

Creating Our Common Wealth

Members of Each Other



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25 April 2016

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<http://inclusion.com/jobrien.html>

In my opinion this Mission, which builds on what people with ID/DD, their families & service providers have achieved over the last two generations, dedicates the system to a purpose that calls for new ways to organize and administer publicly funded assistance. This purpose calls for a period of learning through social innovation: doing new things in new ways.

The Department is dedicated to creating, in partnership with others, innovative and genuine opportunities for individuals with intellectual disabilities to **participate fully and meaningfully in, and contribute to, their communities as valued members.**

The kind of learning necessary to realizing the Mission requires commitment to intentionally widening awareness of community & deepening appreciation of people's highest purpose.

Measurement of outcomes becomes a challenge: indicators need the context of narrative to capture & transmit relevant learning.

Deeper listening

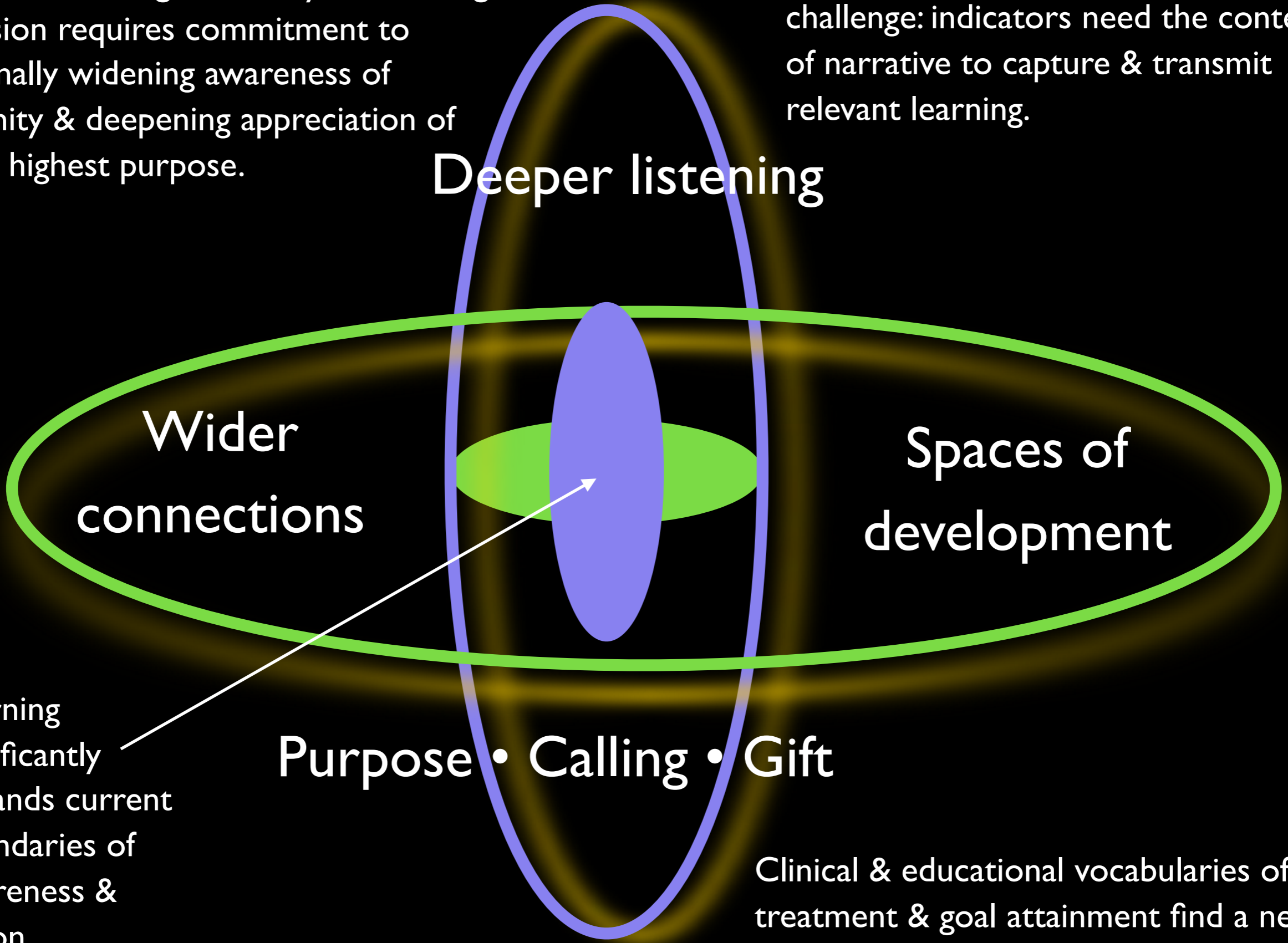
Wider connections

Spaces of development

Purpose • Calling • Gift

Learning significantly expands current boundaries of awareness & action

Clinical & educational vocabularies of treatment & goal attainment find a new context in an active inquiry into purpose.



A ruling story does not so much combat alternative ideas as thrust them beyond the very bounds of the thinkable.

–Terry Eagleton

Common ruling stories make the congregation & segregation of people with ID/DD seem natural – just the way things are. When these stories go unquestioned we learn nothing about supporting people in valued social roles.

They are happiest with their own kind (i.e. other people ID/DD they have been placed with in a human service program).

No other citizen could understand them or would accept them as a friend.

They have nothing meaningful to contribute.

Until they develop social skills by following their program, they will be unacceptable.

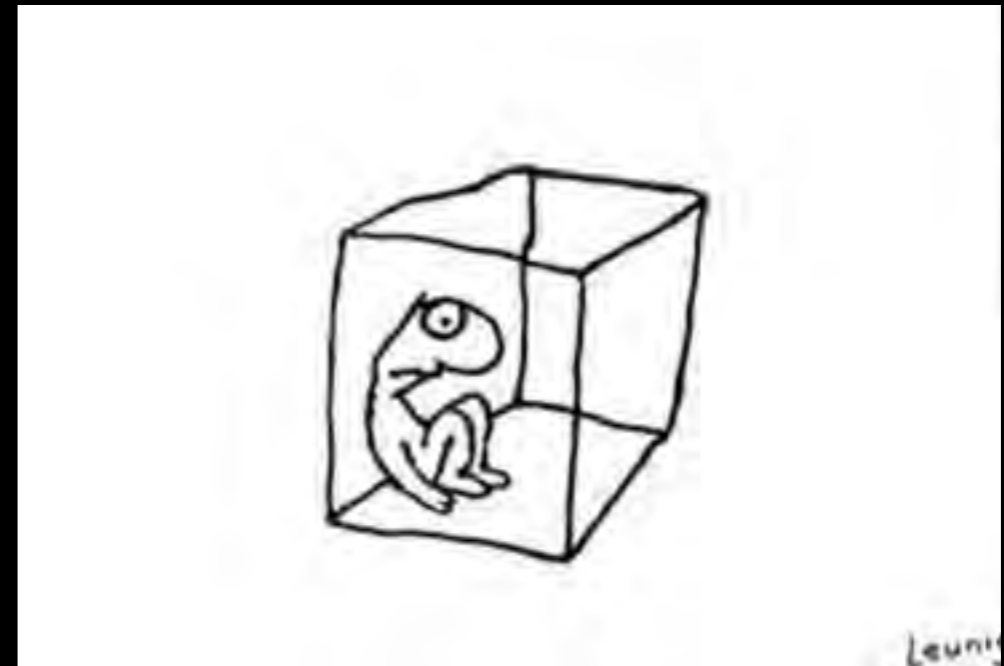
Innovation begins when we notice & take responsibility for the limits in our current capacities. This breaks us out of the common defensive claim: *We're already doing this*. It drops us into the uncertainty of a search for new ways to accomplish new things.

A ruling story does not so much combat alternative ideas as thrust them beyond the very bounds of the thinkable.

–Terry Eagleton

The most constraining stories make themselves invisible.

We are not usually aware that we are living inside them.



Old stories can serve important interests. The point is not to eliminate them but to knock them off their thrones, bring them into the light & into contest with perspectives consistent with the purpose of participation in contributing community roles.

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–Terry Eagleton

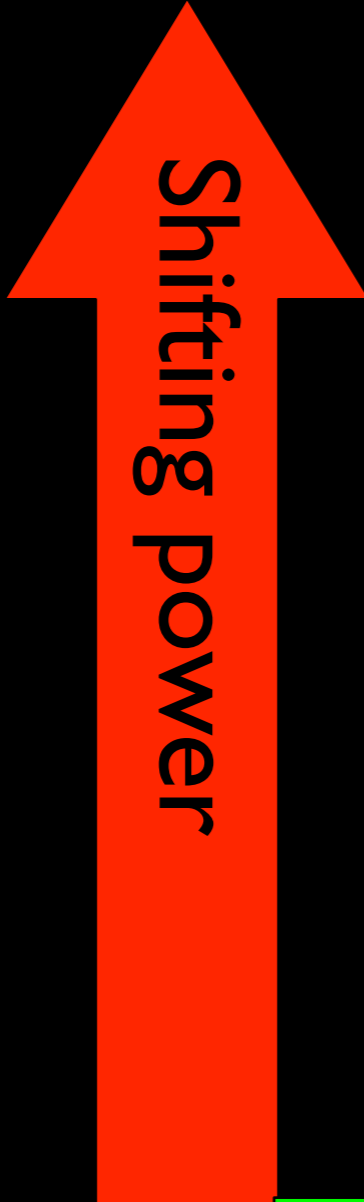
New stories emerge in the space created when we disrupt stories that limit our freedom.

