

# Valta virtaa



Valta virtaa -konferenssi  
osallisuudesta ja itsemääräämisestä  
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## Supporting Community Contribution and Self-Determination Through Person-Centered Work

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You can find links to the books my friends and I have written and free papers to download at [www.inclusion.com/jobrien.html](http://www.inclusion.com/jobrien.html). Inclusion Press books and DVDs can be ordered from England: [www.inclusiononline.co.uk](http://www.inclusiononline.co.uk). There are many free papers to download at The Center on Human Policy, Law and Disability Studies, <http://thechp.syr.edu/rsapublications/> and at The Centre for Welfare Reform [www.centreforwelfarereform.org/who-we-are/fellows/john-obrien.html](http://www.centreforwelfarereform.org/who-we-are/fellows/john-obrien.html). There are lots of other great resources at all of these sites.

Books of mine that I think are most connected to these talks:

John O'Brien and Carol Blessing, Editors. *Conversations on Citizenship and Person Centered Work*.  
[www.inclusion.com/bkcitizenship.html](http://www.inclusion.com/bkcitizenship.html)

John O'Brien and Beth Mount. *Make a Difference: A Guidebook for Person-Centered Direct Support*.  
[www.inclusion.com/bkmakeadifference.html](http://www.inclusion.com/bkmakeadifference.html)

How an organization is making the journey from services delivered to groups to individualized supports developed in partnership with people and their families (just off the press):

Hanns Meissner. *Creating Blue Space: Fostering Innovative Practices for People with Developmental Disabilities*.  
[www.inclusion.com/bkcreatingbluespace.html](http://www.inclusion.com/bkcreatingbluespace.html)

If you have an iBooks reader there are two free books to download from the iBook store:

Beth Mount. *Journey to the Beloved Community*. (Catalog for an exhibit at the of quilts telling stories of self-determination and contribution.)

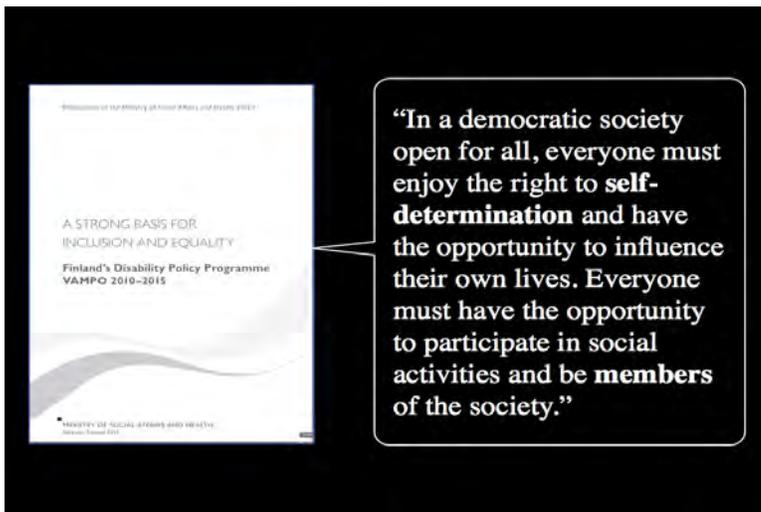
Heather Simmons and friends. *The Values of Inclusion*. (A video lecture on Heather's account of the real meaning of inclusion and commentary).

A preface about my way of proceeding.

Since the late 1960's I have learned from people with disabilities, their families and professional allies. Early in those years my learning was mostly local and personal, as part of organizations that sought to replace institutions with community settings. Later on, my learning has happened on a bigger geographic map. Regardless of where I am, almost all of my attention has been on people with intellectual and developmental disabilities in community life.

I am not a scientist and I no longer practice as a clinician. I try to be a learner. I assist people and organizations to reflect on their experiences, bring their ideals into focus, consider the future they want to be a part of creating, and think about how to get there. Sometimes this involves individual people, sometimes organizations, and sometimes systems of services. Often I have had the chance to continue my learning as a regular visitor and some of these relationships have lasted for many years. In doing my work, I collect stories from people who seem to me to be creating new possibilities in community life. I think about what I learn from listening to these people and to the people who oppose the changes that they are living (or at least remain unmoved by them). Sometimes I speak and write about what I have learned. Some people and their families and allies have kindly given permission for me to share a bit of their story and I am deeply grateful to them.

I know that the stories I have to tell and the ideas I have to share will not be new to you. People with intellectual and developmental disabilities and their families and allies are changing communities all over the world and I am sure that there are many rich stories among us. My hope is that I can provide a sense of connection between your struggle for more just and inclusive communities and what others are learning from their efforts toward a similar ideal.



As I read the English version, Finland's Disability Policy sets the highest standard for services to people with disabilities. Social participation and self-determination are a matter of right for everyone.

I want to share a little of what people in other places have learned about increasing the capacity to meet these standards for people with intellectual and developmental disabilities. No one that I know of has yet fully met these aspirations. What we have now are a variety of good tries and growing knowledge of what sometimes works and what sometimes does not. We are very far from a recipe for self-determination and inclusion. It can't be commanded or prescribed and controlled –we have not even agreed on what self-determination and membership mean in practice. The meaning of these vital concepts has to be created by people with the intention to discover what they can mean. They can't be delivered as a finished product: "much assembly required".



The UN Convention on the Rights of Person's with Disabilities reinforces the goals of Finland's disability policy in many ways. I want to focus today on how person-centered work enables two of the rights established by the convention: the right to employment in an inclusive labor market and the right to support for living included in the community.

I recognize that honest readers can interpret these rights in different ways. For example, some people would see a sheltered workshop as a legitimate setting in an inclusive labor market. I do not. I read these articles as calling for the radical change necessary to offer individual people with disabilities the real opportunity and required. personally tailored support to participate in ordinary community settings in valued social roles.

- ✓ The whole society is responsible for action to assure the rights to full participation & equality: cross-sector & throughout government
- ✓ Listen to the organized voices of people with disabilities (& families) whenever making decisions
- ✓ Carefully monitor life conditions of people with disabilities & adjust policy & practice as required
- ✓ Increase positive perceptions of the capabilities & contributions of people with disabilities




Finland's disability policy wisely aims at change across the whole society.

I think that people with intellectual and developmental disabilities, especially people who require substantial amounts of very competent support, are one good measure of the progress of these powerful strategies.

The more effective these strategies are, the more people with substantial disabilities we will meet as co-workers, as contributing members of our civic associations, and among our neighbors.

