Links in this document are not live. Until this technical problem is fixed you can find live links in a web browser version by clicking the box below.

Sharing our stories

Exploring transformation

John O'Brien & Beth Mount

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Where do we stand?

Course map

1. Story 2. Inquiry 3. Weaving Whole group 4. Harvest

Sharing stories

Session I Session III Session IV

Story groups will stay the same for 4 sessions. Reflection groups will have different membership.

Another lens

Session IV

A look at what we are learning through the lens of Beloved Economies, a guide for social for change and the consequences of different mindsets for attempting change.

Looking ahead

Session VI

Home teams consider how their stories of transformation might unfold from here.

Transforming organizations

People with disabilities, their families and allies continue to open new possibilities to live lives of distinction. Old stories, boundaries and structures crack open and as more and more people build careers in an increasingly accommodating labor market, assume leases and mortgages on their own homes, and bring their gifts to community life. New forms of support for decision making and new ways of funding and organizing support offer greater choice and control. Social networks grow more diverse.

A Home & Community Based setting is integrated in & supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment & work in competitive integrated settings, engage in community life, control personal resources, & receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.

-HCBS Community Rule

How might we offer people the option to live in their own home with the individualized support they need?

How might we support people's engagement in valued roles in community life?

How might we offer people of working age the option to do a paid job in the community?

How might we use person centered plans to increase people's influence on the supports they need to live a community life & access the same community resources & roles as other citizens do?

These pathfinders' achievements inform policy, including the CMS Community Rule. As we read it, the Rule intends to offer increased control of supports to greater community participation to everyone who benefits from Home and Community Based Waiver funding. How effective the Rule will be depends on our collective capacity to adapt to new possibilities in a challenging environment. To benefit many more people we need to develop capacity for transforming every level of organization from individual supports to system administration.



One way to think about transformation is to imagine an organization as an iceberg. What we see is produced by repeating practices and patterns of activity; which are shaped by structures that define flows of resources and accountability; which reflect ways of thinking about disability, community, public responsibility, and change; all of which have their source in relationships.

Transformation engages the whole iceberg. A transforming organization learns to build co-creative relationships that give life to the conviction that differences in body, brain, and mind call for accommodations and support for citizenship and wellbeing. These ideas shape structures to facilitate practices that support new and more varied community roles and relationships. Person-centered work finds fertile ground. What we see is people flourishing in community with good individual support.

Transforming takes time and proficient leadership. Demographic, social and political changes produce a shifting pattern of opportunities and scarcities, including shrinking space to innovate. Many current services were designed a generation or more ago around a narrower sense of possibility and deficiency focused ways of thinking. Cost control measures promote transactional connections and impersonal treatments. What we see is professionally designed and controlled programs delivered to groups of people whose disabilities define them as "others" and place them at the margins of community life. Person-centered work is a continual struggle. Breaking out of this history involves addressing loss and embracing uncertainty and the need to let go of familiar assumptions.

Often, you can't get more of what you want by simply solving the problems with what you have. -Russell Ackoff

Stories of change

The stores that interest us in these sessions gather up up and carry two kinds of knowledge.. Know-Why Stories communicate purpose and encourage action by describing the differences a change has made and makes them meaningful. Know-How Stories describe moves that led to change and lessons learned along the way.

We are confident that this group's stories of change are a resource worth cultivating and we trust that listening to and reflecting on each other's stories will guideour work of transformation.

Stories play an important role in transforming organizations. Telling stories provides a way to gather, organize and share learning. Stories can...

- ...bring values like choice and inclusion to life and provide examples to learn from.
- ...build desire to discover what more is possible.
- ...inspire stepping into the tensions that define a transforming organization.
- ...guide and encourage leadership.

When we reflect together on stories of change, we can...

- ...clarify and extend our understanding of how to activate and sustain meaningful changes.
- ...appreciate the conditions that make transformation possible and options to develop them.
- ...expand options for engaging constrains on transformation.
- ...enrich our stories of change.
- ...notice our own responses to new possibilities and practice listening to learn with curiosity, compassion and courage.