Disrupting ruling stories opens the way for emergent learning

Emergent learning often begins in disconfirmation.

We recognize that the (implicit) story that guides our practice & underwrites our current structure undermines our purpose

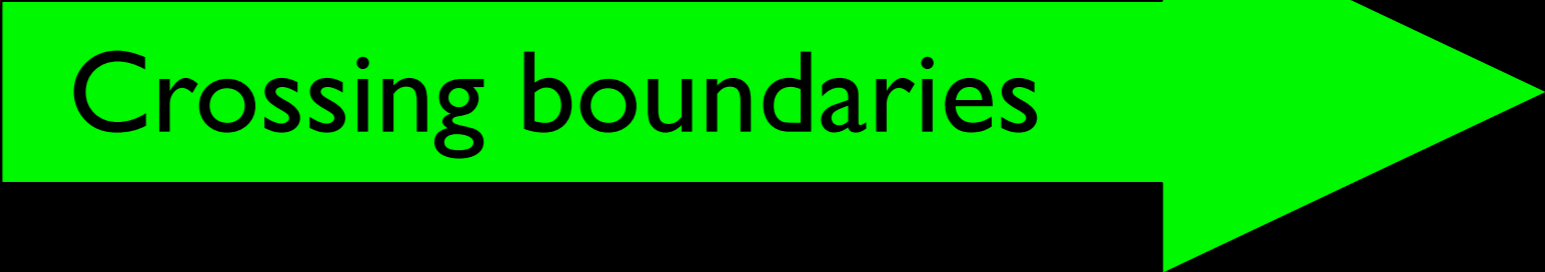
power-with
co-creation



The history of the postwar movement to act on recognition of the dignity & potential of people with ID can be told as a sometimes halting & imperfect series of moves to increase freedom by crossing boundaries from clienthood in professionally controlled space to self-direction & valued participation in community space. These moves cannot be coerced; they must be co-created by people, families, assistants & community members.

Each positive move overturns a ruling story that shapes control & exclusion by making space for social innovations which create a new story that can be held & revised more consciously.

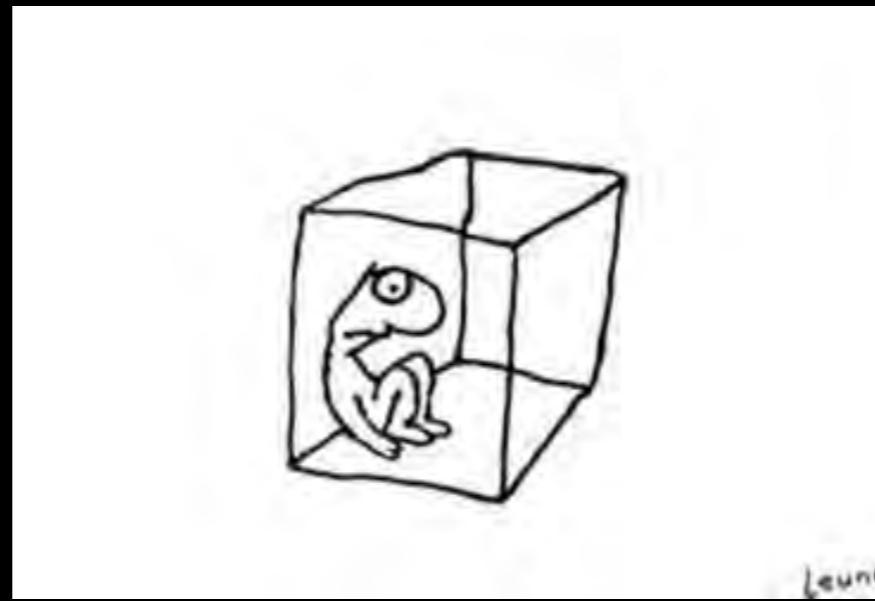
power-over
coercion



controlled
ID space

common
space

Willing to notice & question
what's taken for granted
discloses ruling stories.



The story has us when...

It's common sense

Everybody knows

It's reality

We filter out messages that question or present another
way to think and act.

We get anxious or angry when the story is confronted.



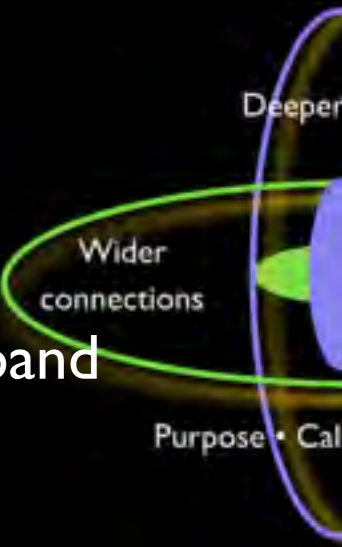
We have the story when...

We recognize it as one way to make sense & guide action

We look for & test its boundaries

When the story is challenged –especially in a way that opens more space for positive action– we regulate our anxiety & consider revising or updating our story.

Awareness grows when we engage in new conversations. Putnam & his colleagues have generated a conversation about the individual & communal benefits of diverse networks that expand trust & invite collaboration across boundaries.



“...the well connected are more likely to be hired, housed, healthy and happy.”

“The central challenge for modern, diversifying societies is to create a new, broader sense of ‘we’.”



Robert Putnam

www.hks.harvard.edu/programs/saguaro/

Putnam distinguishes two forms of social capital.
Each has personal & social value.

Bonding

Actions that link people who
see themselves as similar
—tend to be inward looking

Gathering people & families on the basis of ID/DD & bringing in other citizens in volunteer staff or caring roles promotes bonding: Special Olympics, Very Special Arts, self-advocacy, the Down Syndrome Society are all examples of bonding connections. Participation does not challenge the social boundary around ID/DD though it may shift social perceptions of the capabilities of those involved.

Some people will find bonding relationships sufficient; others will draw on the strength they find here as a springboard to bridging action.



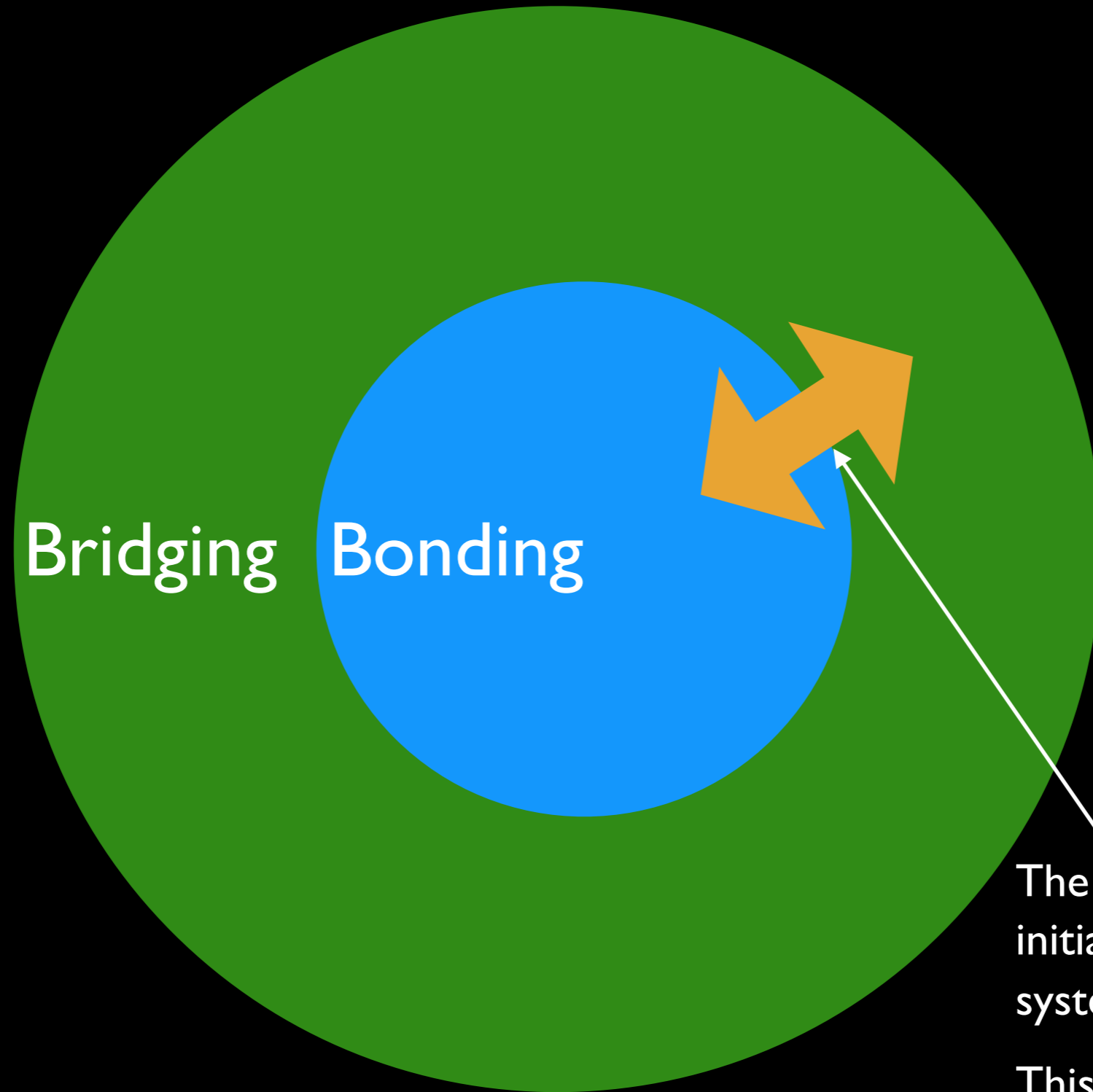


Bridging

Actions that bring together people with different interests & identities –tend to be outward looking & are harder to create than bonding networks.

