demonstrate that if our knowledge of people with disabilities is incomplete, then what we know about “the human condition itself is thus fundamentally incomplete” (Charlton 4). In the largest sense of this question the roles of people with intellectual disabilities at both ends of the leadership scale – as people without choices and as people who hold responsibility for making decisions for others as part of policy-making groups – may teach us a great deal about the power dynamics and practices of our whole community.

In reading Parker Palmer, I was frequently reminded of the late Past-President of B.C. People First, Arnold Bennington, who, during his life had been repeatedly discarded for various reasons related to his disability, and became an excellent front of the room speaker and boardroom negotiator, charming and used to making himself heard in all kinds of communities. It was fascinating to watch Arnold ride his scooter

through a room, weaving here and there, whole tables of people leaning towards him, and as he moved on they stood a little taller, or moved to a seat closer to the front of the room, believing in themselves and their ability to give voice to their cause a little more. Palmer has written that many who lack confidence in their voice and power, having grown up “in educational and religious institutions that treat us as members of an audience instead of actors in a drama,” as adults are able to “find our voices, learn how to use them, and know the satisfaction that comes from contributing to positive change – if we have the support of a community.” He believes that this requires a concurrent action of creating community, as “[w]ithout a community, it is nearly impossible to exercise the ‘power of one’ in a manner that multiplies; it took a village to translate [Rosa] Park’s act of personal integrity into social change” and that the “steady companionship of two or three kindred spirits can kindle the courage we need to speak and act as citizens” (45-6).

Graphic facilitation

Only one participant had previously seen graphic facilitation and throughout our time together, it was obvious the drawing held their interest. Some were playful with the idea:

“Can I change the topic now? – There is still plenty of room up there [indicates graphic] {everyone laughs}.”

“I am very busy with lots of things – you might need two sheets of paper for me!”

“Oh, that’s a very big heart. I wanted you to draw it for my girlfriend but that’s so big... But you’re the professional – you must know what you are doing!” [winks at girlfriend.]

The art work assisted with the flow of the dialogue and reduced possible stress, moving the conversation along and allowing people to look up and see where we were in the conversation, and build from there.

Did the graphic recording make things easier to understand?

YES!!! {Enthusiastic general agreement, nodding their heads}.

“It was good to see the pictures” [four people].

“I just agree with everyone in the room – as we were talking, this was very helpful – to draw pictures and hear voices at the same time.”

“Yeah, visual language is like sign language... like ASL...” [I assumed this indicated that it was an alternative visual language, but an ASL interpreter later suggested that this may mean that, like sign language, pictures in graphic facilitation are interpreted by the facilitator within the context of discussion].

Other comments were, it “was pretty cool,” “it made it more interesting,” “it was helpful,” it would be “more dry” without graphics. There were a

few variations of liking the combination of words and pictures and, “I preferred the pictures to just words actually.” 100% of the participants, 11 out of 11 people, thought the pictures made leadership concepts easier to understand.

In what ways was graphic facilitation helpful [to understand a complicated conversation]?

Participants felt the complexity of the conversation was well served by graphics, which incorporated everyone’s ideas and made evident our conversations: “I liked how everyone got their ideas up there. More pictures [than text] would be better.” Similarly, “I got a better sense of diversity and different ideas.”

Some participants felt the method addressed particular learning needs. Most commonly these were variations of, “I am a visual learner so it worked for me,” and “I love listening to stuff but I have to have something like this actually.” Another interesting comment was that, “Sometimes I find I listen more when I am doing something – I can’t just sit and listen, so the drawing sort of helped - to some extent it worked for me to watch you draw.”

One participant liked the potential for inclusion: “It was useful to have the visual because most people do have problems – when somebody says something to you, feedback or whatever, they say, ‘What did you say?’ and they don’t understand - they have to figure it out by talking it

back to them [repeating it back for confirmation] but this helps so that everyone gets to be on the same page.”





The particularization of the graphic facilitation was important. One participant said, “I liked all the pictures, and I liked the pictures of me,” and many said that, “I really liked the colors” {much nodding and agreement}, as I had drawn their stories in their favourite colors.