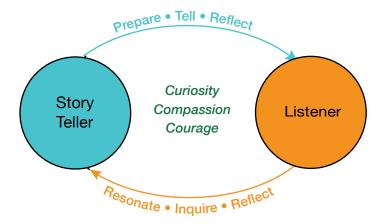
Assembling your personal guide to transforming organizations

There are many frameworks, processes and practices to guide change (Amazon offers 7,000+ titles on it's *Change Management* page). We have found some of these general stories about how to make change useful, but have not yet found the ultimate guide. So rather than focus on other's change models, we invite you to start with a blank page and assemble your personal guide to transforming organizations from telling, listening to and reflecting on our own stories of change.

As we share and discuss our stories we can collect images, insights, questions, ideas, quotes, references, practices that have resonance or offer a challenge. We think that this practice will produce a resource you will want to revisit and add to.

Sharing our stories





Intention

To access curiosity, compassion and courage and focus on stories of change in order to build our collective knowledge of transforming organizations.

In a story telling group

- The storyteller prepares and tells a 10-15 minute story of a change they have learned from.
- Everyone takes a moment of stillness to allow the story to connect.
- Listeners share responses to the story.
 - > What resonated? What touched, inspired, concerned me?
 - > What words or phrases have power: what sticks in memory and encourages action?
 - > What images come up from hearing the story?
- Listeners inquire to discover more about how the change happened.
- The group confirms next week's story teller and who will back-up.

In a reflection group

- The group weaves together what its members have learned from the different stories they have heard.
- Everyone reflects, identifies, shares what they take away from the storytelling: questions, ideas, insights, possibilities for action.
- Everyone adds to their personal guide.

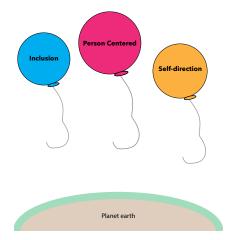
To honor the story and the storyteller:

- Slow down.
- Notice and quiet the urge to offer advice.
- Keep focus on going deeper into this story, don't jump in with your own story.
- Pay attention to what is different about this story; don't assume that your experience or understanding is "just the same".
- Be alert for interesting, challenging or disruptive ways of understand common ideas like "person-centered planning."
- Review the notes on Listening on page 20

Preparing your story



Your story is a gift from your experience of a meaningful change. It starts a focused conversation that builds knowledge of what it takes to make a positive difference in the way supports are designed and experienced.



Many key ideas-inclusion, self-direction, person centered-float far from everyday experience and become new labels for business as usual. Your story will pull key words down to earth by describing a bit of your experience of preparing the soil for the new to grow in your own organization, rooting new ways to do new things and nurturing their growth. Cultivating these capacities is difficult, imperfect, unfinishable work.

The ground will sometimes be hard and dry, there will be weeds, and bugs and deer

weeds, and bugs and deer will try to trim their growth. Telling this story provides a respite to feel and think what making change has been like and what its

lessons are.

For example...

There is no one right way to tell a story. Here are some options.

For another telling of the Urban Innovators experience: eth Mount, *The art of belonging* (20 min) tinyurl.com/2p8m-dyhb

To see a bit of the thinking that came from reflection on Urban Innovators go to page 14.

For a 10 minute example of a transformation story see Chris Liuzzo, *Transformation for right relationship* tinyurl. com/3jpv7bnp

Beth and Chris use

slides;you aren't expected to. Find links to a number of longer change stories on page 22 Think of telling this story as like catching up with friends over a meal rather than presenting to a conference. Your aim is to contribute to collective knowledge of transforming organizations by starting a process of reflection. Your story contributes to know-why by saying something about the difference a change has made. It contributes to know-how by saying something about how the change is coming about. Conversation initiated by your story will do much of the work.

Getting ready

You can only tell a little bit of any story of change. Select something that brings what you are learning about why and how to be a transforming organization up for reflection.

- Identify a change that has meaning for you. A story of a small or incomplete change or even a failure could hold as much knowledge as big shifts can.
- Decide on a perspective on describing the difference a change has made and the experience of changing. You might choose your own personal experience of thinking differently, or describe your view of change for a particular person, or identify how direct support or professional roles have changed, or widen the lens and describe a shift in program structure or in your whole organization.
- Think about the key things you want to share about what has changed and why it matters (know-why) and how this episode of change unfolded (know-how).