Making new connections among people who see themselves as different in important ways creates the conditions for contributing roles & friendships to emerge. Stereotypes & inequalities patrol the boundaries that separated people with ID/DD so bridging can be awkward and shaped by anxiety.

People with a foundation in their relationships with family, friends & staff are more likely to be resilient to boundary crossing. Those with no strong relationships can be vulnerable to attracting people who will exploit or abuse them.



Bridging

Bonding

The Mission & related initiatives positions the whole system at this growing edge.

This is the space for pathfinders to expand & deepen awareness & learn by reflecting on action.

Good direct support is essential. Exploration with many long-serving & capable direct support workers shows that the work is fundamentally relational, engaging heart, mindful & intelligent hands, & consciousness of highest purpose.



O'Brien J. & Mount, Beth (2005). *Make a Difference: A Guidebook for Person-Centered Direct Support*. Toronto: Inclusion Press. <http://inclusion.com/bkmakeadifference.html>

DANCE IN THE SHADOW



Learn more about Rebecca's story by watching her video at

<http://www.planningnetwork.ca/Resources/18697/Dance-in-the-Shadow>

and visit her website at

<http://www.tmw.to/members.php?uri=rebecca-beayni>



The circles identify where Rebecca shows up in contributing roles

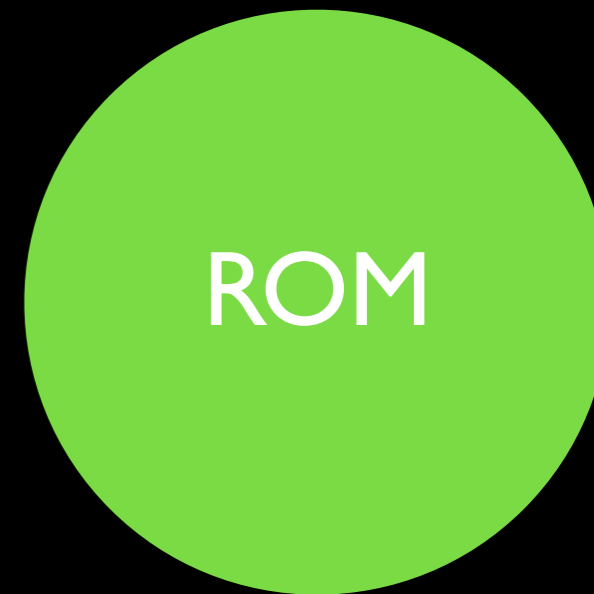
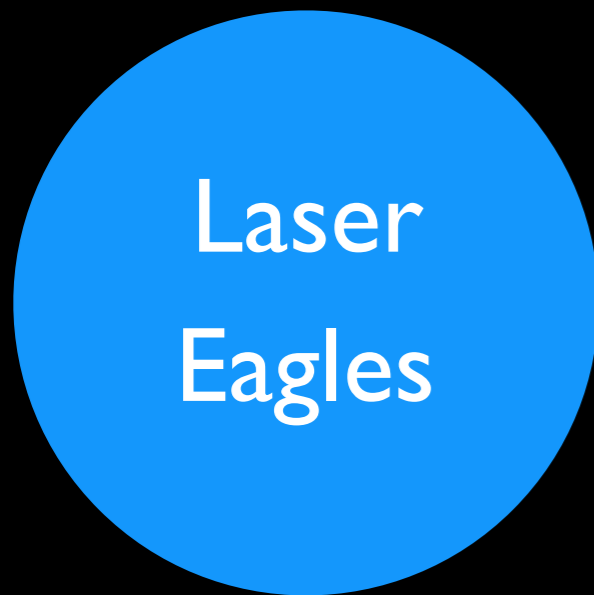


Dance

What matters to Rebecca -as understood by her family & heart network

Art

Teaching



Social Justice • Healing • Relationship

Ubuntu: I can't be free to be fully me unless you are free to be fully you.

Individualized supports to Rebecca's life & contributions

Heart Network

Church

Holds story of Rebecca as contributor

Emotional support

Practical help & problem solving

Sense-making: interpreting Rebecca's gifts, will & preference

P4P <http://www.partnersforplanning.ca>

Laser

Eagles

Control of assistance through Individual Budget

Liturgical

Prayer

Spirit

Weavers

Dance

Company

Rosalie

Hall

Mustard

Seed

Centre

ROM

The focus of person-centered planning when the purpose is contribution to community.

What gifts can you bring that express your highest purpose and build your community?

What does it take for those gifts to develop & be received?





Church

Liturgical
Dance

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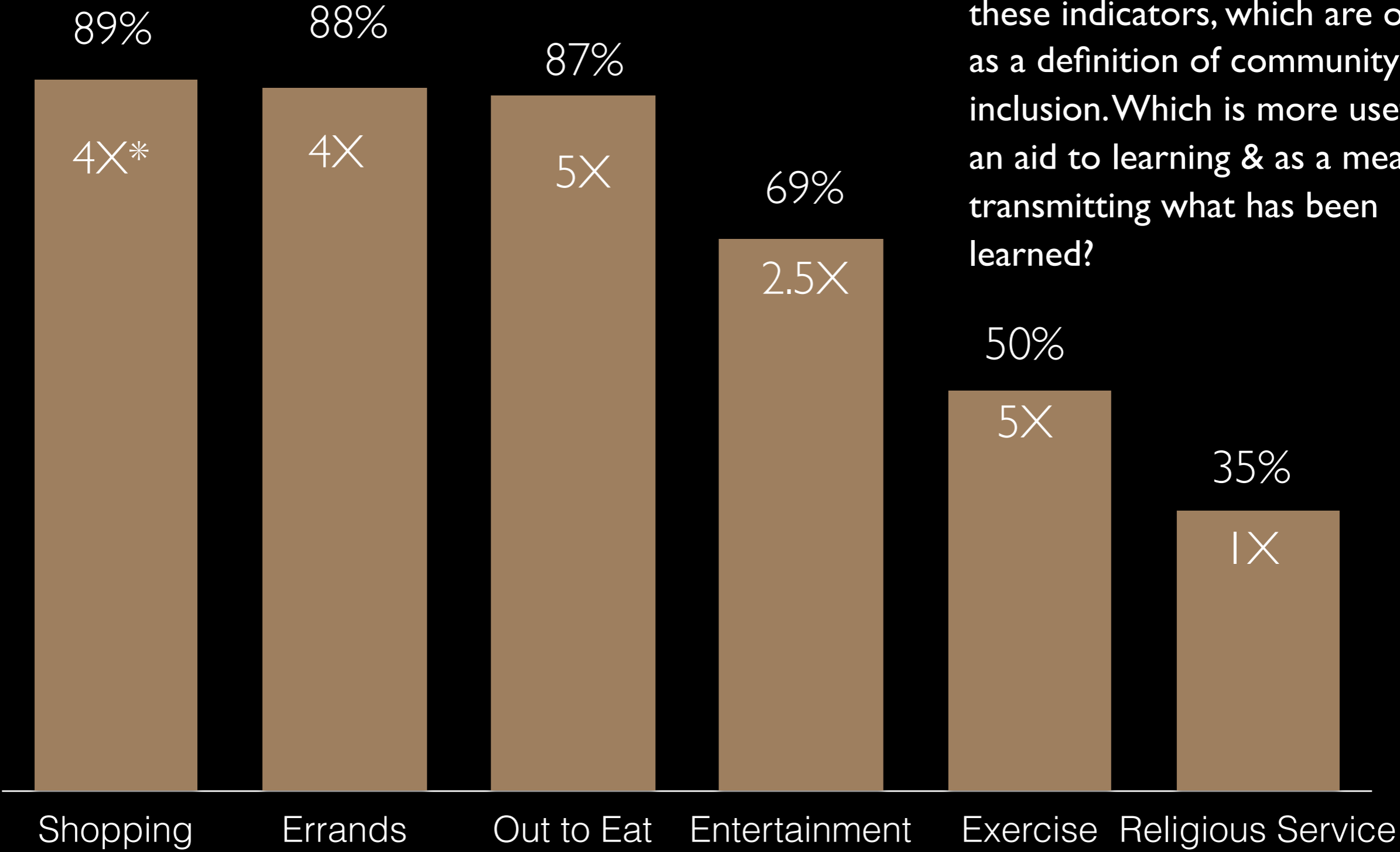
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Community Inclusion

Compare the depiction of Rebecca's roles & the related story with the information contained in these indicators, which are offered as a definition of community inclusion. Which is more useful as an aid to learning & as a means for transmitting what has been learned?