After the conference, I got this question by e-mail. ***Do you think every one can have a fulfilling job and get paid for it -no matter how much assistance they need?***

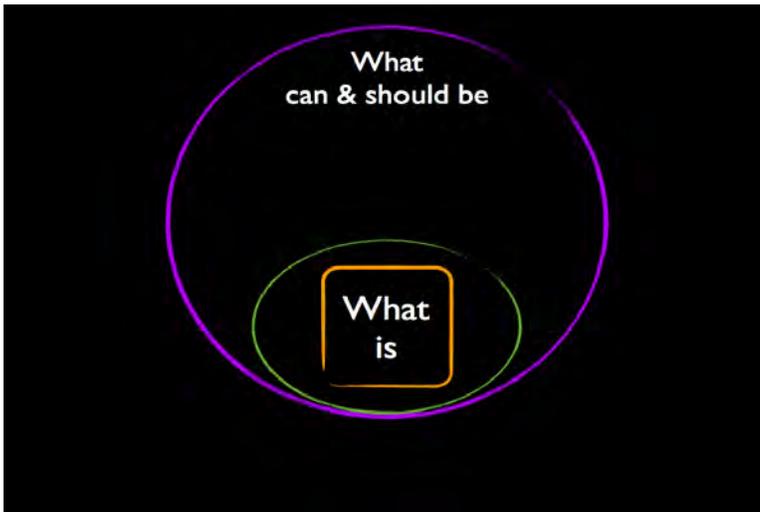
I am deeply convinced by what I have learned from people with profound and multiple disabilities and their families that every person has gifts of real benefit to those who will open themselves to receive them (and I reject the notion that some assert that there is anyone born who is not a human person).

How many people with intellectual disabilities will express some of their gifts and capacities through paid community work roles depends on how much we are willing to learn together. There is no way to know how many people could make good use of the opportunity to work, because our current system in the US is upside down and designed to assure unemployment.

Both our social security benefits and our intellectual disability service system are based on the false assumption that there is a very large group of people who are incapable of work or of work of comparable economic value to non-disabled workers. This mistake is compounded by a second myth: that it is possible to assess and predict who will be employable, who will be employable with training, who will only work under special conditions (sheltered workshops with an allowance not a paycheck), and who will never work. People with intellectual disabilities and their allies among employers and service workers have shown thousands of times that these "realities" are simply myths that justify unequal opportunities and unequal treatment, however benevolent.

I believe that we have enough good evidence to justify turning our existing system right side up and starting from the idea that we should adopt an "Employment First" policy. This means beginning from the idea that every person with an intellectual disability deserves an equal opportunity to work. That some might, for various reasons, not pursue this opportunity doesn't justify a policy that defaults to the exclusion of the majority of people with intellectual disabilities. For people who need highly individualized accommodations and highly competent assistance this means individualizing supports rather than tying people to day centers and workshops. Under these conditions, I am sure that there are some people for whom paid employment in a community job will not make sense for a variety of reasons. But I am equally sure that, beyond a very few people whose impairments severely limit their consciousness and volition, it is utterly impossible to predict who cannot work given competent individual support.

At present in the US there is a variation among service regions that ranges from less than 1% to a bit more than 75% of people who receive intellectual disability services employed for pay in individual community jobs. Overall employment rates explain only a moderate amount of this variation. For the whole US, about 20% of people funded for intellectual disability services are so employed. This range gives us plenty of room for growth because it shows that unemployment among people with intellectual disabilities a result of the way services are offered rather than any inherent limit associated with people's labels.



Making the rights to work and home real is a matter of working together to expand possibility. One lesson of my 46 years of learning about community life for people with intellectual and developmental disabilities is this: what is possible and positive, what could and should be for people and their communities (the purple circle), is always far bigger than what is currently happening and far bigger than we can imagine at any time (the green circle).

As those with the courage to imagine better join together and try new ways to live better, the boundaries of current practice grow and so does the green circle of imagination.

Imagining better means challenging our certainties and assumptions, holding a clear and deep belief in people with intellectual disabilities, and translating that belief into good, individualized person-centered support. Andre lives in a county that challenged two beliefs common when he was born, 35 years ago. An alliance of service workers, advocates and policy makers decided that it is completely unacceptable for children to grow up in institutions or group homes. To make this possible, they offered birth families intensive supports and, when for family reasons a child could not live with his or her birth family with support, they challenged the belief that families would not adopt children with profound and multiple disabilities. This gave Andre a family.

Andre's county has also believed that it is worth working hard to be sure that every adult with an intellectual disability has a real choice to work in a paid job in an ordinary community workplace that is meaningful to them and makes an economic contribution to their employer. They are not yet successful: about 25% of the 1,300 adults they serve continue to attend sheltered workshops or day centers and many people do not work as many hours as they want or at jobs that reflect their career choices.

Since 1995, Andre has had a personal budget that allows the level of individualization in his supports necessary for him to live as an equal citizen. Andre counts on his family and his circle to invest his personal budget in services tailored to him; because other's understanding of Andre's communication is limited to positive or negative reactions to his experiences, he also counts on those who know and love him to interpret and imagine what makes the most sense for him. If he were one of a group served through the block purchase of "places" in a group home or day center, he would be very unlikely to live with support in his accessible and ordinary home or work as he does.

It takes leaders with the courage and skill back their imagination of better by working through conflicts with those who strongly disagree and acting as social inventors in partnership with people with intellectual disabilities and their families.

## **A Statement in Support of Families and Their Children**

The following statement was developed by advocates and parents in 1986 at a meeting sponsored by the Center on Human Policy at Syracuse University, and still stands today as a clear assertion of the importance of family for children with disabilities.

These principles should guide public policy toward families of children with developmental disabilities and the actions of states and agencies when they become involved with families:

All children, regardless of disability, belong with families and need enduring relationships with adults. When states or agencies become involved with families, permanency planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults. As a guide to state and agency practice, permanency planning requires family support, encouragement of a family's relationship with the child, family reunification for children placed out of home, and pursuit of adoption for children when reunification is not possible.

Families should receive the supports necessary to maintain their children at home. Family support services must be based on the principle "whatever it takes." In short, family support services should be flexible, individualized, and designed to meet the diverse needs of families.

Family supports should build on existing social networks and natural sources of support. As a guiding principle, natural sources of support, including neighbors, extended families, friends, and community associations, should be preferred over agency programs and professional services. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.

Family supports should maximize the family's control over the services and supports they receive. Family support services must be based on the assumption that families, rather than states and agencies, are in the best position to determine their needs.

Family supports should support the entire family. Family support services should be defined broadly in terms of the needs of the entire family, including children with disabilities, parents, and siblings.

Family support services should encourage the integration of children with disabilities into the community. Family support services should be designed to maximize integration and participation in community life for children with disabilities.

When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family. Consistent with the philosophy of permanency planning, children should live with their families whenever possible. When, due to family crisis or other circumstances, children must leave their families, efforts should be directed at encouraging and enabling families to be reunited.

When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued. In fulfillment of each child's right to a stable family and an enduring relationship with one or more adults, adoption should be pursued for children whose ties with their families have been broken. Whenever possible, families should be involved in adoption planning and, in all cases, should be treated with sensitivity and respect. When adoption is pursued, the possibility of "open adoption," whereby families maintain involvement with a child, should be seriously considered.

While a preferred alternative to any group setting or out-of-home placement, foster care should only be pursued when children cannot live with their families or with adoptive families. After families and adoptive families, children should have the opportunity to live with foster families. Foster family care can provide children with a home atmosphere and warm relationships and is preferable to group settings and other placements. As a state or agency sponsored program, however, foster care seldom provides children the continuity and stability needed in their lives. While foster families may be called on to assist, support, and occasionally fill in for families, foster care is not likely to be an acceptable alternative to fulfilling each child's right to a stable home and enduring relationships.