Some story patterns



Your own way



Contrast experiences before the work of transforming began with the current state of change & identify keys to the shift.



Map the story onto a framework that guides change

(Don't get stuck in explaining the framework)



Share a moment of insight: a time when your own understanding changed in an important way.

Describe what happened to make this insight possible & what the consequences have been



Describe a conflict, how it worked out & what difference it has made.



Take the long view: identify big steps your organization has taken over years, even decades, & sketch how these changes came about.

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Inquiry



Inquiry builds knowledge of transforming organizations. Knowledge grows when we listen carefully, notice different ways of seeing and possibilities for action, sense other people's different feelings and intuitions, and allow new connections and ideas to form. This takes a sense of spaciousness, created when we can be present with an open mind, an open heart, and an open will (see page 20). Making space to think and feel our way into new understanding asks us to set aside the sense of impatience and hurry that can drive our day-to-day.

The best form of inquiry lets the story we have heard activate our curiosity and invite the storyteller to unfold more of the story. "Please say more about..." a part of the story that, for whatever reason, has captured our listening attention often yields more than administering a set of question. Practicing attentive silence invites the storyteller to remember or discover more.

Testing, challenging, criticizing and debating have their place in building knowledge but we want to practice slowing down and opening up to shared stories before applying these forensic practices at another time. To understand another's story is not necessarily to agree with it or commit to it's path: its understanding we are after.

Inquiry time makes room to pursue the desire to find the how-to of transformation. Those who want a choreography of steps that guarantee transformation will be disappointed. Those interested in a better understanding and wider array of options for transforming supports will add to their knowledge.

Your very first steps on the path to transforming

Organizational strengths transforming draws on

How your thinking

about good support

has changed

Responding to losses

Making space for transforming support: freeing time & increasing flexibility You own personal & professional growth Increasing power to co-create among people you support

Engaging families,

DSPs & others as

co-creators

Tell us more...

What has surprised you

Sustaining action when things are tough

Rredirecting funds to individualized support.

Issues that keep showing up What has worked to support community roles & relationships

Refreshing your sense of highest purpose

Weaving



People leave their Story Groups to form Reflection Groups that will weave learning from the stories into deeper knowledge of transforming change. Reflection Groups...

- ...share some of their learning from the story they just listened to.
- ...imagine the ways that what they are hearing might make a difference in their own work.
- ...identify patterns and themes across the different stories.
- ...frame questions and identify what they want to think more about.

Harvest



The whole group gathers for...

- ...journaling and allowing an image of the day's learning to surface.
- ...statements of what has been meaningful in today's session.

Knowing our community

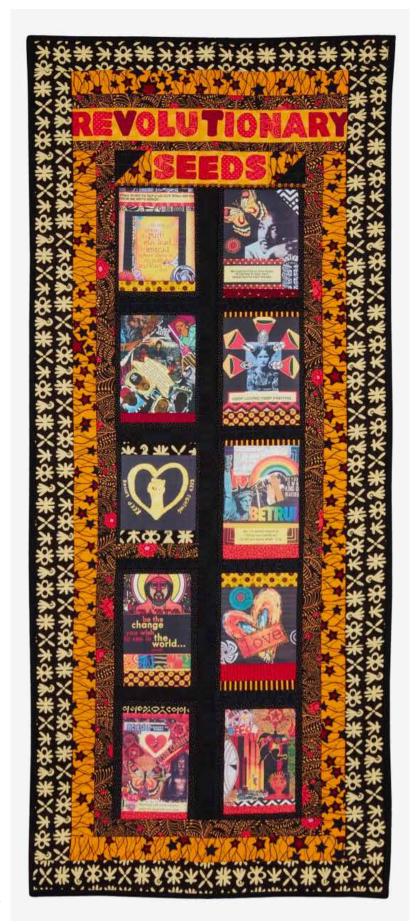


We are seeds!