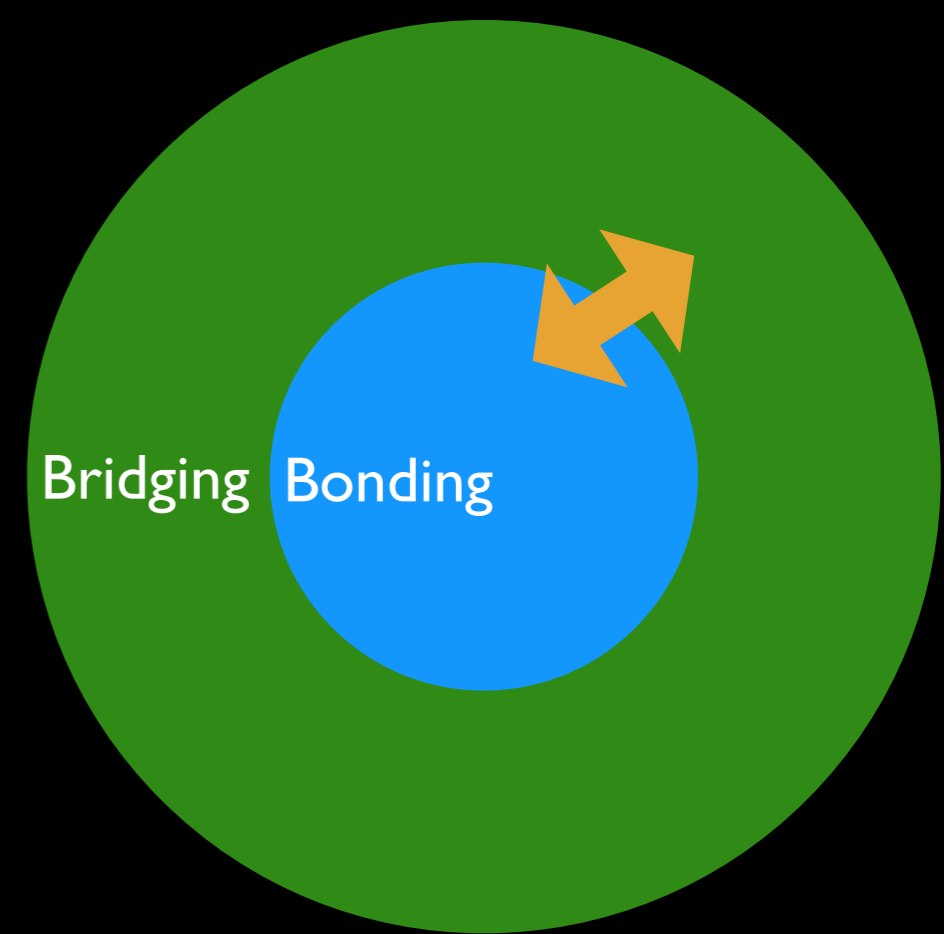
* Average number of times per month

The iceberg provides a useful metaphor to identify the depth of change involved in moving into the Mission.



Some changes can be imposed under a regime of compliance, incident reporting or billing procedures for example.

Learning to support the bridging actions that offer opportunities for contributing roles can only emerge from commitment. Those who innovate will be thirsty to learn through action how to realize the Mission. They will be curious & courageous in noticing what ain't right for purpose in current practices, structures, stories & relationship to source. Noticing & stepping into contradictions & competing intentions are important for discovering what is misaligned with the Mission.



First the fish needs to say, “Something ain’t right about this camel ride and I’m feeling so damned thirsty.”

–Hafiz

What's the Difference?

Special words

Natural support

Jargon words are easy to spot: unless your grandmother were an insider to the field you would have to explain the term to her. They have their proper uses but they can obscure meaning if they lose context. Because the context for contributing roles is ordinary life, ordinary words are a better guide to what we want to learn to do.

The phrases in the next column were used in a presentation by a person with long experience of supporting people to build diverse and powerful relationships. On reflection, she says she can't recall ever using the term "natural support".

Ordinary words

People who walk with you

People to hang out with

Acquaintances —> friends

Call his people together

People at her church

People who have stuff in common

People [who are active in community] willing to get to know a person



In some systems *natural support* has accumulated additional meaning. It has come to stand for what the system will not pay for. From the point of view of supporting the emergence of friendships, this frames the work poorly. It flips the notion of what a person can contribute to the common wealth to what others can do to save the system money. It puts system representatives in the role of Tom Sawyer, looking for others to paint the fence, often paying for the privilege by conforming to system rules (e.g. police checks before they can spend time with a neighbor).



75 Things You Can Do To Build Community

John O'Brien

Community grows stronger through hundreds of little and big actions citizens take every day. As you scan the list...

- ✓ Put a check mark next to any of these actions that you or a family member has done either in the past month or so, or for more occasional actions, in the past year or so.
- + Put a plus sign next to any of these actions you have supported a person with a developmental disability to do in the past month or so, or for more occasional actions, in the past year or so.
- ? Put a question mark next to any of these actions that a willing person with a developmental disability would find harder to do because of a service organizations' policy or current practice or routines or setting.

1. Attend a political meeting
2. Support local merchants
3. Volunteer your special skills to a community organization
4. Donate blood (with a friend)
5. Work in a community garden
6. Mentor a person of a different ethnic group
7. Surprise a new or favorite neighbor by taking them food
8. Avoid destructive gossip
9. Help another person outside your home fix something
10. Attend local school or children's athletics, plays, & recitals
11. Get involved with scouts
12. Sing in a choir
13. Attend a party in someone else's home
14. Get to know the clerks and salespeople at your local stores
15. Audition for community theatre or to support a production backstage or volunteer to usher
16. Attend a lecture or concert
17. Give to your local food or clothing bank
18. Play cards or games with friends or neighbors
19. Walk or bike to support a cause and meet others
20. Participate in a political campaign
21. Attend a local festival or parade
22. Find a way to show personal appreciation to someone who builds your local community
23. Coach or help out with local (youth) sport
24. Offer to help a neighbor with garden work or shopping or a ride
25. Start or participate in a discussion group or book or film club
26. Start or join a carpool
27. Plan a "Walking Tour" of a local historic area
28. Tutor or read to children or have children read to you
29. Run for public office
30. Invite neighbors over for a meal
31. Host a party
32. Offer to serve on a committee outside of work
33. Form a walking group (or a swimming group) with at least one other person & encourage each other
34. Play a sport
35. Go to church
36. Ask an elder to teach you something
37. Host a potluck supper
38. Take dance lessons with a friend
39. Become a trustee
40. Join a campaign & take action that brings you into contact with others (not just a donation)
41. Gather a group to clean up a local park or cemetery
42. Bake something for neighbors or work colleagues
43. Plant trees
44. Volunteer at the library or primary school
45. Call an old friend
46. Sign up for a class & meet your classmates
47. Accept or extend an invitation

*Adapted from www.bettertogether.org which identifies 150 social capital building actions.

75 Things

As a group we took the question of availability of these 75 bridging actions to willing people with ID/DD in different ways. Some said every activity is available. They emphasized what is possible with good support. Some had more question marks –even as many as 75. They emphasized the impact of staffing patterns suited to group rather than individual activities, policies that control who a client can spend time with without staff present, etc.

Those who experience these possibilities realized have stories worth telling & lessons about organizing staff time & negotiating regulations that others find inhibiting worth sharing. Those who detect obstacles can shape an agenda for system wide learning.



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48. Log off and go to the park
49. Say hello to strangers
50. Find out more by talking with a neighbor you don't know very well yet
51. Host a movie night
52. Help out with or create a newsletter
53. Collect oral histories to discover the interesting things people have done
54. Cut back on TV
55. Join in to help carry something heavy
56. Make gifts of time
57. Greet people
58. If you think someone needs help, ask to find out & do what you can
59. Fix it even if you didn't break it
60. Pick up litter even if you didn't drop it
61. Attend gallery openings & art exhibits
62. Organize a neighborhood yard sale
63. Read or listen to the local news faithfully
64. Attend a public meeting or hearing & speak up
65. When inspired write a personal note or send a card to friends
66. Offer to watch a neighbor's home while they are away.
67. Help out with recycling
68. Ask to see a friend's photos
69. Invite a local politician or official to speak to a group you belong to
70. Start talking to people you see regularly
71. Listen to the children you know and find out what matters to them
72. Plan a reunion of family, friends, or people with whom you had a special connection
73. Hire local young people for odd jobs
74. Write a letter to the editor
75. Join a group that is likely to lead to making new friends of different ethnicity, or religion, or income, or life experience



For those in publicly funded living arrangements, this inventory poses a test of the degree to which a place embodies three characteristics that define a home. They can say...

I control the threshold & can freely invite my fellow citizen across it as my guest.