Up-to-date information at [www.everychildtexas.org](http://www.everychildtexas.org)



Andre and his allies live out Ed Robert’s revolutionary definition of independence.

Ed was a co-founder of the Berkley Center for Independent Living, the first disabled person to lead a major state agency, and a life-long disability activist and theorist.

Learn more about Ed at <http://mn.gov/mnddc/ed-roberts/index.html>

Andre’s situation is by no means typical of people with multiple disabilities in the US. Most spend their lives at home with family or in specialized residential facilities and day centers.

Things are different for Andre because at every crossroads since his adoptive mother met him, she and his other allies have taken a person-centered approach to imagining better and acting to stretch the limits of what is. Often their actions have met opposition that could not be overcome. Often they have failed to accomplish what they wanted with their first or second or fifth effort. But at each decision point, they have never failed to ask the two most important person centered planning questions on Andre’s behalf.



Their answers are not certainties but best judgments in uncertain conditions.

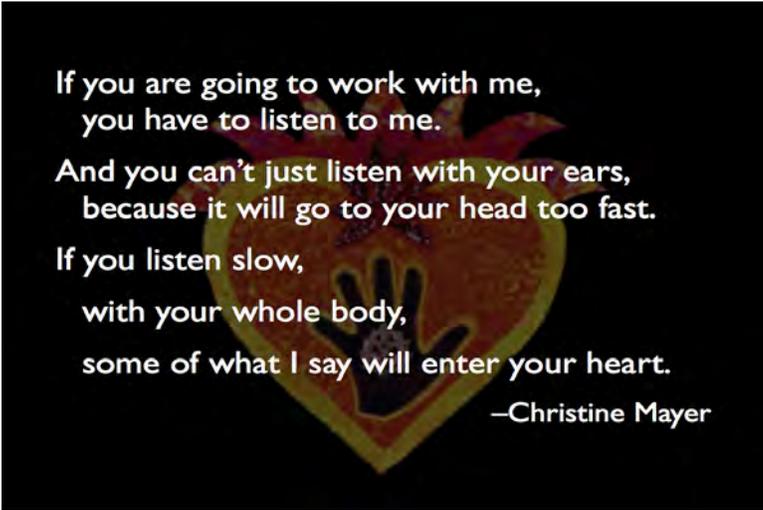
### **All good person-centered approaches...**

- ...strengthen the voice of the person & allies  
by offering a space for
  - ...respectful listening
  - ...thoughtful consideration of what is  
important
  - ...negotiating conflicts
  - ...committing to action
- ...lead to a better fit between the person &  
required supports

There are many different approaches to person-centered planning. Done well, all can contribute to self-direction and membership.

Because a good experience with person-centered approaches strengthens voice, the process can create a virtuous circle: as supports fit better and voice grows stronger the sense of possibility grows. When effective, the process is open-ended and its participants feel the excitement and anxiety that comes with discovery.

No person centered planning can be better than  
**the quality of listening**  
that people find in the process  
and  
**the creativity of the action**  
that people take based on what they hear



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.  
If you listen slow,  
with your whole body,  
some of what I say will enter your heart.

—Christine Mayer

Christine speaks from the experience of a life long journey toward recovery from damaging experiences. This was her advice, as an expert from experience on challenging behavior, to a group of professionals engaged in “managing” challenging behavior.

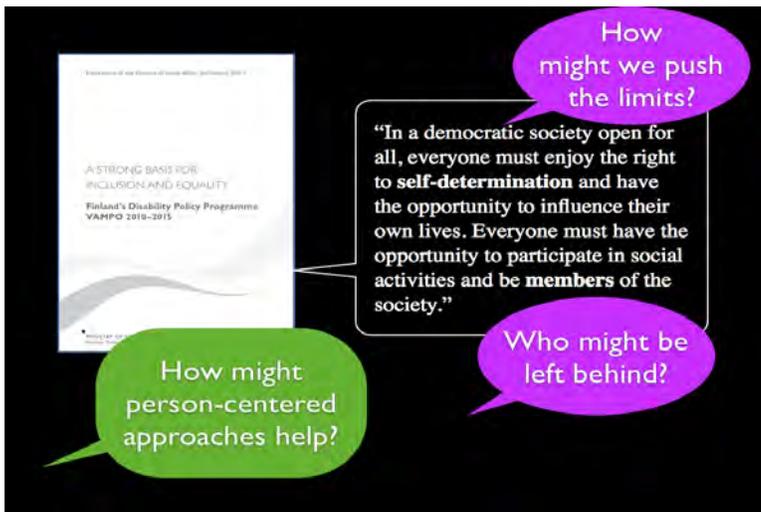
She makes it clear that the quality of listening and awareness that grounds her relationship with anyone who wants to be helpful to her is far more important than any technique or procedure or smart formulation of her problems.

Meeting the challenges of self-direction and membership means taking thoughtful action from our hearts. And listening deeply to those who have suffered exclusion and coercion and maintained the desire for a good life nonetheless can be painful for the listener. This kind of listening, and the action that flows from the relationship that deep listening creates, demands the most mindful consideration of personal and professional boundaries. Those who want to be of help need to be mindful and distinguish between respect for a suffering person's boundary and erecting a defensive perimeter around their own capacity to be moved by the person's experience. Person-centered planning can not be effectively facilitated by people who are afraid of their own emotions.

Listening as Christine advises leads to resilient relationships, but by no means to a cure. She and her allies live a truth: it is possible to be both a person with times of extreme challenging behavior and a person whose contributions give her a life that she has many reasons to value living.

Learn more about the organization that supports Christine and read more of her thoughts: [www.inclusion.com/bkcelebratingtheordinary.html](http://www.inclusion.com/bkcelebratingtheordinary.html)

For good ways to approach challenging behavior, see David Pitonyak's thinking at <http://dimagine.com/page5.html> Start with *10 things you can do to support a person with challenging behavior*.



The policy is right; the strategies make sense. The question is, how might person-centered approaches help?

An answer can be found by asking two more questions.

- Who might be left behind as most disabled people benefit from a more accessible, more accommodating society that is more willing to acknowledge and welcome their contributions?
- How can we push the limits of what is possible in the way of self-determination in people's living arrangements, work and opportunities for civic participation.



In the US, these are some of the people most likely to be last in line for employment in ordinary community workplaces and to be socially invisible in civic life, even if they are physically present.

People who choose not to challenge the boundaries of job or civic roles deserve respect. If they rely on services for assistance, person-centered planning can help create a platform from which people may come to imagine better.

How might we push the limits?

Create partnerships for social innovation with people who might be left behind  
Learn to work together in ways that disrupt power relationships & patterns of exclusion  
Act to discover capacities & gifts in contributing work, civic & home roles

To disrupt power over & social exclusion

**Join** people at risk of invisibility & their families & allies  
at the **edge** of possibility  
to create the **social inventions** necessary for our communities to benefit from their **contributions**.

The deficiency view of older people with mobility, sensory and cognitive impairments doesn't lead to much optimism about possibilities for a meaningful job.