© 2015 Beth Mount

Level of Knowing	How We Know	
Level 1 Habit	We know the way to familiar places that adequately meet our needs for occupation, shopping and leisure. We recognize other people who frequent the same places and may exchange cordial greetings or pass the time of day. We navigate familiar pathways by habit. What we know is encoded in routines.	Familiar routes; no search for new possibilities
Level 2 Data collection	We research community resources to identify activities of possible interest and resources of potential use. We check on-line directories, social media, research reports, neighborhood news-boards, We do walk-arounds and asset mapping exercises to locate potential activities. We compile activity catalogs, maps and event calendars to inform ourselves about what's out there.	Information without connection
Level 3 Personal engagement	We are personally engaged. We take active roles in established opportunities in neighborhood, civic, sport, culture, education and work life. Knowledge increases as relationships grow more diverse and cross boundaries. News of community life and opportunities flows through the web of conversation and everyday exchange of requests and agreements with others who share our activities. Our identification with local initiatives gives us a feel for more of the life of our community and we understand more of the diverse perspectives and gifts of our fellow citizens at a gut level.	Knowledge through a network of participation
Level 4 Co-Creation	Intentional relationships among people concerned to build a community that works better for everyone generate an awareness of the whole community. This awareness reveals the highest possibility for the community and a recognition of what wants to be born to better realize that possibility. We know our community as co-creators -engaging heart, head and hands in developing new capacities. Knowledge is carried in stories of self and community, rich with possibility, shared in trusting relationships.	Knowing through co-creation

The table mirrors the story quilt, *We are seeds!* Both are reflections on the Urban Innovator's experience. The quilt expresses the four levels of knowing community in shape, color and symbol as it tells the story of the Urban Innovators journey from the margins of civic life to individualized experiences of contributing community roles and relationships. The table invites assessment of an organization's ways of knowing.



Several Urban Innovators formed a cooperative enterprise, Revolutionary Seeds, to realize income from their art work. This banner proclaims some of the images they converted to merchandise.

© 2015 Beth Mount

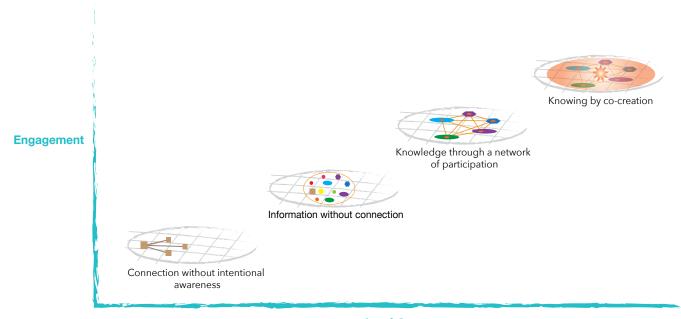
The way we know our community is fateful for our capacity to support people at risk of marginalization to contribute, belongs and develop diverse good relationships.

This framework on page 2 visualizes a person with DD, their allies and partners as if they form a neural net: each person can act as a sensor and the whole can make sense of what comes in and orchestrate action toward interesting opportunities and more useful knowledge.

The worksheet on the next page encourages assessment of two determinants of the extent, depth and suppleness of community knowledge:

- The extent to which we are personally **engaged** in the settings and activities that compose life in community.
- The degree of intentional **openness** to sense possibilities for involvement and action.

Use the worksheet to start a conversation about how you currently know your community and how you might come to know it better.



Intentional Openness

Beloved economies

A design for innovation

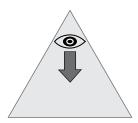
For 7 years Jess Rimington & Joanna Cea convened co-learners to study breakthrough innovation: ways of working that produce exceptional results while prioritizing well-being, meaning, connection & resilience.

A book, <u>Beloved Economies: Transforming how we work</u> (2022) & a website, <u>belove-deconomies.org</u> describe what they are learning.