I can offer hospitality without asking permission.

We can share a meal at my table.



You Can Still Go to Hell

In Shop'N Save I'm trying to get Lorna to reach up
and grab a box of Little Debbie pink heart cakes
and though she won't lift her hand above her shoulder
and is making anxious honking sounds, still,
I'm trying to get her to do it, because reaching up
will strengthen her back and there's a hab plan written
somewhere that says she's going to,
when I realize a little French woman is repeating,
Excuse me, and Louise, hands glued to the grocery cart,
is frozen in place blocking her.
I reach over and touch Louise's right elbow and she
takes two big steps forward and says loudly, *Yeah right*,
while Leo, his mittens fastened to his sleeves,
flaps his arms like a seal and Lorna knocks
three boxes of Nutty Buddies on the floor.

The woman pats me on the arm and says,
There's a special place in heaven for people like you,
and even though I like being thought of
as a saint and want to go to heaven
I know this isn't really enough.
She only says it because she doesn't know
the people I work with or how normal they are,
and all of us, therefore, don't know,
as well, what normal is.

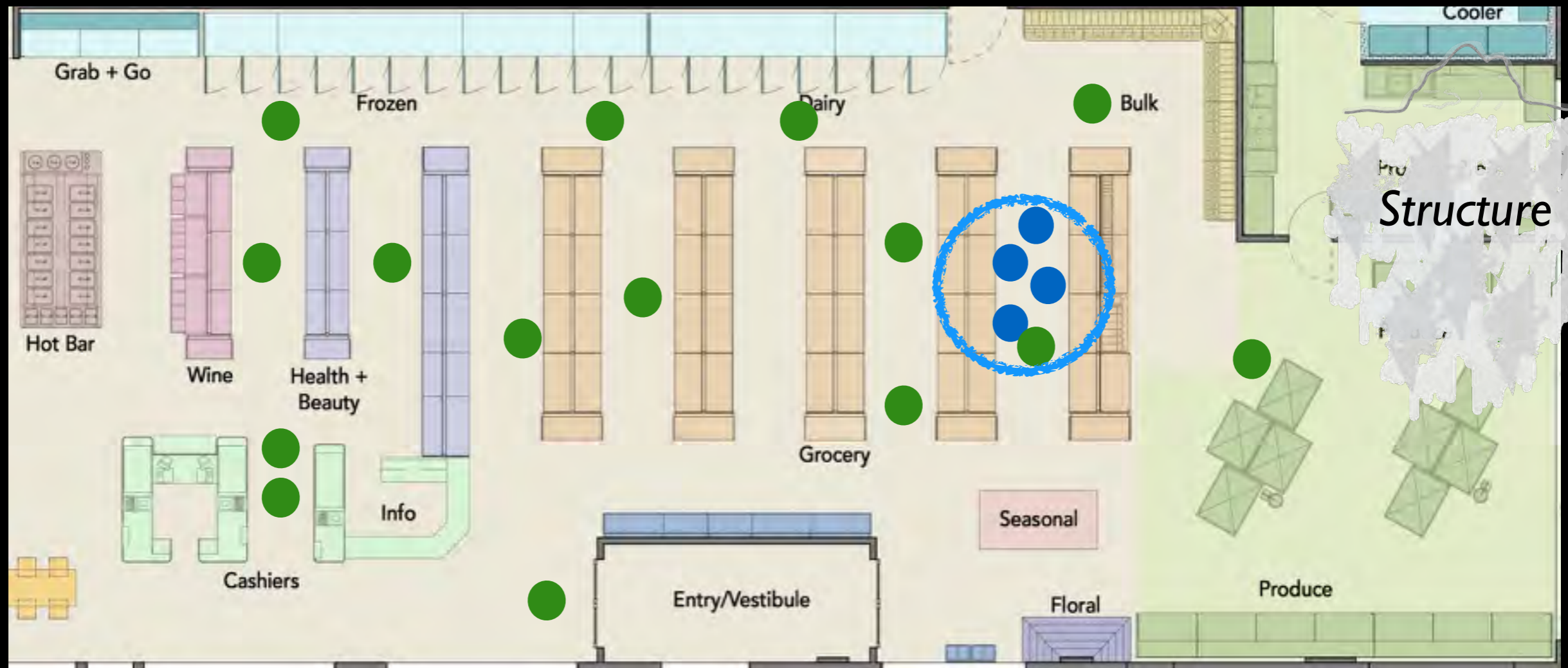
But I know Louise loves to sing,
We're off to see the wizard...
and sometimes, completely out of nowhere,
she'll walk up to Leo, give him a hug
and kiss him, gently, on top of his head.

Dave Moreau (2011) *If you're happy and you know it clap your hand*. Inclusion Press www.inclusion.com/bkifyouarehappy.html

*she doesn't know the people I work with
or how normal they are,
and all of us, therefore, don't know,
as well, what normal is.*



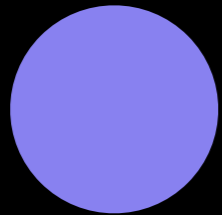
People with ID/dD can make a good life without negotiating the boundaries between blue and green. But this diminishes the common wealth. It deprives the community of the strength that comes from their gifts and the freedom that grows when we all become less fearful & more capable of appreciating & accommodating difference.



One reading of the poem offers a lesson in the effect of structure on the capacity to deliver on the promises made in planning sessions. Imagine this as an offering of a Community Experience Program, intended to build skills in social relationships & make community connections. Three people with IDD, each of whom apparently requires individualized assistance, are accompanied on a trip to the grocery store by one staff person. Structure works against the stated purpose. The grocery store is a busy place where most people are in the aisles in order to add items to their cart. It's not a place that most people would seek to meet new people. A grouping that occupies a whole aisle and keeps the single staff member shifting attention from one person to the next within the group shrinks the odds of a positive experience with other people.

What's the Difference?

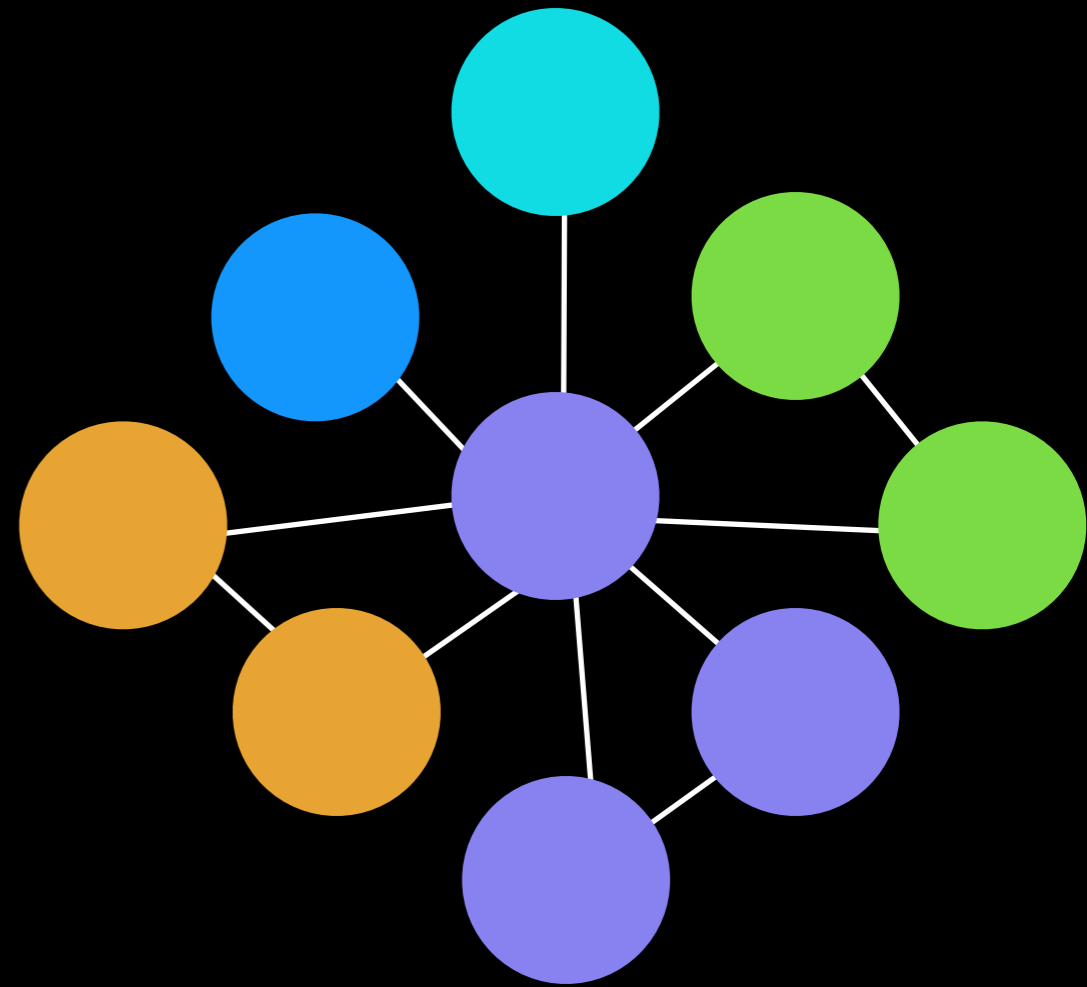
The individualistic bias of the dominant culture leads us to stories of *person* as if a person were a single entity in competition with the interests of other isolated individuals. It views friendship as if it were a matter of economic exchange in which each party keeps score so as not to be cheated. This casts people with ID/DD in a devalued position by obscuring the interdependence at the heart of human existence.