Disrupting this constraint on an equal work opportunity for Jack –and others that were beyond the current competence of the service that supports him– meant intentionally going to the edge of possibility and joining Jack where he was most likely to be invisible: the workplace. It meant choosing to join Jack in exploring the possibilities in this question: “How might Jack show up in a meaningful job?”

The practices associated with Customized Employment, a person-centered approach to creating individualized community job roles for people who are failed by typical employment supports, gave Jack and his team a set of practices that refined the question. “Where can Jack’s capacities meet an employer’s need and result in a job role that is meaningful for Jack and economically beneficial to his employer?”

This has led Jack to a new source of satisfaction and contribution, “Putting love into cats.”

An extended, systematic period of discovery.

A detailed account of interests & competencies.

A search for employers willing to negotiate guided by discovery.

A negotiated job that is meaningful to the person & economically beneficial to the employer.



Learn about Customized Employment at [www.marcgold.com/Publications/whitepapers.html](http://www.marcgold.com/Publications/whitepapers.html)

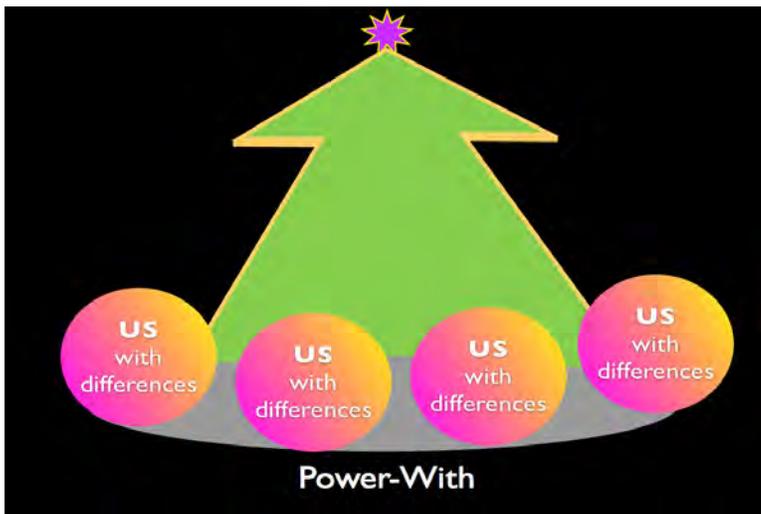


In North America, this is the default relationship between people with intellectual and developmental disabilities and those who assist them. This unequal relationship is founded on the power to define deficiencies and enforce limits on opportunity and self-determination based on those attributed deficiencies. What a person is presumed to lack—especially what they are assumed to lack in the way of judgment—creates a story that justifies the exercise of power-over that person. Sometimes it is a story of paternalism. US, the staff, have control THEM, the people with disabilities, for their own good. Without US telling THEM what to do they will degenerate into ill health or unhappiness. Sometimes it is a paranoid story: unless US exert supervision and control others will be hurt or inconvenienced by THEM. In both stories there is a clear line between US, who must exercise power, and THEM, the objects of power-over.

Professionals draw this bright line by the conventions that fix labels and prescribe a regimen for the management of the identified conditions. Regulation and custom assign staff complete responsibility for the health and safety of those assigned to their care. Because the fact is that people with intellectual disabilities do count on others for needed assistance and because that assistance is often attached to settings and practices that take control of living conditions, most people submit and it is not uncommon for people and family members to internalize a deficiency perspective of themselves. Those who don't learn helplessness and submission earn extra labels and levels of control as non-compliant or mentally disordered.

It is very hard for people who are stuck in a power-over system to make the best of opportunities for self-determination. Their horizons of possibility are often set by the boundaries of the power-over system, or at least the limits of what they dare to share with those who control their life circumstances. Even people who can direct a personal budget typically buy more of the kinds of service that keeps them at the margins of their community in roles that limit their contributions and subject them to power-over relationships than compromise their equality with other citizens.

Political scientist Karl Deutsch observed "Power is the ability not to have to learn anything." When organizations attempt person-centered approaches without a commitment to learning to change through partnership for social invention, power-over usually prevails.



Person-centered approaches are most effective when they break out of power over relationships and generate power-with in a circle of allies. Power-with does not deny differences in ability or needs for assistance. Differences allow people to work together as equals and accomplish more than they could alone. People are brought together by free choice because they find meaning in inventing new ways of seeking a common vision.

Escaping the power-over trap often involves finding new ways to understand the effects of people's impairments on their lives. The disabled people's movement gave the world a great gift by identifying disability as a social production rather than a pure and simple medical condition.

The voice and the work of family members are critical in creating power-with and expanding what is possible. Pat joined her son Dan's fascination with chemical storage tanks. Where professionals saw a symptom of autism to be extinguished, they found a golden thread that has led to a productive job. She describes this:

The formation of, and often intense emotional investment in, unusual categories of things by people on the spectrum might also be explicable as a tendency of this developmental difference to support a wide variety of unusual, creative associations (including complex algorithms for calculating and recalling them). Referred to as "preferred interests" or "passions," and sometimes rising to the level of "savant skills," they can be a motivating force that powers development if approached respectfully. Even an enthusiasm which at first glance seems narrow can ultimately be linked to a potentially limitless array of other topics. From the time he was a toddler, my oldest son [Daniel] was fascinated with big industrial storage tanks. While this was not a category of object that appealed to most children, he experienced them as awe-inspiring. We took trips to admire storage tanks the way others travel to view the Pyramids. Examining them visually may have served an exploratory function similar to the play with buckets and boxes through which his age peers developed the concept of containment (Lakoff and Johnson, 1980, pp.30–32), but on a more heroic scale. We engaged with him around this interest, eventually introducing him to laboratory beakers, which were "like objects" that also stored chemicals in rounded containers. When, in adolescence, he made the leap from beakers to an interest in test tubes, we began to glimpse a career; as an adult, he is now employed as a phlebotomy technician, enthusiastically filling test tubes at a local hospital. *Frontiers in Integrative Neuroscience*, April 2013. [www.frontiersin.org/Journal/Abstract.aspx?ART\\_DOI=10.3389/fnint.2013.00027&name=integrative\\_neuroscience](http://www.frontiersin.org/Journal/Abstract.aspx?ART_DOI=10.3389/fnint.2013.00027&name=integrative_neuroscience)



**A diagnosis is a way of not seeing; don't be trapped.**

**Prediction is unreliable.**

**Consider people's interests for golden threads of self-direction.**

**A person-centered approach may need to direct attention & real world tries for years.**

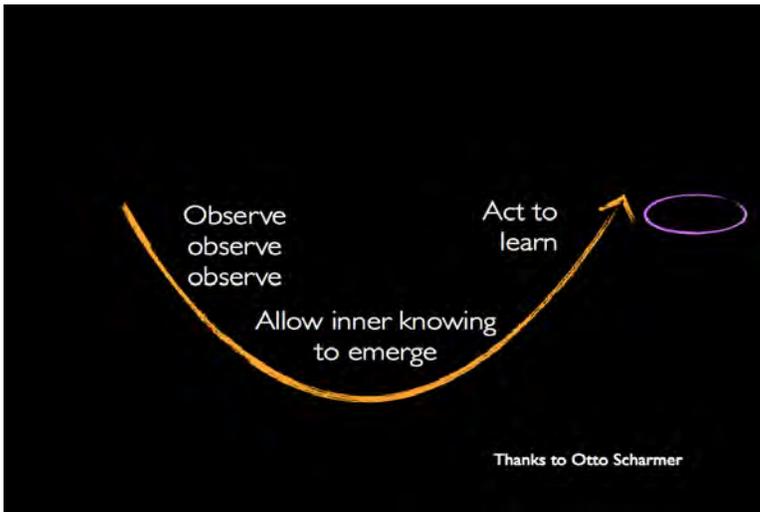
There are many lessons in this small fragment of Pat and Dan's story. Here are four.