Key ideas

- Business as usual uses people up without providing for renewal. Full lives are sacrificed to efficiency & exclusion. Budgets balance on the extracted labor of families & direct support workers.
- Business as usual is not sustainable. It drains people & other resources & generates inequality. We have to change how we work.
- Broadly distributed rights to design are the key to breakthrough innovations that liberate us from business as usual.
- When diverse groups imagine what more is possible & act together they can change the social constructs that repeat business as usual.
- · Beloved economies are already being imagined & co-created.
- Breakthrough innovators tend to follow seven practices (summarized on the following page).

We exercise our <u>right to design</u> when we imagine, decide, & build together



Consolidated Right To Design

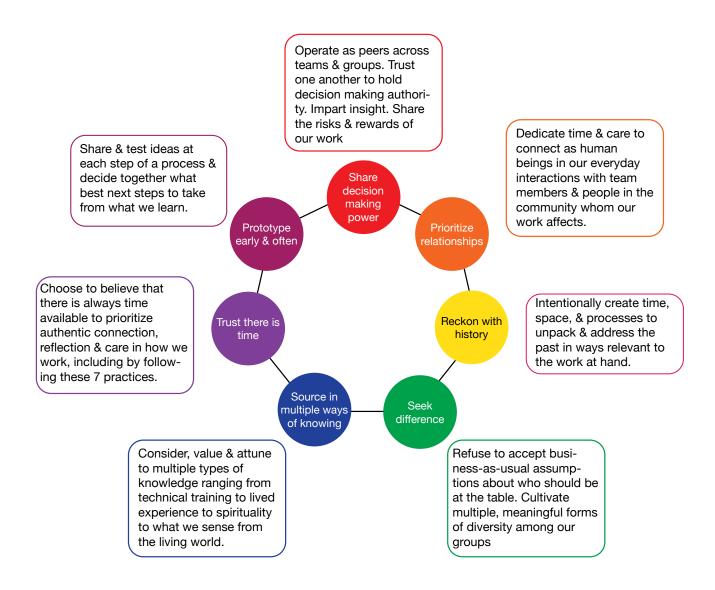
Business as usual consolidates the right to design & holds it at the top of a hierarchy. Those authorized by the top define possibilities, decide on strategies & assign subordinates to execute. Others may be consulted or sold the design but they do not own the process.



deconsolidated right to design

Diverse actors with authority to decide, employ multiple ways of knowing to search for what more is possible. Investment in relationships & acknowledgment of history builds trust & enables sharing learning, insights, risks, & rewards. Shared reflection & evaluation of rapid prototyping cycles open the process to shared decision making. A sense that time is sufficient develops.

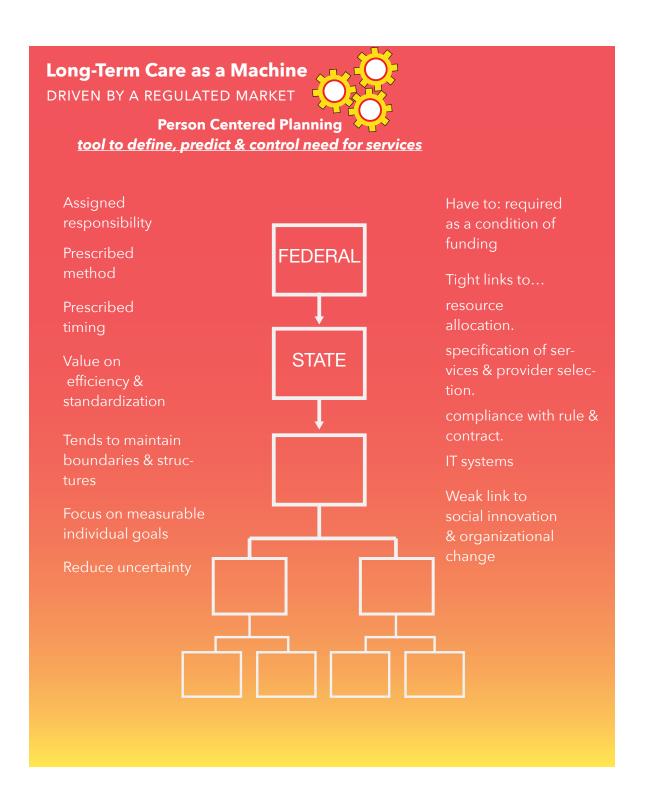
Deconsolidation of the right to design is the first step into breakthrough innovation.