Person

It is our ability to be in relationships with others rather than our ability to be self-sufficient that should anchor our understanding of what it means to be a person. We do not become a person without the engagement of other persons -their care, as well as their recognition of the uniqueness and connectedness of our human agency, and the distinctiveness of our particularly human relations to others and of the world we fashion.

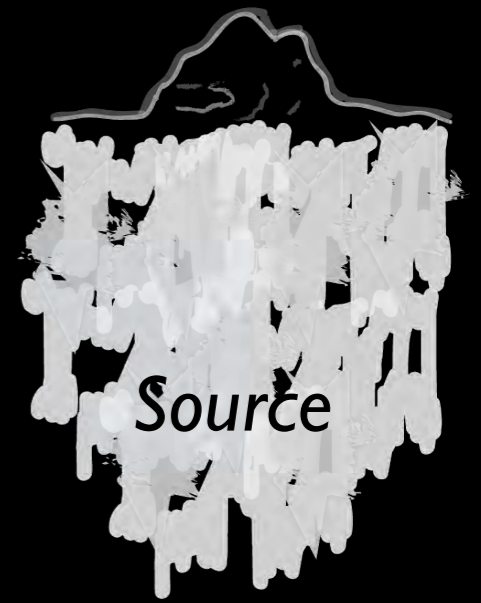
—Eva Kittay



Person



Chris shows us where to find the Source of work that supports a person to show up as a contributor & discover possibilities for friendship. The work arises from a willingness to listen deeply & be moved to shared action, faithful to what listening reveals.



If you are going to work with me,
you have to listen to me.

And you can't just listen with your ears,
because it will go to your head too fast.

You have to listen with your whole body

If you listen slow,

with your whole self,

some of what I say will enter your heart.

—Christine Mayer

Appreciation of interdependence leads to questions like these, held in the heart, that have sustained Tom Kohler's continual learning as a Citizen Advocacy coordinator for more than 30 years. <http://www.savannahcitizenadvocacy.org>



What can people come to mean to one another?

What can those people come to mean to the common good?



A scarcity story has grown in influence on supports to people with ID/DD. Cost controls grow in prominence. A system closed in on itself will find itself in spirals of escalating scarcity. A system that invests substantially in Sarason's discovery will have more to offer in time.



Resources multiply in networks created by intentionally building relationships that cross boundaries & serve people's deepest purposes.

Seymour Sarason

Many current structures are designed to house, occupy & develop or treat people with ID/DD in groups. Focusing on individual contribution to community in ways that encourage diverse friendships opens a space for social innovation.

Taking Sarason's insight into multiply resources seriously, the GA Council on DD invests in a design that turns typical structures on their head. Instead of moving out from the DD system in search of valued roles, the council invests in community organizing aimed at brings people with ID/DD together with their fellow citizens to work for some aspect of the common good. What brings them together is a shared interest in making progress on an issue that will make the community better for everybody.



About Real Communities

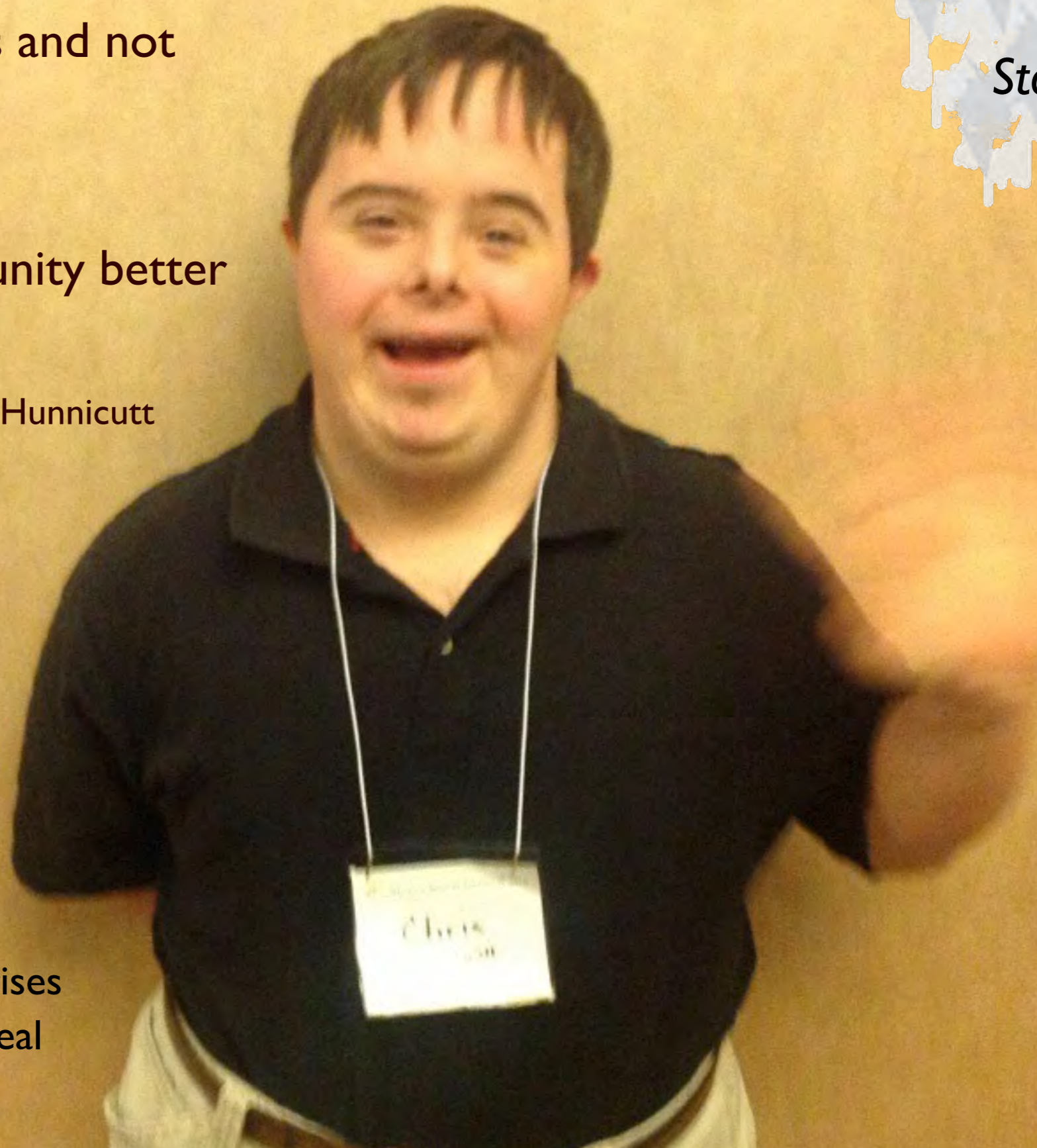


<http://gcdd.org/real-communities/about-rc.html>

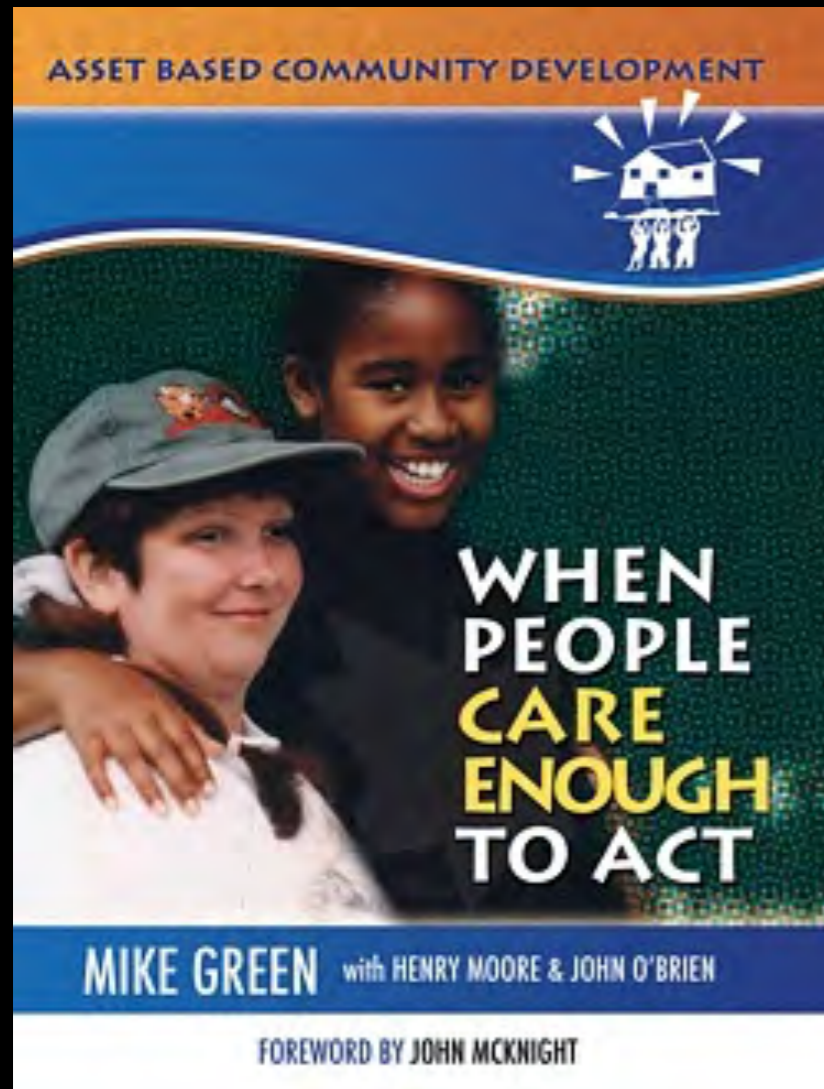
My best definition of inclusion is:
People with disabilities and not
participating together
to do something
that makes the community better
for everybody.