A diagnosis is useful when it directs attention to helpful measures we can take. We ask it to do too much work when we ask it to point to a cure or tell the whole story of what is possible for a person.

Diagnosis and prognosis seem to go together. But no one, not even Dan or Pat, could predict Dan's job from his label (initially "severe infantile autism and severe mental retardation"). The shape of people's impairments is powerfully influenced by responsive relationships, flexible and imaginative supports and willingness to risk a search for community opportunities.

Dan's access to work that is meaningful for him and useful to his community depends on his parent's willingness to de-construct "autism" and try on alternative ways to appreciate what looked like symptoms. Joining him in his close study of storage tanks turns his effort at connection to objects into a medium for connection to family.

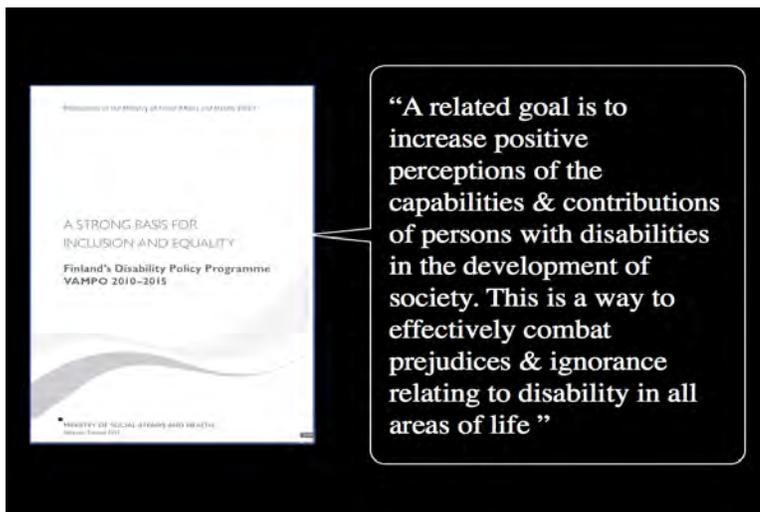
Some people confuse person-centered approaches with meetings that produce documents. Meetings provide occasions to gather, celebrate what has been learned and think about next steps. If meetings don't lead to trying new things they are little use. Discovering good enough answers to the basic questions –what are this person's gifts and how can our community receive them– can take years.



The process of social invention that opens the ways to community contribution can be mapped like this:

- A group of equal partners, composed of people who cross usual boundaries, choose to expand what is possible and step outside their usual patterns of relationship and practice. They work at acting from power-with.
- They try multiple new ways to observe different dimensions of the person, the community and the field. Their search is for knowledge at the edge of possibility.
- They create a space in which they can get a sense of the new that wants to come into being. This calls from just the other side of the current edge.
- They act, with whatever resources they can mobilize in the moment, to learn a new way. Action from the new generates information that allows learning through multiple cycles of trying > reflecting > revising.
- They bring what they have learned to the rest of the organization and find ways to sustain and strengthen the new ways.

Otto Scharmer and his colleagues are developing ways to understand and facilitate this kind of change with their work on Theory U. Learn more at [www.presencing.com](http://www.presencing.com)



For me the most effective way by far to increase positive perceptions is through personal experience, participating with people who have taken contributing social roles. In North America, this is especially important for people who require highly individualized accommodation and assistance, because so many people still see them as incapable of contribution and requiring state provided, paternalistically controlling services apart from community life. Indeed even some families and people themselves wonder if they have anything to contribute that anyone in their community would value.

Those who have experienced the band, *Pertti Kurikan Nimipäivät*, with their fans have felt the truth that there is no substitute for direct participation with diverse others who share a passion. The reflections on the band's becoming visible offered by Sami Helle and Teuvo Merkkiniemi provide important lessons for any effort to disrupt public views of people with disabilities.

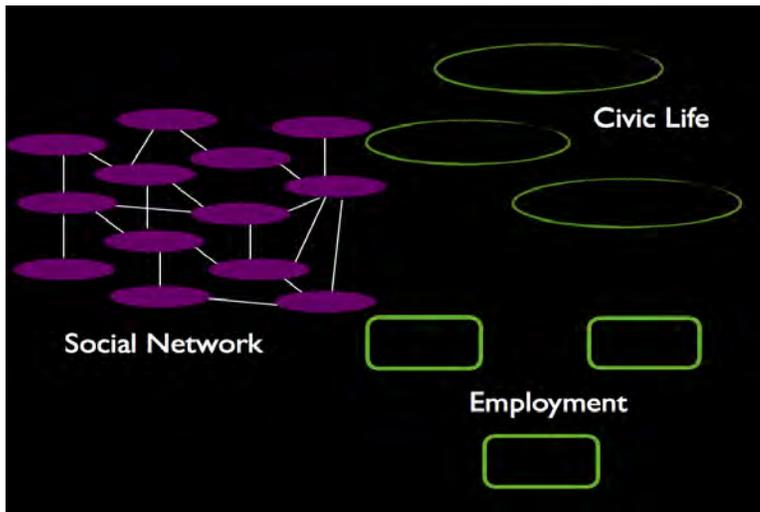
Think about acting on what matters to you as making art in your life  
 Find a scene that fits with your passions & capacities & find your framework for participation in that scene  
 Let your emotions move your actions: bad feelings can be a source of energy (if you hate parliament, make a song of it)  
 Let things be unpolished & unfinished: take a risk  
 Try things out & expand your expression  
 Success and failure happen; feel good about either  
 Listen to new people from different walks of life (journalists, artists, etc).



Thanks, Sami & Teuvo!

We often make the mistake of “getting people ready” for an abstract idea of community life, checking their appearance and behavior against a code of generic social skills. Valued (and paid) roles in the European punk scene meet different expectations than those typically taught in “Life Skills” classes. This principle highlights the difference between the framework for success as a McDonald’s worker and the framework for creativity as a punk rocker.

English speakers can learn more at [www.centreforwelfareform.org/library/by-az/lyhty-finnish-punk-rock-and-much-more.html](http://www.centreforwelfareform.org/library/by-az/lyhty-finnish-punk-rock-and-much-more.html)



There are at least three kinds of social settings in which people with intellectual and developmental disabilities can make their competence and contribution visible.

