

Encouraging Social Innovation

A Learning Institute Inquiry



The organizational Learning Institute **Encouraging innovation** met from 9 April to 28 May with a follow up session on 2 July 2024.

Representatives of ten social innovation initiatives participated:

Three of these initiatives are engaging with an organizational Learning Institute for the first time. The rest have been represented in a number of Learning Institutes, some since the first in 2009.

Some initiatives are underway, others are taking shape. All are next steps toward person-centered support for community life that are situated in particular organizations and communities.

- A1 Service Coordination
- The Art of Advocacy
- Centro de Amigos
- Community Mainstreaming
- East End
- Goodwill
- Job Path
- OPWDD Peer Specialists
- People, Inc
- Uniting Disabled Individuals

Beth Mount, John O'Brien, and Chris Liuzzo facilitated four group sessions on Zoom, conducted individual dialogue interviews with each organization, and supported planning and production of some social innovation stories. John O'Brien compiled this record.

Encouraging Innovation is one of a series of learning opportunities offered by The New York Alliance for Inclusion and Innovation as part of the New York Department of Health Person-Centered Planning Statewide Training Initiative, administered by PCG, Public Consulting Group. Find more about the Training Initiative [here](#).

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Quotations in *italics* are selected and edited from notes and recordings made with participants permission.

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Our perspective

By its policy of assuring full access to the benefits of community living, the [HCBS Settings Rule](#) encourages social innovation—the discovery of new ways to support new engagements in ordinary relationships, roles and community places. As they co-create paths to more diverse relationships and roles, people and their allies match their gifts and interests to community opportunities for contribution as workers, good neighbors, and active citizens. To offer good support, organizations transform services designed to manage groups into individualized supports and administrative authorities adopt practical ways to co-create the conditions for person-centered work.

Social innovators embrace [What more is possible?](#) as a generative question, a question that draws collective attention to the next step toward a more inclusive community. This question asks more of those who receive support, of those who provide support, and of community. Social innovation mixes working out practices, policies, and structures that tailor support to individual circumstances with the inner work of testing and revising the thinking and habits that promote social exclusion and diminish freedom and agency.

We are convinced that no law, policy or procedure can offer the benefits of community life unless it is enacted with moral imagination in a strong social field, that is, a diverse and growing web of relationships that enables the discovery and exchange of gifts and the extension of choice.

We want to offer social innovators the opportunity to invest time in reflection and renewal in company with others who share a commitment to increase the capacity for person-centered work in organizations funded by New York State's Home and Community Based Services system.

We will invite exploration of current opportunities for social innovation through multiple practices.

- Dialogue interviews with organizational teams with summary notes and reflections.
- Co-creating and sharing images of the landscape for innovation.
- Journaling
- Trying different ways to share stories of innovation and generating insights into creating change.
- Working toward the co-creation of artifacts that will inform others about what more is possible.

In addition to encouraging the participating social innovators we sought other benefits, including these.

- Better grounding our own understanding of current issues in implementing the HCBS Settings rule.
- Producing material for introductory Learning Institutes.
- Informing the upcoming Learning Institute for Policy Makers and other efforts to transform supports.

See [Transformation](#) a 7 minute video by John O'Brien & Christopher Liuzzo.

Our intention

As we moved from invitation to meeting the actual participants we adapted our intention. This is the final, retrospective version.

Encouraging Social Innovation

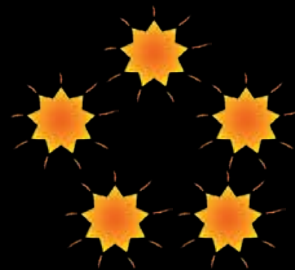
9 April—28 May 2024



I
Reflect
Dialogue Interviews
9-19 April



II
Make sense
Co-sensing
30 April, 14 May



III
Co-create
30 April—28 May



IV
Bridge
28 May

0.1

It has become a common feeling, I believe, as we have watched our heroes falling over the years, that our own small stone of activism, which might not seem to measure up to the rugged boulders of heroism we have so admired, is a paltry offering toward the building of an edifice of hope. Many who believe this choose to withhold their offerings out of shame.

This is the tragedy of our world.

For we can do nothing substantial toward changing our course on the planet, a destructive one, without rousing ourselves, individual by individual, and bringing our small, imperfect stones to the pile.

In this regard, I have a story to tell.