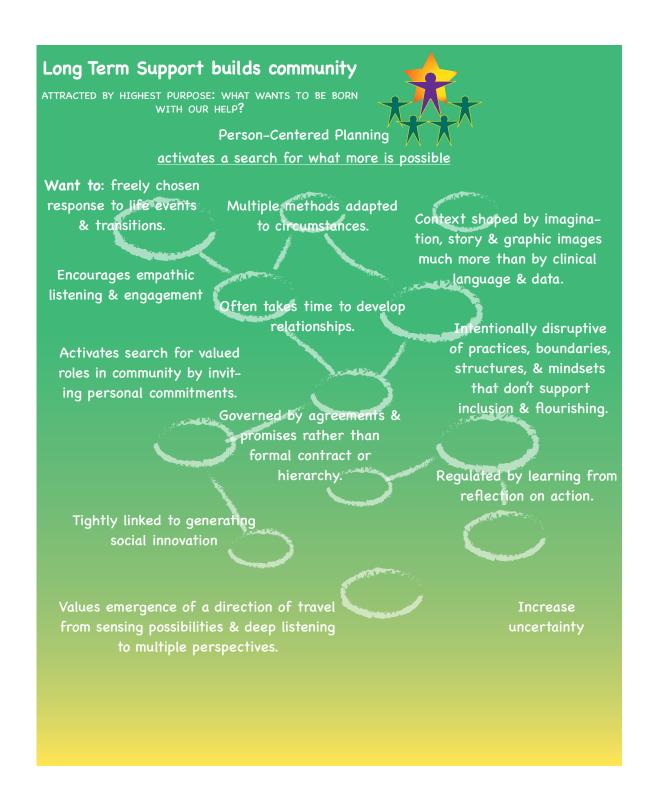
0.3 Sharing our stories **17**

Different mindsets, different paths

Person-centered planning figures in many approaches to reforming or transforming services. Different mindsets about how to make change generate different purposes, functions and practices.



Sharing our stories **18** 0.3



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Listening

Shifting attention...

...from self-protection

...to possibilities for change.



The Voice of Judgment makes the mind busy sorting: realistic from unrealistic, possible from impossible, right from wrong, & on & on. Turned inward to listen only to itself, mind rejects whatever fails to confirm current patterns of thinking & practice

The practice of curiosity opens the mind to new thoughts & challenges to what is taken for granted.





The Voice of Cynicism drains feeling, meaning & energy by stacking up reasons that desired change can't happen. Common tricks include over-focusing on scarcity, belittling desire for better futures as naive, & denying the possibility of altruism & gift exchange.

The practice of compassion opens the heart, bringing feeling & embodied knowing alive.





The Voice of Fear freezes action & encourages turning away by amplifying a generalized sense of vulnerability & risk.

The practice of courage opens the will, allowing learning by taking steps into a desirable future & responding to what happens as a result.



shallow breaths • closed posture

The voices of judgment, cynicism, & fear can be helpful in a context of evaluation or threat. The point is not to eliminate them but to notice when they show up & let go when they get in the way of understanding others' perspectives & discovering what more is possible.

deep breaths • open posture

To hold space means that we are willing to walk alongside another person in whatever journey they're on without judging them, making them feel inadequate, trying to fix them, or trying to impact the outcome. When we hold space for other people, we open our hearts & let go of judgment & control.