-Chris Hunnicutt

This definition of inclusion arises
from Chris's experience of Real
Communities.



Asset Based Community Development (ABCD)



When people discover what they have, they find power.

When people join together in new connections & relationships, they build power.

When people become more productive together, they exercise their power to address problems and realize dreams.

<http://inclusion.com/bkwhenpeople.html>

ABCD informs the story, structure & practices of Real Communities.

In collaborating communities, the Council invests in a part time organizer. In return for support for learning & often a stipend for some of the organizer's time, a group commits to purposeful learning by action with three qualities.

Engages people with DD in collective action with other citizens

Builds community capacity for civic action

Real Communities will not invest in projects aimed at doing for people with ID/DD, this includes advocacy or advocacy training. (The Council has other channels to support this.) The aim is action with people with ID/DD to make things better for everyone.

Makes progress on something that matters to the whole community



In this rural county, a fleet of 8 12 passenger vans now makes it easier to get around with a car. This is the result of collaboration of activists including people from a nearby community college, members of People First, local elected officials and county administrators, representatives of several churches and a nearby hospital.



Ben Hill County Georgia

Office (229)426-5100
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Fitzgerald, Georgia 31750

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Deceptive clip art. The vehicles are used vans.

Ben Hill Transit



Deceptive clip art

426-RIDE (7433)

\$3.00 One Way

**Must Schedule Ride
24 Hrs in Advance**

"All Rides must be scheduled thru 426-RIDE"



Mill Hill: East Macon Arts Village



Donate to the renovation of the Mill Cottage at 217 Schell Avenue. [Click here to donate now.](#)

Stay informed! [Click here to sign up for updates on this project.](#)

Request for Qualifications: Neighborhood and Cultural District Master Plan

Mill Hill: East Macon Arts Village is a neighborhood revitalization effort that seeks to develop approximately four blocks of the historic Fort Hawkins Neighborhood in East Macon into an arts village in order to address blight and foster economic opportunity. The effort is a partnership between neighborhood residents, Macon Arts Alliance, the Macon-Bibb County Urban Development Authority, and many community stakeholders.

The Mill Hill effort seeks to address the challenges of blight and lack of economic opportunity in the neighborhood known as the "Birthplace of Macon." Originally a "mill village" located adjacent to the Bibb Manufacturing Company's Bibb Mill No. 1, the neighborhood consists of a variety of low-priced, architecturally significant housing stock that is largely in need of renovation and restoration. According to a recent inventory conducted by the Urban Development Authority, 46% of the parcels in the neighborhood are vacant and blighted. A key asset of the neighborhood is a dilapidated auditorium, built by the Bibb Manufacturing Company in 1920, when the neighborhood was predominately mill employees. The auditorium has been identified as the site for the proposed Mill Hill Community Arts Center.

Organized by the Minister for Community Building at Centenary UMC, a diverse group of young people have summer jobs as Roving Listeners. They listen to people on their porches & in their homes to discover the gifts & assets of residents in a neighborhood involved in a renewal project that seeks to avoid the problems that often follow gentrification. They identify common interests & invite people to shared meals. Shared action can emerge from these meals.



Learn more about Roving Listening in this TEDx Talk by DeAmon Harges, the original practitioner of the art in his Indianapolis neighborhood. Council support makes DeAmon available as a coach for Macon's Roving Listeners.



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The Forsyth Farmers' Market

Mixed Greens

A group committed to food justice



ORS

THEY ARE AWESOME!

Basmat Ahmed /Clarkston Relationship- Building Group

A Real Communities Project



ABCD Organizing by Basmat Ahmed has resulted in a variety of local initiatives & a growing network of developing citizen leaders in Clarkston, a community with a very high concentration of refugees from many countries.

Georgians For Alternatives to the Death Penalty (GFADP)

A Real Communities Project



People with ID who have survived prison share their stories & add their energy to actions intended to reverse the shameful effects of Georgia's prison pipeline, which disproportionately affects people with ID. The current agenda includes legislative change to the standard of proof to establish that a person is exempt from execution because of "mental retardation."



to



The leadership at Starfire, a successful Cincinnati day program, have chosen to turn their existing structure & practices inside out to fit a mission.

They have extensively documented their learning in...

...a blog. This entry <https://cincibility.wordpress.com/2016/04/21/coming-to-you-live-from-my-cocoon-a-special-save-the-date/> describes the annual cycle of collaboration projects through which people with ID/DD organize a gift to their community (such as the creation & production of A Funeral for Hamlet: The Film)

...a youtube channel <https://www.youtube.com/user/StarfireCincy> with 80 brief stories of contribution

...an iBook Tim Vogt (2013) Cincibility: The Five Valued Experiences. Available free from the Apple iBook store.

To explore the why of turning a successful program inside out, spent 13 minutes watching Business As Usual <https://www.youtube.com/watch?v=LfX2O7HP104>

Starfire was highly successful, but...

Group Activities

1987-2014

Group Service activity



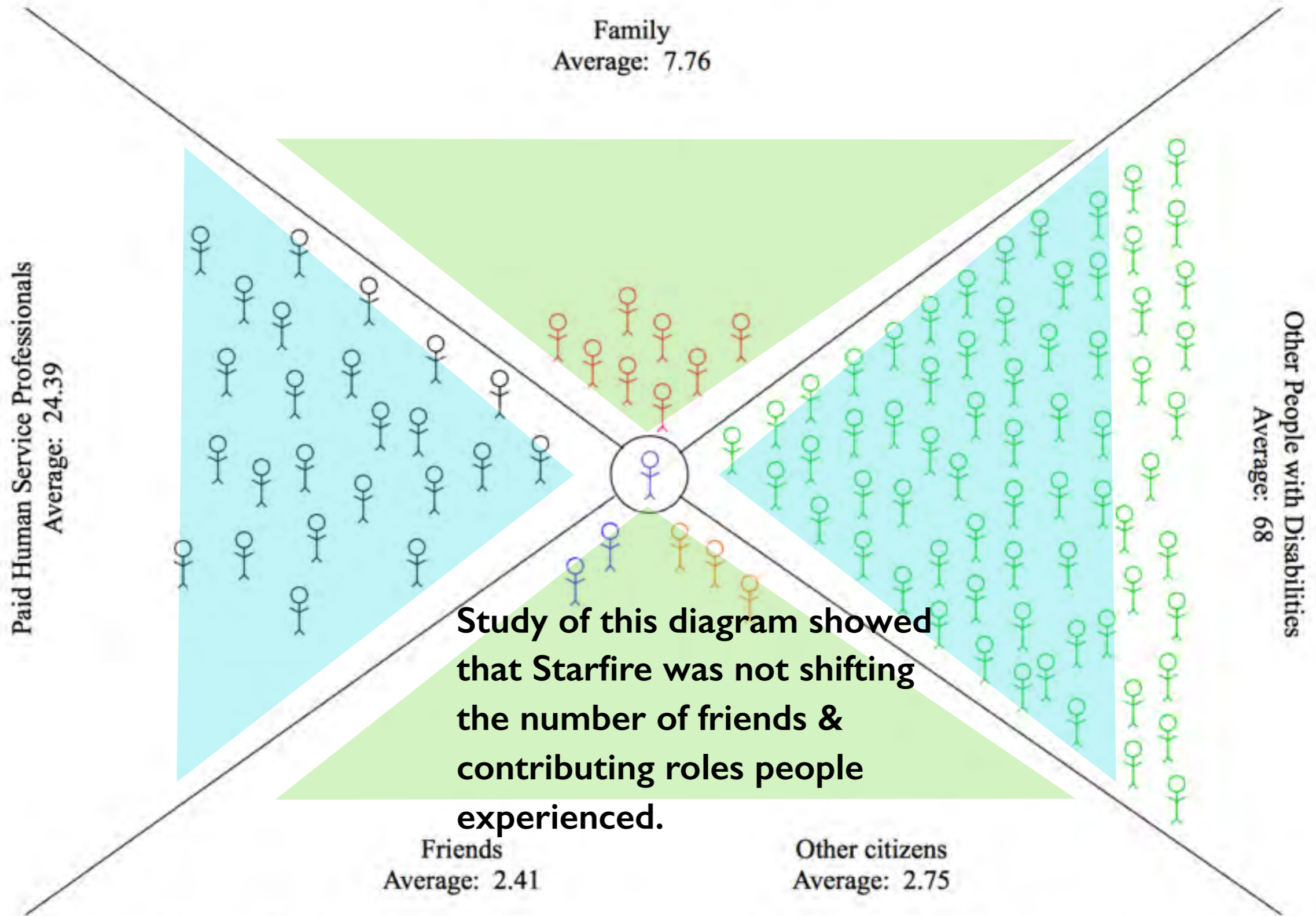
1,200/year

Use local amenity

Enjoy each other & the community

Attend event

51 People with disabilities



Note: 9 of the 51 people had only paid human services professionals and other people with disabilities in their circles.