—Alice Walker

Anything we love can be saved



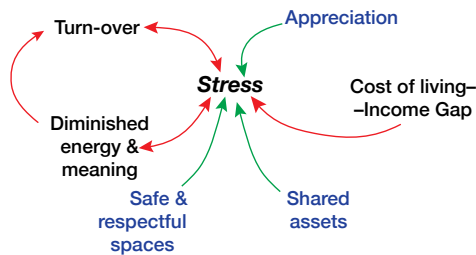
Influence with families grows with trust. Trust grows with truth, truth shared in many conversations over time. Truth begins in noticing possibility, sensing from within the small signs of hidden gems of interest and contribution. To sense from within, enter each encounter as if it were a blank canvas, alert to what is beautiful, to what is good, to what has potential to connect. Be in awe of small signs of what wants to grow and take action to nurture them. –UDI

The systems serving people with IDD need to be more responsive to those they serve and they can only be changed with effective advocacy. Our hope is to inspire more people with DD and more family members to work together and become more involved and effective in advocacy. We are developing The Art of Advocacy, a systematic way for people to grow their advocacy and leadership skills and a toolbox of resources to support them. –The Art of Advocacy

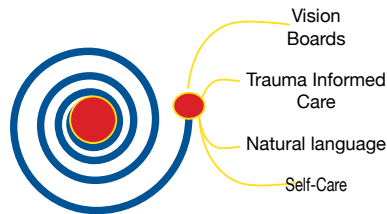


We are loyal to the mission of employment in real community jobs. We are positioned in services funded as Day Hab and Pre-Voc. Our challenge is to offer a clear and effective Employment Track in services that are too easily associated with outdated assumptions that work is not practical or even possible for their participants. Current employment focused options can find it too hard to imagine what work people might do with customized support or too difficult to fit into the way their services are defined and funded. We keep bringing people experiences that change perceptions of what is possible and open pathways to real community jobs. –Goodwill

We need to take care of ourselves and our DSPs in order to provide the best support for the individuals we serve. Even with some improvements in compensation the gap between DSPs income and local costs of living grows and increases stress. As well, a growing number of staff need considerably more support to meet the responsibilities of being person-centered. The Culture Club is a group of managers responding to stressful conditions by opening safe and respectful spaces for DSPs to find opportunities in their work, experience appreciation for their contributions, and share in the assets those with longer experience have developed including knowledge of and connections to local resources and services. –East End



We have to take better care of those who take care. Both the people we support and those who support them are vulnerable to stress that compounds anxiety, depression, and poor health. Approaches to wellness offer resources worth testing with a prototype group of people we support and DSPs. The possibility of funding from outside the Medicaid system provides the space for innovation. –Community Mainstreaming



A way of working...
 Make time for each other
 • safe space • speak from diverse perspectives as authentic selves • achieve deeper understanding through dialogue • mutual support & challenges • modeling & advocating • collaborating

...that generates innovations in patterns of thinking & practice like these

We have operated as an internal Learning Institute for the past 4 years. Valuing the people we support is the heart of the work. Our way of working has generated a variety of initiatives. In dialogue we have established an understanding

of person-centeredness as a culture that intentionally acknowledges any persons wants, needs, and dreams as being the focus of supports. Developing that culture is our group's mission. –People, Inc.

Without those of us who need the system, there would be no need for it. So we need to be a part of it.

The peer specialists will be at the table where decisions are made, representing everybody with a developmental disability. They will hear from as many people as possible and take that information to the table. It's not just about them as individuals. They are the voice of a collective us.

This is history in the making. –Peer Specialists

Our question: how do we maintain person-centeredness as our self-direction program grows larger. Being person-centered means having respectful relationships that expand choice and a sense of empowerment and goal directed action to discover what more is possible. The foundation is listening. Responsibility for complicated paperwork, high turn over among Care Coordinators, and the demands of bringing in new participants are just some of the pressures that compete with empowering relationships. –Job Path

Differences in culture and language can severely limit access to services people have a right to. Family caregivers play an essential role in assuring quality supports. Everyone will benefit when caregivers see their family members as having rights and choices, know how the system works, and understand how to function in assessments, planning meetings, and when their loved one's rights are being violated. Caregivers knowing "you have to say what your need is to get the need met" makes the assessment process better. The challenge is to find multiple ways to educate caregivers who's experiences make embracing person-centered approaches difficult.. Not only does understanding seniors' rights and choices matter in the caregiver's role as an advocate, it also affects many caregivers in their role as paid supports to their family member. Far more than language translation is involved. This effort can seem like bringing water to people in a desert who have grown too used to thirst to make an effort to drink. –Centro de Amigos