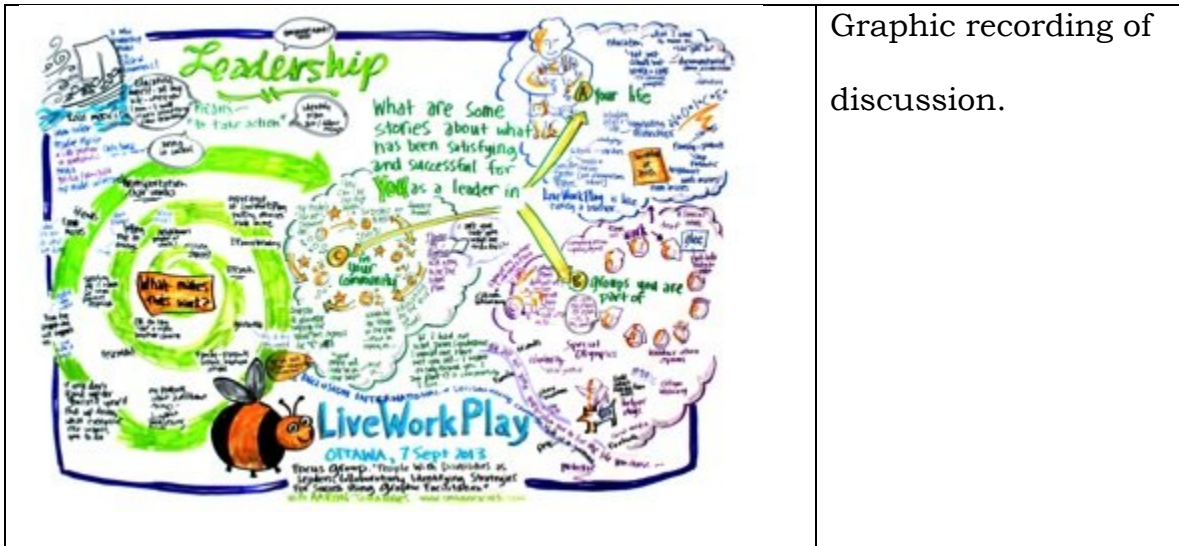
An increase in personal ability to reflect and empathise was noted by one participant: “[The combination of drawings and facilitation/] taught me something, that there are other people out there – that it is important that there are people who can do less [empathy?] – that was really important.” Unfortunately this participant, who had been motivated by the drawings to talk more, became quite shy when asked to say more about this idea, perhaps feeling challenged.

Similarly, Mullen and Thompson in their research found that “graphic recording facilitated the majority (69%) of participants understanding of the material presented . . . [while] a majority of participants (79%) agreed that the information portrayed by the graphic recording enhanced their experience and over 85% . . . reported that they enjoyed the graphic recording.” In their interviews the authors found many similar themes to that expressed in this group, particularly that the process aided group participation and “showed the movement of the group’s ideas” (12-15). Tyler et al, researching the efficacy of graphic facilitation for a diverse group, found that “the application of graphics

built bridges of communication and understanding between individuals and groups in a multilingual, multi-ethnic, and multifaith context” (140).

As a final research step, I compared the participants themes to the graphic chart to see if I had graphically prioritised the themes in the synchronous drawing to represent those that were most important to them: was the graphic a true recording of the conversation that reflect not just the information but the data of the transcription?

			
<p>Theme 1: relational learning – graphic of a network, including media and role models.</p>	<p>Theme 2: life long learning in formal environments and through community experience.</p>	<p>Theme 3: importance of agency and staff supports: LiveWorkPlay logo.</p>	<p>Overarching theme of supports in community for leadership activities.</p>



Graphic recording of discussion.

Having not compared the graphic recording to a transcription before, I was pleased with successfully having captured the priorities of the focus group. As Brandy Agerbeck has written, “In the meeting, everyone watches their conversation take shape. Everyone can see the work made tangible on the map. Everyone can find clarity within the complexity through a well-organized drawing” (40).