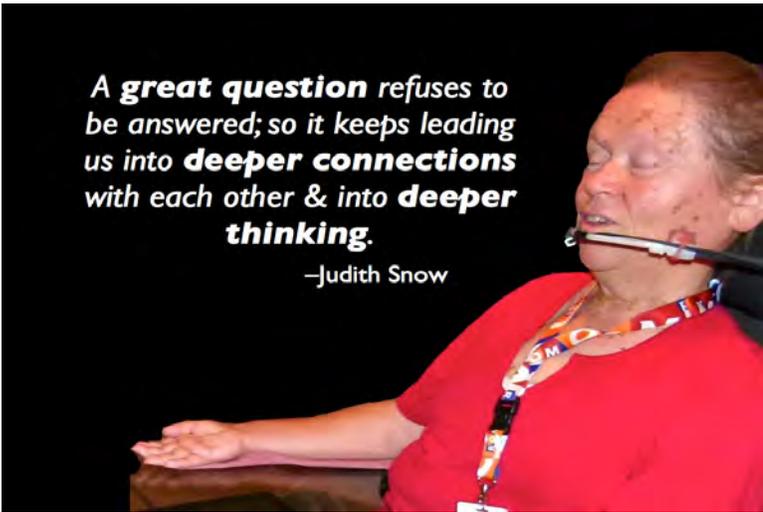
People can be employed in one of a great variety of ordinary workplaces, alongside non-disabled co-workers with the accommodation and assistance necessary for them to be successful. They can fill ordinary jobs or customized jobs.

They can participate in civic life as members of the many groups and associations, formal and informal, who come together because they care about something enough to take action. The range of associations is wide, as people come together for sport, for festival and celebration, for learning, for worship, to improve their health, to promote a cause by acting together, and simply out of shared interest in some topic or activity.

For the practical application of **Assets Based Community Development in civic life:**

[www.inclusion.com/bkwhenpeople.html](http://www.inclusion.com/bkwhenpeople.html)

People can be an active member of a social network: offering a ride, visiting others, loaning a tool, exchanging stories, exchanging small favors, being a good neighbor, celebrating a co-workers birthday, sharing a meal, exchanging gossip and other information of value to another person. Social networks are an important source of practical help and social support. They build the personal connections and trust that strengthens community. Most of the actions that strengthen a social network don't take much money or sophisticated planning, just mindfulness and a practical sense of compassion, fun and hospitality.



[www.judithsnow.org](http://www.judithsnow.org)

My friend Judith is a strong voice for the social inclusion of people with intellectual and developmental disabilities. She is an especially powerful and thoughtful ally for people whose communication other people find it difficult or impossible to understand.

One source of her passion for inclusion is her own life experience. With her circle's assistance, Judith became the first person in Canada to control an individual budget and organize and manage her own support. Read the story of the early days of Judith's circle of support and some of Judith's thoughts on person-centered planning [www.inclusion.com/bkfrombehindthepiano.html](http://www.inclusion.com/bkfrombehindthepiano.html) . Read the first volume of her autobiography and see some of the paintings from her recent art exhibit at The Royal Ontario Museum (and learn how she paints) in *Who's Drawing the Lines?* [www.inclusion.com/bkdrawingthelines.html](http://www.inclusion.com/bkdrawingthelines.html)

Her pioneering work applying self-determination in her own life allows her to work with people who are vulnerable to exclusion and their allies to live good included lives, resilient to all the difficulties, disappointments and defeats that come with that quest. She thinks, teaches and writes about inclusion.

One of Judith's insights is that inclusion -whether at work or in civic life- is not a problem to be solved but a great question to be lived in company with others. The knowledge we need will come from deeper connections with more and more people who are more and more different from one another. There is no final answer. A great question refuses to be answered so we can't pretend we have ever fully grasped the possibilities for inclusion.



With this perspective on inclusion, Judith gives us at least 4 things to think about...

...inclusion is not something done for people with disabilities just for their benefit, it is done with people with disabilities as part of the work of building a more healthy community; it is a work of citizenship

...all people have gifts and there are others who need those gifts

...we are responsible to actively develop our gifts

...our gifts are found in our differences



Chris is a pioneer of inclusion. who has recently completed a University sponsored program that gives people with intellectual and developmental disabilities access to University life without offering them a degree. His definition of inclusion is based on his life experience until now. Working with others to make a positive difference to his community is an important source of meaning and happiness for him. Like more and more of his generation, Chris and his family expect the individualized supports they need to hold a job, take part in community life and live in their own home in a way that they choose. Group homes and sheltered workshops are no part of Chris's ideas about his future.

Judith and Chris's understanding of inclusion resonates strongly with work in Finland presented at **Valta virtaa**. Research conducted by Demos Helsinki and reported by Aleksi Neuvonen makes it clear that, for more and more citizens in Finland a sense of community is not a given but something that requires intention. The work of creating a new us is not a disability issue, it is a cultural demand. As people with intellectual disability share, learn with and become important to their fellow citizens the new us will be diverse and accommodating of difference.



Unless people with intellectual disabilities are actively involved as responsible contributors and learners, the new us demanded by collective adaption will be as exclusionary as the old us has been because people will not have become important to one another regardless of the presence of impairments.

**Build in self-direction & community contribution from the ground up**

**Create ways to bring diverse people together in collaborative design**

**Those who will inhabit the place**

**“Outsiders” who contribute (don’t assume incompetence)**

**Ask, “How do we want to live in this place?”**

**Ask “What does this neighborhood need & what can we do about those things?”**

Thanks, Susanna!



From the point of view of community participation this question is priceless. From before the first shovel of earth turns, people explore the surroundings and ask what can we do to make a positive difference in this place. This is a world away from simply making a list for someone else to do and delegating away responsibility for doing what we can.

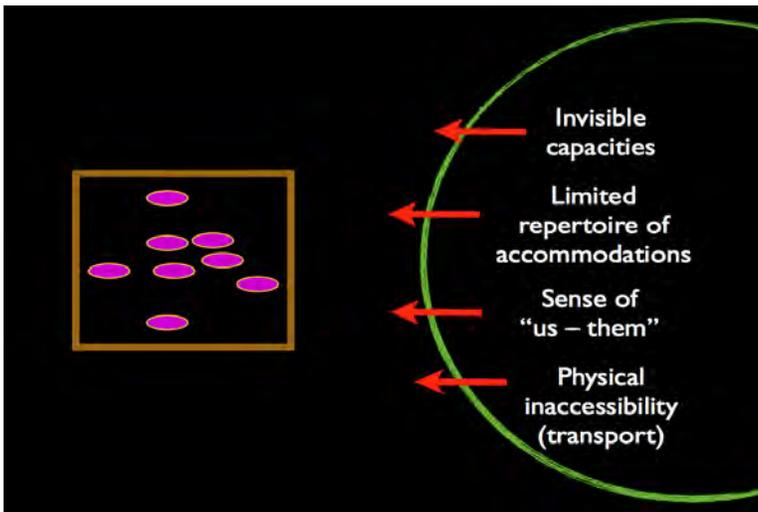
The approach to collaborative housing design developed by Susanna Hintsala and her colleagues not only embodies the value of self-determination by including the people who will live in new housing as co-designers from the earliest stages of development, it builds contribution into the foundation by asking, “What needs doing in this neighborhood and what can we do about it?”