We have the opportunity to build an organization that treats all involved in a person-centered way. This means inviting everyone into collaboration. We believe we will grow stronger and better by moving into situations that many Support Coordination organizations avoid. We choose to reach out and include people with substantial needs for individualized supports, difficult housing situations, hard transitions, and extra complicated paperwork. We want to work thoughtfully through the policies, procedures and accountabilities that Medicaid demands rather than outsourcing our thinking to consultants. We want to strengthen the field by offering training and support to local networks and our regional office and advocating for improvements in systems for people with TBI and people in nursing home transition. –A1

Our intentions in a phrase

Keep providing person-centered supports as people get older

Grow the program while maintaining same level of person centeredness

Promote & protect person-centered practices & outcomes

Establish a Trojan Horse for employment. Support the person, not service codes

Define person-centeredness for an agency & a way to measure for opportunities for growth

Provide a fountain of resources for an area lacking the reach to anything more than drops

Encourage families to discover gifts & raise expectations

Raise expectations & strengthen the voice of people, families & allies

Guide Peer Specialists in their new role

Develop "The Art of Advocacy"

Provide a holistic approach to wellness for the people we support & the people who support them.

Person-centered approaches are for everyone: people we support; families, support workers

Support & connect our staff with resources for self care

Create our new agency around promoting person-centered practices for both the people we serve & the people that work for us.

Encouraging social innovation
6 May 2024 - 5.0

These telegraphic statements of intention point to next step issues in a years long effort to build capacity for person-centered work. Concerns reach beyond compliance with rules to the ongoing transformation of practices, structures, and mindsets through social innovations that support inclusion and choice. The organizations represented, and many of the participants themselves, “got involved with person-centered planning when it was still a conversation and not a mandate”, as one put it.

Three themes can organize this social innovation agenda.

Promote and protect person-centered practices and outcomes...

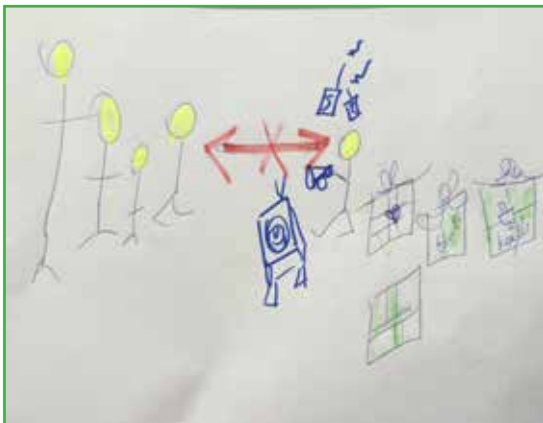
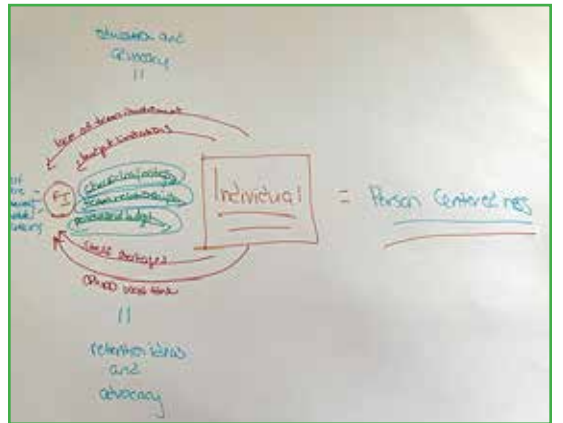
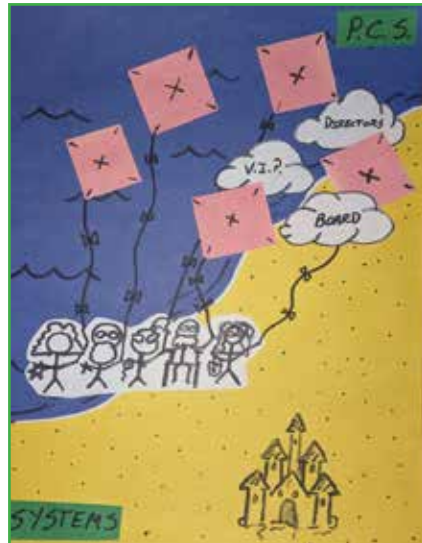
- ...as people and family members age or otherwise lose supports or require different supports.
- ...as more people opt to self-direct their supports, risking diminished voice and isolation from knowledge of what more is possible.
- ...as programs grow and adapt to reforms and growth in demand.
- ...continuing to resist a “not able/not ready” perception that excludes people from access to employment and other aspects of community life.
- ...guide reflection, self-evaluation and innovation in embodying person-centeredness in daily life

Strengthen the voice of people, families, and allies...