-Heather Plett

Level of Listening	Experience	Result		
Listening LEVEL 1 downloading	Just what I expected.	No new understanding. No increase in desire to act. Mostly a repeat of the same ideas.		
Open Mind expresses curiosity & quiets the Voice of Judgment				
Listening LEVEL 2 debating	I became aware of some new facts & ideas that challenged my assumptions & shifted the way I make sense of the situation.	Taking account of new realities; better informed. More aware of assumptions. New ideas & alternative ways to understand cur- rent reality.		
Open Heart activates compassion & tames the Voice of Cynicism				
LISTENING LEV- EL 3 dialogue	I have seen the situation, & my place in it, through the eyes of someone whose experience is different from mine. I have a new sense of how another person experiences the situation & how they feel it. My own feelings resonate with those of someone different from me.	Awareness of real differences in experience & evaluation of the situation; new perspective; better understanding of aspects of the situation that have been hidden or avoided.		
Open Will draws on courage & transforms the Voice of Fear				
LISTENINGLEV- EL 4 collective creativity	I am not the same person now than I was when I entered this conversation. Together we generated understanding & possibilities that did not exist when the conversation started.	A stronger sense of the highest possibility in the situation & an increase in the will to bring that possibility into reality.		
The table is bas	ed on a video on levels of listening presented b www.presencing.org/news/news/theor			

0.3 Sharing our stories **21**

More stories

Thanks to the New Your Alliance for Inclusion we have access to recordings from the recent International Conference on Shared Living. These are longer stories of change (each is about an hour) that add new perspectives on change and a variety of ways to tell a story. These stories bring support to living in one's own home in community down to earth.

Brooklyn St. An Intentional Community

Mary Lou Accetta and George H Fleischner

The story of an Intentional Community in North Adams Ma. The goal of Brooklyn Street Neighbors is to create a community that combines the best aspects of our childhood with insights from more recent decades. For us, this means a neighborhood where children can play safely, neighbors can count on each other, families live separately but share many resources, that promotes healthy and sustainable living, and includes a common space for regular community events. Mary Lou and George speak to the natural yet intentional integration of people without disabilities with people with disabilities.

Lessons learned about crafting supportive ally relationships

Hope Leet Dittmeier,

Mattingly Edge has assisted numerous people with disabilities to live in homes of their own with the support of a live-in or neighboring ally. Each and every situation was facilitated in a similar person-centered manner; however, each has differing characteristics. Much has been learned about the roles of all parties involved, the process of designing and facilitating supportive agreements, financing alternatives, and the factors that are most vital to success.

The Complex Beauty of Sharing Life

Patti Scott,

In many ways, Tyrone was the heart of his community and neighborhood. At 13 he became homeless for a period of time, and then for more than 20 years lived in a variety of insti-

tutions, nursing homes, and foster care placements. In his late 30s, Tyrone followed his vision and moved back to the community he left as a teen. There he became a homeowner, a neighbor, a student, an employer, a citizen, and an incredible connector. Tyrone's life experiences became his deep source of compassion. Over the last 10 years of his life he shared his home and life with someone, growing deep bonds as friends and family. The life they shared changed him, her, and her family - who also became Tyrone's family.

They Said He's Too "Dangerous" to Succeed: How Showed Them How Wrong They Were

Cheryl Ryan Chan,

My son Nicky spent 5 years in a hospital-based institution for severely behavioral children. They locked him behind a desk & put him in restraints any time he did anything they decided they didn't like. When it was time for him to transition into adult services, the agency said he was a monster who would never have any value to the world. I refused to believe them. After learning about SL - and being given a challenge by an adult agency director to have more faith in my son's potential - I embarked with that director to create a "hybrid" SL situation: SL with group home staff levels to provide what was necessary to be safe and access his community. 10 years later he & his provider Ben share a life of love, dignity & everything bachelors do that Mom doesn't need to know! Here's our story.

Minnie and Her Parasol

Karey DeGenova,

This is the story of Minnie and her long-time life sharer, Karey. Listen to the the ups and downs of their journey sharing lives and developing a deep bond over decades. We will look at several themes, including: How to promote resilient, flexible, and durable relationships between people with and without disabilities; What are the tensions between shared living and the systems that govern them and how might those tensions be addressed; What organizational values promote shared living and how can those values be protected; How might shared living offer ways to move beyond traditional systems; What more is possible; and How might governments support and promote shared living?

The Promise of a Home That Makes Sense

Josh Crupi,

Milparinka. in Melbourne Australia, works alongside people who have disabilities to move into homes of their own, with people they choose. For many people the journey of discovering what 'Home' is, is exciting but frightening; because it's new and challenging. In the past many people have had limited living options and answers to their needs that were prescribed by bureaucrats and institutions - by people and places that used all of the right words as disguises for restrictive and life limiting options.