To connect with a US organization committed to inclusive housing options chosen by those who will inhabit them: [www.movin-out.org/about.html](http://www.movin-out.org/about.html)

**Media for all  
Born of social need  
Creating voice  
Act equality by producing together**

<http://meka.tv/english/>

The story of MEKA-TV, told by Piia Helminen and Ari Impola holds important lessons. Contribution is born when a deep social need attracts people who want to develop their skills to a high standard. The desire of people with intellectual disabilities to be proficient in using TV to create voice for themselves has led them to offer the experience of producing stories that matter to children, young people and seniors. They have created a way of producing TV together that allows them to act as equals. This collaborative organization of work around complementary skills contrasts in a positive way with the more usual staff role of directing and teaching from a position that demands deference.



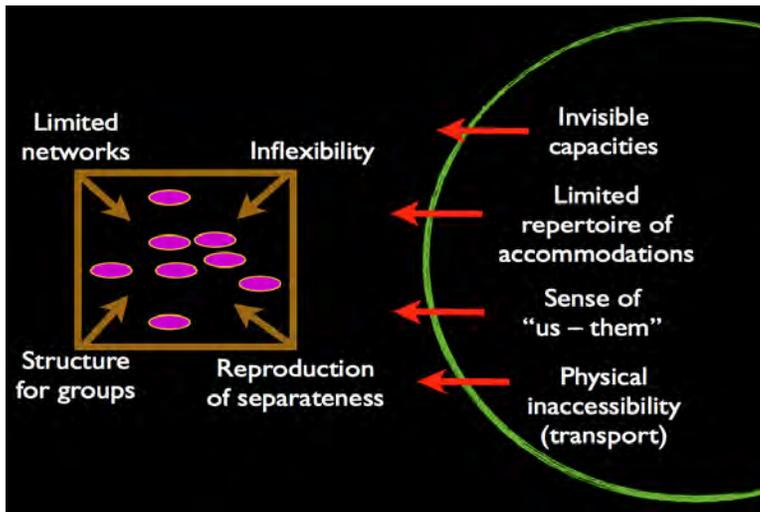
In North America, most people with intellectual and developmental disabilities who want to join Chris in doing things with other citizens to make their community better for everyone have figure out how to cross two boundaries.

The green boundary defines community opportunities for ordinary employment and association. It is the space of membership and community participation. Those inside it belong and have options to choose participation; those outside it may be visitors, but they belong somewhere else.

The brown boundary defines clienthood. It is a social space managed by rules and professional traditions. Its formal structure separates clients—who are present because of some officially documented deficiency— from staff—who have responsibility for rehabilitating clients and keeping them safe and healthy. It’s informal structure is often a web of friendships and rivalries that meets most people’s social needs.

The community boundary is protected and can push people who try to cross it back to its outside edge. Each of these potential breakdowns provide a point at which mindful attention can lead to important learning. This kind of learning takes courage because boundary crossings are anxious places for many people.

- Many places are inaccessible. Even if wheelchair users can get around a setting, transport difficulties limit access for them and for people who can navigate stairs. Literacy barriers and a poor welcome can keep people out.
- A sense of “us and them” is common and sometimes spoken aloud “Aren’t they better off with their own kind... with others like them?” “The state or charity provides special places and activities for them, surely that’s where they should be.” Sometimes feelings of discomfort or even disgust come up, though they may not be spoken aloud.
- People may feel inadequate or uncomfortable in accommodating a person’s impairments. “We wouldn’t know how to talk to someone like that.” “We aren’t trained to deal with people like that.” “You staff people are so good (or so patient) with them, they need to be with you.”
- The capacities a person with an intellectual or developmental disability can bring may be invisible, hidden by the assumption of incompetence.

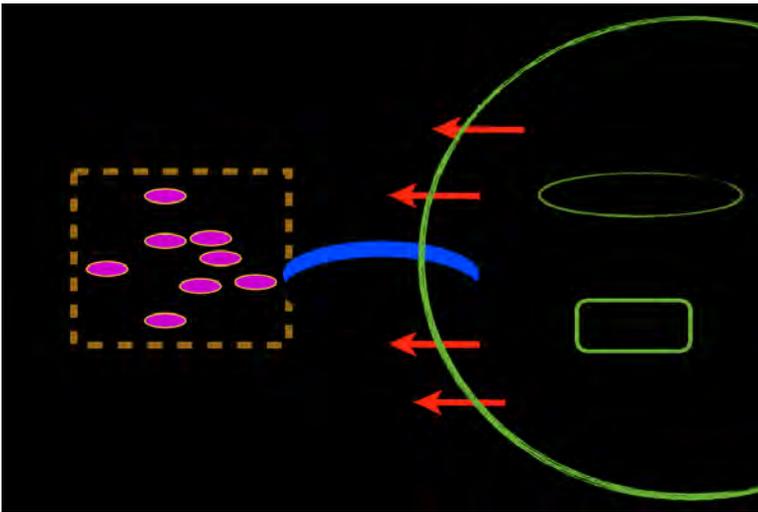


The boundary around service settings can create a social island. People have local addresses for their residence and occupation but very little active connection with other citizens. Unless there is a will to loosen these constraints, at least for a few inclusion pioneers, there will be little progress toward personal inclusion.\*

- This boundary grows stronger when a service is structured to congregate and manage people as clients in groups formed by professional judgment.
- Routines and staffing patterns often limit the flexibility required to assist someone to discover and pursue an individual interest in company with other citizens inside the green boundary.
- Service organizations and their workers may not have a wide enough range of local connections to know where the opportunities for participation are.
- Services can reproduce separateness. For example, organizations I have learned from have become aware of ways that people get a message that community settings are somehow dangerous and people are safer within service boundaries. They have noticed practices that reinforce the idea that people with intellectual and developmental disabilities should look to their service provider to meet every social need. In reflection, they have noticed that none of their person-centered plans require crossing the boundary into community in any other role than being a visitor, a spectator or a consumer.

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\* This diagram leaves out the many people with intellectual disabilities who live with their families and do not use day services. Some of them will be found living their lives within the community boundaries as part of their family's life or through their own efforts to belong and contribute.. Unfortunately, others live in more marginal roles and are at risk of exclusion and even of isolation within families who lack good support and must devote much of their energy to their family member with a disability.



People with intellectual disabilities and committed staff-often make social islands at the edge of communities a good place to be. The question is, how can the strength and confidence that people gather on that social island energize efforts to identify people's gifts and develop bridges to the workplaces, associations and networks of the larger community's life?

This means purposefully opening the boundaries of services and partnering with people with intellectual and developmental disabilities to be the social inventors of bridges to contributing roles in community life.

Inventing bridges to community participation and employment is a process that is served by person-centered planning. At least 6 things are involved in a successful boundary crossing.

- A good sense of your capacities, gifts & available resources
- Realization that your gifts are needed by people you don't know yet
- The confidence that comes when those who know you are behind you
- A good idea of the access, accommodations & assistance that make you successful
- Expanding your local knowledge of places your gifts could be welcome
- Contacts on the inside who can extend an invitation & a welcome

**“...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

A short excursion to briefly summarize the conclusions of two researchers who have much of importance to say about building community by intentionally crossing boundaries.