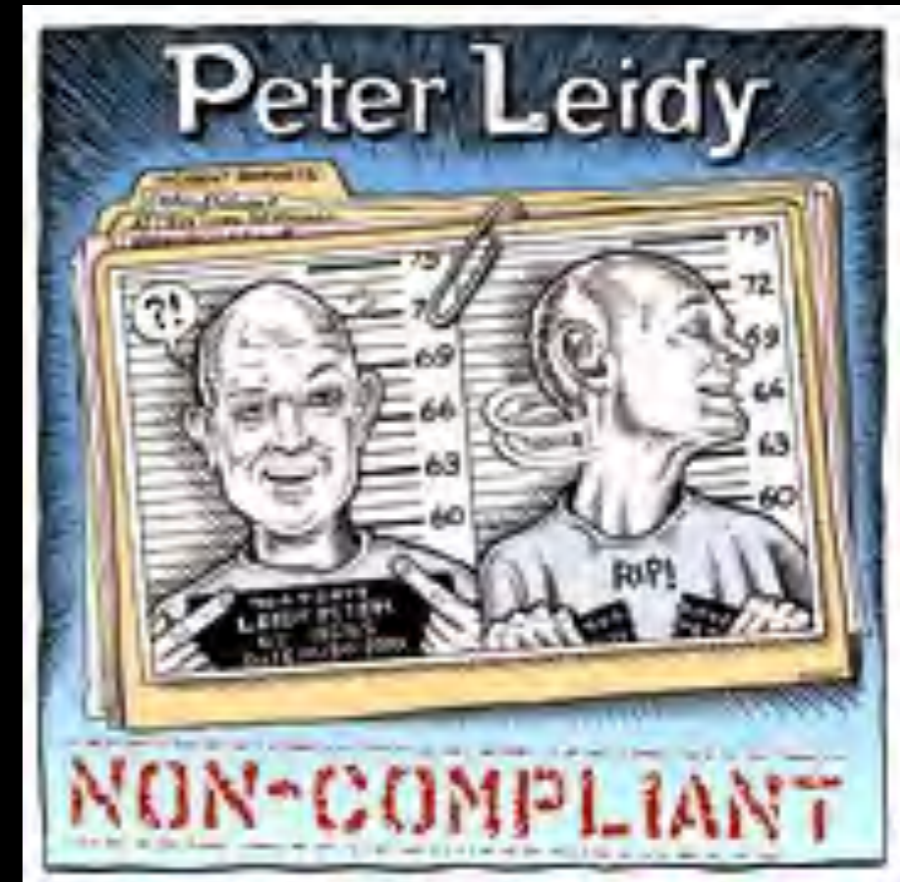
Encounters with Judith Snow at the Toronto Summer Institute refined Starfire's story.

Inclusion is about willingness to take a unique difference and develop it as a gift to others. It is not about disability.



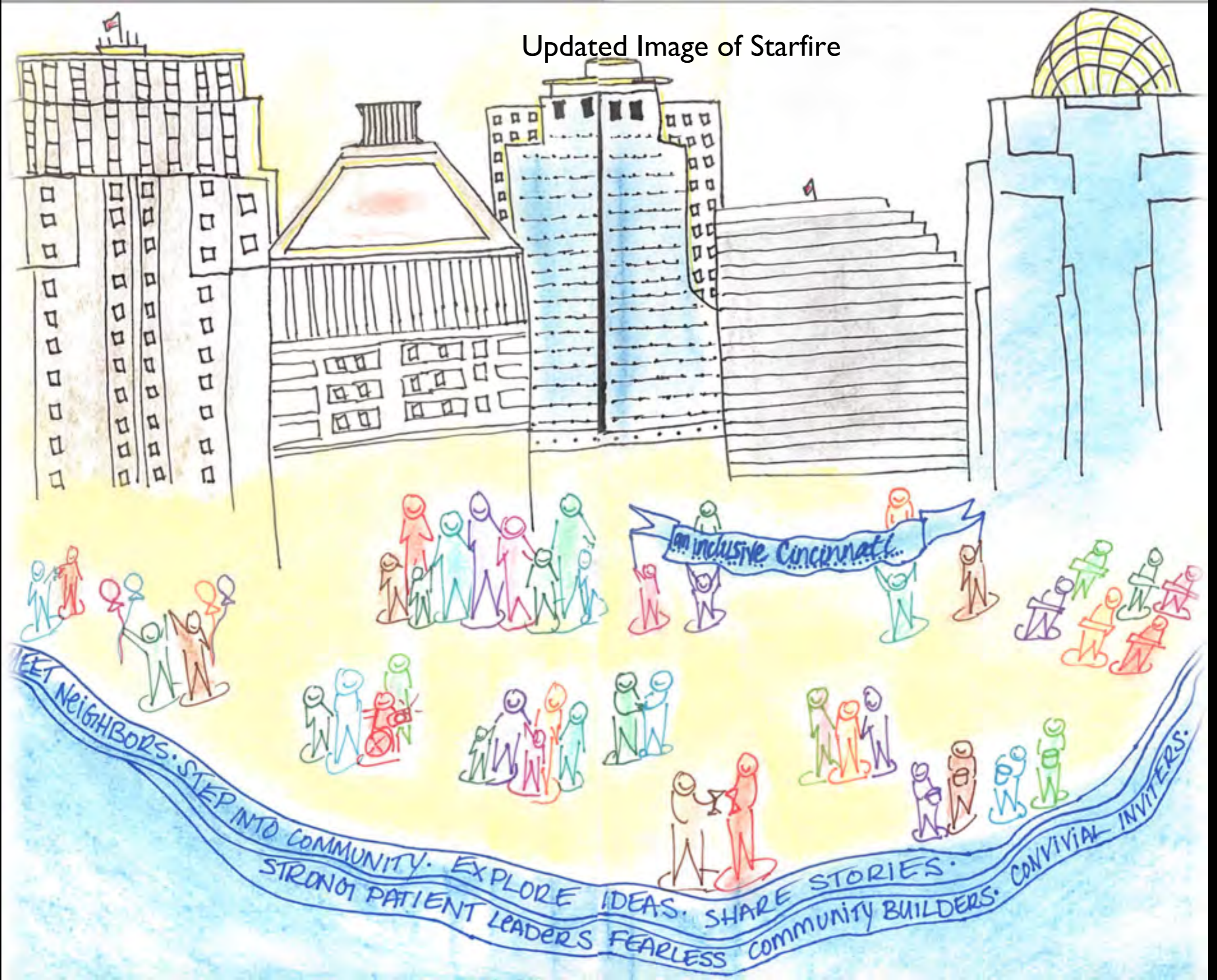
Peter Leidy's Outings song brought laughter & a shock of recognition.

The Outings Song



www.peterleidy.com

Updated Image of Starfire



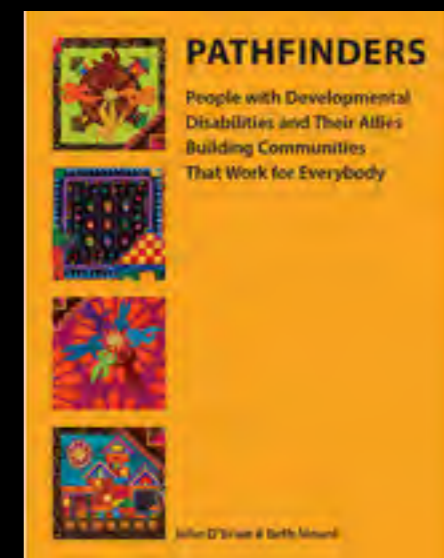
Without allies people with ID/DD are more vulnerable in any setting. People whose communication challenges others capacity to understand even more. People whose neurophysiological differences express themselves in ways that threaten others even more.

Without allies, the path to contributing community roles will be too steep for all but an exceptional few.

When people's connections to family & community have been severed, the foundation for new roles & relationships can only be supplied by those in actual contact with the person.

Direct Support Workers who have time & support to build trusting relationships are critical to people's participation. Sometimes they are called to offer people the foundation on which they can build a more diverse variety of roles & relationships.

Read *Ken Chose Me* by Gail Jacob in the Pathfinders book you got at the first session of CCW, pp. 145-147 for an account of alliance & the difference direct support relationships makes.





Celebration by Mari Evans

<http://poetree-house.tumblr.com/post/15726767590/celebration>