- ...support resistance to prejudices that trap people, families and allies in low expectations.
- ...promote discovery of gifts and mobilization of personal, family and community assets.
- ...organize and educate people and families silenced by language and cultural differences that compound common devaluing assumptions about elders and people with disabilities.
- ...encourage people who receive supports and family members who accept potentially influential roles, such as OPWDD’s peer specialists, to discover and speak with their sense of a collective voice.

Cultivate person-centeredness as a way to be for everyone rather than just a technique applied to “them”....

- ...build new initiatives on inclusion, generative listening, shared purposes, and co-creation.
- ...explore shared experiences with discovering personal and community gifts, wellness and self-care that involve people supported and DSPs as equal participants.





Our tree is our landscape because we're growing from the bottom up. This heart is as we are, our shape. These green birdies, our staff. These green butterflies, the people we serve. We're all in this blue space because we're innovating and collaborating all together.

But then we've got a dark side of the tree that we can't yet get to bloom, where things stand in our way: the regional office and the Department of Health not fixing things that we need them to fix; a red snake is deficit based paperwork that is not catching up with what we're doing; TBI rates that don't match NHTD rates and disadvantage people with TBI.

Even these red beings have openings to possibility that motivate us: one little red bird here has a green foot; one red butterfly has green in the middle.

The innovation is our entire agency. We are creating something new.

Christopher Liuzzo identified these conditions in reflection on a Learning Institute focused on Encouraging Innovation, Spring 2004

Social innovators committed to person-centered work cultivate these internal conditions

Intentionality

making space for relationships & learning

deeply listening to people's stories

discovering gifts

seeking what more is possible

Resistance

to low expectations

to imposing control

to compliance

to a scarcity mentality

Identification & empathy

standing with people not over them

being in awe of people's gifts

feeling the costs of injustice, social exclusion, life wasting & deathmaking

seeing the limits imposed by service boxes

Passion to do the right thing

In our work with hundreds of organizations in New York and elsewhere, we've discovered that people who embark on these journeys consistently cultivate and demonstrate certain interior conditions. We want to share them with you and ask you, taking your first step on this journey, to consider your own interior conditions.

The journeyers we have met are intentional. They don't rely only on chance, on the boss, on their coworkers or external conditions. They are intentional about making space to learn, to cultivate relationships, to listen deeply to those not usually listened to, to seek what more is possible. They work at this. And they are aware of the voice of cynicism, the voice that says "this cannot be done." They work to quiet the voice of cynicism.

They have the courage to cultivate resistance. They work to resist the deadly curse of low expectations, to imposing control on others and to being consumed by compliance activities. They resist a scarcity mentality that declares "there are not enough resources to do this". And they are aware of a second voice, the voice of fear, the voice that says "beware of resisting. You will get in trouble". Instead, they work to quiet the voice of fear and cultivate the voice of courage.

These quest takers strive to identify with and demonstrate empathy for devalued persons. They choose to stand with, not over, the people they support. They choose to be in awe of undiscovered gifts those people bring to the world. They see the price those people pay due to social injustice, social exclusion, spending years working on life wasting goals, even to the point of death making. And they work to quiet yet another voice, the voice of judgment, the voice that says "these people" cannot live the good life, are too vulnerable, too incapable and too undeserving. Or that their families stand in their way.

These travelers are deeply passionate about doing the right thing. When confronted by seemingly insurmountable obstacles, they create workarounds. They seek out small cracks to, as Leonard Cohen wrote, let the light in. They act to learn, they prototype, they make mistakes and set out again. They get discouraged but their passion won't allow them to succumb to complacency.

Stephen Covey might say they've found their voice. Their vision is clear. They practice discipline, using their skills and abilities to walk the road less traveled. Their conscience provides a moral compass. Their passion to do the right thing keeps them going.

–Christopher Liuzzo



I'm a disabled man with a lot to say BJ Stasio on Being Person-Centered

Being person-centered grows from good relationships

Allies are necessary and allyship begins in listening

True change starts when your ally comes alongside you, somebody you trust, and says, "Yes, this needs to change."

When there's a level of deeper listening, it creates allyship. You know that allies want to go on this journey with you. They are here because they want to be your ally.