Robert Putnam has spent a long and distinguished career exploring the effects of social connectedness. This phrase sums up his research: “the well connected are more likely to be hired, housed, healthy, and happy.”

It’s important to note that this is not only because of direct effects on individuals. Communities with higher levels of ties and connections and more diverse associations, and the higher levels of trust that those connections promote, are more economically productive, safer, and healthier. The more differences these ties and connections bridge in a community, the stronger the effect. This leads to the challenge to create a new and “bigger we” (Putnam’s name for Demos’ “new us”).

For more: [www.hks.harvard.edu/programs/saguaro/](http://www.hks.harvard.edu/programs/saguaro/)

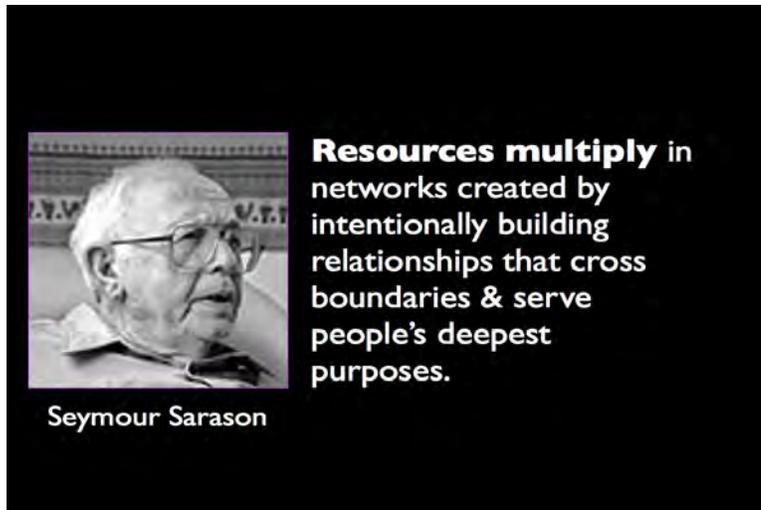
**What people who build community do is understand & emphasize the importance of relationships & personal connections to achieving their objectives.**

As a practical matter building community means intentionally crossing boundaries and making new connections while working toward worthwhile objectives.

In the past, a good day center aimed to support personal development. But it typically pursued all of its objectives among those people available in the organization: people with disabilities, staff, family members, volunteers. People needed education; the center provided classrooms and workbooks and easy read books. People needed jobs; the center provided a big room filled with “pre-vocational tasks” and, when people were judged ready and work was available, a chance to do some piece work, perhaps unpaid packaging for a charitable organization maybe for a small amount of pay. People needed a social life; the day center provided parties and dances (often

during the center's regular hours). People needed contact with the community; the center staff took groups of clients on outings for community activities. People needed opportunities to make their views known; the center provided a member's council and current events discussion groups.

The design of the center –which, like fish in water, those within took for granted as “just the way things are”– made it hard for people with intellectual disabilities to shift the perceptions and attitudes of community members because community members had so few opportunities to get to know them as individuals with capacities and gifts. When individual identities are submerged inside a socially devalued group label, its easy to react to stereotypes of the group. The “Not in My Back Yard” response that a few citizens in Finland are showing is safer to direct at a facility for a cluster of unknown people than to one or two people taking their place in typical housing.



The great psychologist Seymour Sarason was deeply interested in how communities grow resilient and support their citizens to live good lives. The sentence on the slide sums up many years of investigation. Seymour notes the link between deep purpose and intentional boundary crossing.

For references: [www.seymoursarason.com/4.html](http://www.seymoursarason.com/4.html)

Few people can recite a statement of deep purpose without multiple chances for reflection. And many people with intellectual and developmental disabilities have spent much of their lives in settings that assumed that their purpose in life was to cooperate with professional efforts to cure them, amuse them, or get them ready for life. These efforts very seldom succeeded. Except for people who were excluded as “unmanageable” and referred to a more restrictive service, almost no one who needed very much help moved on from day centers and group homes to a better opportunities for self-direction and contribution.

So deep purpose is not on the tip of people's tongue. It is discovered by listening and looking with an open mind, an open heart and an open will for hints of what someone may care enough about to risk crossing the boundaries out of services and into community. Taking time out every once in a while to consider purposes, interest, concerns, capacities and gifts –as we do in person-centered planning– can help people find or return to the trail. Resources multiply when that trail crosses social boundaries and creates a “bigger we”.

Only a few of those hints will show up when people just sit and talk. Sometimes, the most important step in revealing interests is get into action quickly by taking learning personal journeys to places of local hope. Seeking out, meeting and conversing with those people who care enough to act together on something that matters to them builds connections and living breathing links to what a community cares about enough to act. It can also give people ideas. Sometimes a person doesn't know that something interests them until they meet another per-



Find a story of Rita at Tiny Cup:  
[www.youtube.com/watch?v=evJU6nVCmI4](http://www.youtube.com/watch?v=evJU6nVCmI4)

son who is an enthusiast. There is almost always a lot to talk about when people return from a learning journey into their own community.

Some people discover that they need to shift their attention. A power-over system leads us to see people as in need of others' charity or service. We don't think in terms of people with intellectual disabilities exercising the responsibilities of active citizens, we think of what they can get rather than what they can give. We issue a pass that exempts them from positive expectations of active citizenship. We can also get caught in an activity mindset, looking for things to do that will fill people's schedules and be pleasant experiences for them. Poverty means searching for things that are free, cheap or charitable (think of groups of free tickets for a circus matinee distributed to day centers). The most common roles available when we act from a charity/activity frame are those of visitor, spectator and (impoverished) consumer.

If activities have been on our mind we need to shift our attention to membership. There can be hard things associated with membership: difficult or tiring work, the real possibility of failure, conflicts and hurt feelings all go along with belonging to a work place or a community association. And so does satisfaction and a sense of meaning.



Rev. Jim Lawson

The beloved community is not a utopia, but a place where the barriers between people gradually come down & where the citizens make a constant effort to address even the most difficult problems of ordinary people. It is above all else an idealistic community.

For a story of the way a man with substantial disabilities mobilized the impulse to the beloved community in Savannah, Georgia read *Waddie Welcome and the Beloved Community*  
[www.inclusion.com/bkwaddiewelcome.html](http://www.inclusion.com/bkwaddiewelcome.html)

Reverend Jim Lawson is the person Martin Luther King charged with bringing the principles and practices of non-violent social change to the civil rights movement. A statement he made captures the purpose that makes this work meaningful to me.

Both Dr King and Rev. Lawson founded and sustained their action for justice in a vision of the beloved community. Rev. Lawson defines the beloved community in the words above.

Some of the problems of ordinary people are made worse by the social fractures that leave people with intellectual and developmental disabilities outside the boundaries of community, under paternalistic supervision. Those with the courage to hold to the ideal of inclusion and recognize the difficulty of bringing down barriers but still make a constant effort to outwit the forces of exclusion can play a part in building the beloved community.

May those who feel drawn to the continuing struggle toward the beloved community find strength in our gathering to think together in Tampere.