We learnt two key things in our relationships with people, the importance of people being in control of their own lives and the need for us to be authentic in our relationships. The story we have to tell is about authenticity, listening to people and the nitty gritty of finding a home that makes sense.

Ideas that matter from Inclusion Press

<u>Creating Practices While Discovering</u> <u>Our Neighborhoods:</u>

Patti Scott & Kim Brown

Building an organizational culture by co-inventing a practice of intentionally walking neighborhoods, open to new possibilities. (20 minutes)

The Unlikely Evolution of Darwin Ness

Gail Jacob; Randal Wilkins; Peter Leidy Lessons from a 30 year direct support relationship. (20 minutes).

The Darwin Ness Polks

Peter Leidy

A 3 minute story in song of the first 20 years of change in Darwin's Life. An example of bringing your gifts (like song writing) to story telling.

Transformation for Right Relationship

Chris Liuzzo

Transforming a support relationship by closing a group home. (10 minutes).

The art of belonging

Beth Mount

A different telling of the Urban Innovators story. (20 Min)

Stories to read

Hanns Meisner (2013). Creating Blue Space: Fostering Innovative Support Practices for People with DD <u>www.inclusion.com</u>

A book length story of organizational transformation that redirected resources from group settings to individualized supports by developing a culture of social innovation. Reflections on the inner work of moral leadership and connections to frameworks and practices from the fields of organizational development.

John O'Brien & Beth Mount (2015). Pathfinders: People with Developmental Disabilities & Their Allies Building Communities that Work Better for Everybody. www.inclusion.com Includes stories of transformation:

- Tom Allen's lifelong resistance to the institutional mindset that followed him from the back wards to new build state facilities and into "community" services. (Pp. 57-64)
- Tiger Lilly Seeds, a business that shows up in the world of environmental activism. (Pp. 81-82).
- Urban Innovators (third version). Tells the story from the point of view of generating social innovation by letting go of a well established program and letting new ways of co-creating community roles and relationships come. (Pp. 156-163)
- JNCS five year process of closing group homes and day programs by shifting power to circles of support, developing individualized living arrangements, and focusing on work and community participation. The agency serves people with autism with histories of challenging behavior. (Pp. 183-188)

Oliver Koenig, Editor. (2022) *Inklusion und Transfomation in Organisationen*. Free download. Relevant chapters in English:

 Patti Scott & David Hasbury. Cultivating change: A culture of innovation supporting change and citizenship. (Pp. 218-234)

- Beth Gallagher & Kirk Hinkleman. Flipping the script: Intentional teaming through awareness based collective action. (Pp. 235-245)
- Simon Duffy. Citizen Network: Advancing inclusion for all. (Pp. 331-344). An international strategy to build cultures of inclusion and equality.
- Hanns Meissner. Learning Institutes: A space to imagine and birth new social support arrangements. (Pp. 317-330) This one is about us.

Christopher Liuzzo & John O'Brien. Seeking Transformation. (6 pages). Lessons from supporting organizations engaged in transformation. tinyurl.com/49nxjtxn

John O'Brien & Connie Lyle O'Brien Editors. (1992). Remembering the soul of our work: Stories by the staff of Options in Community Living. Free download. Options is a pioneer in individualized supported living. This is a collection of stories staff wrote and read to one another as a practice for renewing and deepening their understanding of their work.

Publication Information

John O'Brien & Beth Mount developed and wrote this guide. They are responsible for the reading of The Community Rule and the understanding of transformation presented here.

This Learning Institute that this guide supports is sponsored by the New York State Department of Health Money Follows the Person (MFP) Rebalancing Demonstration.

To learn more about the Person Centered Planning Training Initiative: <u>NYDOHPCPTraining@pcgus.</u>

For information on Money Follows the Person: MFP@health.ny.gov

For information on the HCBS Rule: HCBSrule@health.ny.gov

Find the NYDOH Person-Centered Planning & Practice Resource Library at www.health.ny.gov/

health_care/medicaid/redesign/person-centered_planning/

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