They shine a light on the humanness of me, all my flaws and all my scars and all the jagged edges that make me human. Even when I'm in front of senators or governors or even presidents, there's still the jaggedness of me, the sharpness of me. But when you have an ally with you that jaggedness becomes a little more dull because you know you're not alone.

That's what happens at a level of deeper listening: the comradery of "Let's do this together because nobody can do the work of advocacy alone."

Deeper listening encourages people to find their purpose in life, flip their internal switch and act

It all starts with asking somebody about themselves, then they'll find their purpose. It's not reading that paper from 10 or 15 years ago and saying, "Oh, BJ, you'll never never know what it's like to talk to politicians." But guess what, I figured it out.

Yes, I've made mistakes. I'm far from perfect. But I'm perfect for what I'm supposed to be doing. That's what I'm perfect at.

The work I do today, I believe it is something God had planned for me. To see it, I had to open up my heart. There were layers of anger. And there were the jagged edges that makes me, me. But once I saw my purpose, I discovered the on switch inside of me. When I flipped the switch I discovered what God has called me to do: using the knowledge that I have to make sure other people get what they need.

Not everybody believes in God, that's fine. So let's start with belief in yourself. Belief in yourself and your purpose is what will set you on the path for the rest of your life.

Most of us with disabilities would rather be on the sidelines and let somebody else do it. But now is our time to do it together. We just have to find that on switch and let it have the effect on us like it did on me.

We just need to get out of that box we're comfortable in, and let ourselves feel things. Because you can't be shielded from what life brings you just because you choose to put yourself in a box, or a loved one chooses to put you in a box. Your families and those around you who wanted to protect you put bubble wrap around that switch. It's time for you to pop that bubble wrap and actually make a difference in your life and somebody else's life.

*BJ Stasio is a disability rights advocate/activist supported by a strong circle of allies and assisted by HCBS waiver funded services. He has worked for the New York OPWDD as an advocate for 20 years and now leads the implementation of a Peer Specialist unit. In February and May of 2024 BJ was the focus of two dialogue interviews with Beth Mount and John O'Brien. This paper draws together some of his insights into person-centered work from those conversations. John O'Brien edited for clarity and continuity. BJ approved the edits.

Discouraging voices can be overpowering

Don't discount people's wishes and dreams because when you discount people's wishes and dreams, you turn off that switch. All it takes is one person to say, "No, that's the wrong idea for you." Because they could really value what you say.

So never discount a person's wishes and dreams because if you discount a person's wishes and dreams, you could be denying their the right to experience something that they've never experienced before.

If someone comes to you and asks you what you think, don't say, "That's a bad idea." Say, "Let's explore it." That's being person centered. It might not work. At least you went down the road with them and wanted to take that walk. It might not lead to anything, but it shows you care. It shows you have compassion as the human being you are.

So lift people up. Don't knock people down

The service system's business can take over

To try to make the system person-centered, the system came up with Life Plans. But Life Plans lead back to the cycle of being seen as less of a person, being billable, being a revenue stream, when it actually should be about what we as human beings want for our lives.

I know my care coordinator's gonna fit whatever I say into the damn drop down boxes because she has to get those billable units out of the Life Plan. But there are valuable human beings at the other end of that billable unit.

I call the system to always think and do more to make it about getting what we need from the service system without being pushed into boxes.

REFLECTION

BJ is an experienced, articulate, and assertive advocate. In a society that celebrates individualism, self-interest and technique, it's worth thinking about his emphasis on relationship, collective voice, and commitment to highest purpose as necessary to being person-centered. Real change needs the presence of affirming allies and a sense of belonging to a bigger cause. Deciding to step outside a narrow sense of safety and switch on acting toward highest purpose transforms lives. The voice of judgment is toxic to dreams. Purpose and meaning can't thrive in processes shaped by drop down boxes that treat people as the means to produce billable units of service. Listening deeply and walking with people to explore their dreams demonstrates the care and compassion that form the foundation of being person-centered.

See videos BJ made in this Learning Institute

Art of Advocacy Story : “It’s a way of life”

BJ Stasio and Max Donatelli began meeting weekly in early 2020 at the Wonder Coffee House to discuss shared concerns about the systems that serve people with IDD. The Wonder Coffee House is run by BJ’s church, then Wonder Church, now called Hope Rising.

Discussions included frustration and concerns with the lack of responsiveness of the systems and real need for greater advocacy.

•As BJ, a person with a developmental disability, was soon leaving his presidency of the Self Advocates of NYS (SANYS) soon, and he had concerns about those in line to take over leadership positions. He wanted to come up with something to help build leadership capacity.