While it may seem a parallel facilitation process to involve a graphic recorder or facilitator to better involve people with disabilities in participatory leadership groups in meaningful ways there is evidence within this small study that people with intellectual disabilities better understand and are able to participate in ways that allow for understanding complex information, accruing information to aid in decision making, providing evidence that they are heard and increasing their comfort level, thus reducing accusations of tokenism.

Limitations and suggestions for further research

Further research with other groups in other places would be a way of continuing concatenations leading to a grounded theory exploration.

Some possible participants may have been deemed through a legal process of committee ship unable to participate because their legal status does not allow them to sign an agreement to participate. It would be interesting to examine what opportunities for decision making or participation such individuals are able to make in a continuum of leadership behaviours.

This group of eleven participants, were apparently Caucasian so this study does not reflect the experience of those people with disabilities who are also minorities, which we know from intersectionality theory may be quite different (Cole). While some participants seemed to have significant communication and cognition issues, those using augmentative communication were unfortunately not part of this study. Again, the leadership behaviours of these individuals, which have barely been examined, would add to the holistic picture.

The priorities of this focus group differ from those of some other studies of self advocate leadership (Drake 1996; Goodley 2000; Carter et al 2010; Caldwell 2010; Balcazar et al 1994). In some sense they may even be disconfirming evidence of a possible alternate pathway to leadership from what is usual. Caldwell writes that, "Experiences of disability oppression not only formed the foundation upon which the process [of self advocacy] was built but also encompassed the entire

process and experiences of leaders [and] . . . informed their approach to leadership” (2010 11). He suggests that self advocate groups are *the* significant potential pathways to leadership for people with disabilities, given a lack of access in schools and in the other environments in which typical citizens accrue experience of leadership. That self advocate leaders from more traditional groups were unavailable on the day of the focus group may have been a good thing as it makes us rethink this assumption. It would be interesting to continue and expand such research with other groups of leaders with disabilities who are not affiliated with “self advocate groups” per se, and to continue a comparative analysis of themes.

The teaching of leadership skills, when it occurs, is imagined for the most part as a hierarchal scaffolding of empowerment – the most common mode is Arnstein’s “ladder” (Arnstein) - but in these situations it seems that participants were concerned to find the right opportunity which consisted of a matrix of many factors – the right supports, appropriate access, the right situation, the right allies, the right aspiration. In those situations they were successful leaders. This might indicate a leadership and empowerment model more like the matrix imagined by Kirby et al, in which no part of the matrix is better or worse, but just different (Kirby et al). Participants emphasized that for the most part they had not had leadership experiences as children in schools, but

were able to act within leadership paradigms as adults. This aspect of pedagogy and transformative learning requires more study.

Funding concerns often dominate the idea of supporting the leadership aspirations of people with disabilities, but like much of what constitutes the conversation about “community” and “inclusion,” there is little evidence about how much money is currently being spent on such initiatives or how much would be useful. To have some sense of actual costs would allow system leaders to explore and budget for possibilities.

Last, while the language of leadership is quite clear for most of us, in the world of self advocates there are many ways of referring to their leadership which, in actuality, may be continuing the social construction of them as “other.” If, for example, no one else in the neighbourhood is called a “community champion,” it is probably better to use the more generic term of “leader” for everyone who leads.

Conclusions

In my research on this group brought together by LiveWorkPlay it would be difficult to imagine a “perfect storm” of community leadership more poised for examination, even though these were not the results I predicted, given that the leaders I expected were not present and a new generation of leaders were. As participants had example after example of successful and satisfying experiences of leadership I began to wonder if my LiveWorkPlay connections had misunderstood and brought in their best leaders. As it turned out almost the opposite was the case, in that

the experienced leaders who are part of traditional self advocacy groups like People First were otherwise involved that day, meaning that my focus group participants were a kind of community cross-section. Later on, going through my notes, I wondered if perhaps those most intent on leadership gravitate to LiveWorkPlay, perhaps because of the agency's interest in autonomy and community connection? However, again, like all contracted services in Ontario, LiveWorkPlay "members" come to the agency through a blind review process based on who has the most need in the waiting line-up and which agency has a vacancy. All of which indicates that LiveWorkPlay is somehow supporting anyone who arrives there for supports around planning, life skills, employment, housing, etc. to become leaders in their lives, in the groups they are part of and in their communities. In the United Kingdom, after the tragedy of Winterbourne, Nunkoosing and Haydon-Laurelut's investigation of the pitfalls and best practices of service and support agencies leads them to make this recommendation:

We suggest a redefinition of the role of the service and support organizations. Rather than solely providing services and support, organizations serve as bridges between people and community supports. For this reason, the concepts and research findings associated with social capital contribute to a reformulation of organizational role. (30)

It would seem that LiveWorkPlay has successfully figured out how to have such a “concierge” role in people’s lives. I was reminded of a passage by Dr. Michael Kendrick, who has been seminal in the leadership of the field of disability supports:

. . . unless efforts are made to expand the vision of what is possible, then people tend to remain where they are.

However, once they can envision better, and have confidence in what this is, then it becomes possible for them to be more open and personally secure about change. Advocates frequently recognise this challenge and respond by assisting in efforts at ‘vision-building’ that can often fill this gap and make it possible to progress in a forward direction. (66)

This constant of “vision-building” in their supports was evident in their stories of those supports, and also seemed to have spread to their interactions with each other. Rather than stepping in to “fix” things a culture of reflecting and imagining better has been created.

My initial intention, some time ago, was to investigate what assists self advocates in their leadership aspirations, and perhaps in particular the qualities of community allies who support people with disabilities as leaders and ensure their success. A self advocate friend suggested this was a patriarchal idea – I could not presume people with disabilities required allies to be successful leaders. Above, I have told the story of self advocates who supported me to restate my research questions

further. At each step of the way people with disabilities assumptions have challenged my assumptions and, not least, my assumptions about what agencies can accomplish.

If, as it seems, the experiential learning through life experiences of people with intellectual disabilities as leaders might be posited as part of transformative learning, it's important that a key component of this focus group process was the opportunity for reflection and critical discourse which participants were so excited to be part of, and the part that graphic facilitation played in this as it created the opportunity for critical reflection and discourse:

Three common themes characterized Mezirow's theory of the mechanism of transformational learning in the classroom.

These were experience, critical reflection, and rational discourse. The students' life experiences provided a starting point for transformational learning (Mezirow, 1991). Mezirow considered critical reflection to be the distinguishing characteristic of adult learning, and saw it as the vehicle by which one questions the validity of his world-view. He identified rational discourse as a catalyst for transformation, as it induced the various participants to explore the depth and meaning of their various world-views, and articulate those ideas to their instructor and class mates. (Cooper)

I was also reminded of Paulo Freire, and that part of the history of graphic facilitation is that it was demonstrably effectively used in his work with people who were illiterate (Ah-hah!), prior to being taken up by the business world, as it was a way of documenting where they were, so that they could envision a different future:

The more educators and the people investigate the people's thinking, and are thus jointly educated, the more they continue to investigate. Education and thematic investigation, in the problem-posing concept of education, are simply different moments of the same process (109).

Or, as the participants said, "We would do research together."

It may be that of all the findings in this research, the most important is how much the participants valued this opportunity. I was asked by a few of them whether I would be doing more workshops like this, and I understand that a few days later someone came to ask when the next session might be.

Maya Angelou, was asked if "resilience is always a bouncing back?" and answered that, "it's also a bouncing forward, going beyond what the naysayers said, saying, 'No, it's not true that I'm nobody. I know that not only is that not true, but I'm more than you can imagine!'" I think in this small group there is good evidence of this dynamic and, in the successful incorporation of people with disabilities into leadership initiatives in their communities as well as the sustained actions of their allies is indicative

of the value placed on them by their friends and colleagues. It would be interesting to access these community allies to understand firsthand their perspective on what people with intellectual disabilities have brought to their leadership teams.

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