•Max, a parent of a young man, Craig, with Down syndrome, and founding member of the Developmental Disabilities Alliance of WNY (DDAWNY) Family Committee, was concerned about trying to get more family members to more effectively advocate for their loved ones, contact legislators, and become more actively involved in advocacy.

•Drawing on Max’s prior experience with taking Tae Kwon Do, a Korean Marshal Art, together with his son, Craig, for several years; each going from novice White Belt and working up in skill levels to eventually working toward their Black Belts, mastery level; he suggested using this as a model for advocacy. There were many benefits for Craig and Max. What stands out was that not only does one learn increased skill levels as one moves up, but also those at upper belt levels have opportunities to teach skills. When one teaches, one learns the skills at a much deeper level as they teach. Many of the habits can then be incorporated into one’s life. When deciding what to call the model, they decided to call it the Art of Advocacy.

•Over the next several months, each offered early points in advocacy efforts and growth as an advocate to help provide suggested tasks to move up in levels. They decided to use colored wristbands to symbolize markers of accomplishment to the different levels. As they wrestled with moving up in skill levels, rubrics were developed to move from White level through Black level. BJ and Max are recognized advocates in their own right, but agreeing on tasks needed to achieve mastery was difficult, and as BJ claims “it’s surprising that we are still friends!” It was a challenging process as mentioned, BJ came from being a person with a physical disability, and Max being a parent of a young man with Down syndrome, an intellectual disability. After rigorous testing, BJ and Max each got matching hoodies with Art of Advocacy on them. On BJ’s it also said “Unstoppable”, and Max’s “Persistent “.

•To reflect progress in the levels, each Band level has rubrics or tasks to complete. For example , when an advocate reaches the Yellow level they are now able to advocate for themselves effectively. When reaching the Green Level, they are able to now advocate for others. At the Red level they are recognized at the locally as a disability advocate. In order to reach the Black level, one is recognized at a broader or statewide or even national level. However, it is made clear that if an advocate reaches Yellow and can advocate for themselves and not go beyond this, this is seen as successful for them; as not everyone can advocate for others or systems. Those that are able to do systems advocacy are supported with a variety of resources and work with a mentor.

•Developing this model took place over many months and help from those around them, the co-pastors of Hope Rising, leaders in the disability community, BJ’s work with OPWDD and SANYS, and Max’s with the DDAWNY Family Committee. They tagged their model, Art of Advocacy: “It’s not a program, it’s a way of life”

•BJ and Max have developed the model, along with a toolbox of resources, and offer it to various organizations to adapt the Art of Advocacy to helping their self advocates, family members, and allies how to become more effective advocates.

•They have created a PowerPoint, gotten the name and model trademarked, have a Facebook page, and are working on 501c3 status to offer it more widely with expanded services to help build a great capacity of effective disability advocates. There is a great need for more disability advocates, and the hope is to inspire and teach more people to learn how they can become more effective in their advocacy efforts for themselves, and possibly even for others. The systems serving people with IDD need to be more responsive to those they serve and they can only be changed with effective advocacy.



–Max Donatelli

East End: Culture Club

Supporting those who provide support

The direct support professionals that work in our community frequently live with the same difficulties that some of the people they support: housing instability, transportation difficulties, and access to available services.

One of the biggest barriers to finding and maintaining a well-trained workforce is the gap between wages and the cost of living in the area. Long Island is a very expensive to live and work. DSP wages are well below a level that would recognize the importance of the work that they do. Rent alone can account for almost 50% of their wages. Many have multiple jobs and /or live below the poverty line.

In the course of doing our jobs many of our management team have learned about resources and services available. We come together in what we call a Culture Club, where we discuss enhancing the culture of our agency and how to better support all members of our community.

It has been the goal of the last several months to bring together a lot of these resources to share with the direct support professionals, many of whom qualify or have family members who may qualify for the supports and services that we have collected. Each member of the Culture Club is organizing a safe and respectful space where we can share our knowledge of community resources.

It is our hope that not only will DSPs find resources to help themselves, but they will also feel how much we value the work that they have done. We are starting with an event but have also discussed how to make this gathering into a regular method for connection to resources.

The discussion evolved from a one day event to a week long event with resources coming together all across Connection, a network of affiliated agencies that East End is a part of. A connection employee has joined our Culture Club with the goal of creating a guide to resources all across Long Island. This guide will be both physical and digital.

We have resources coming together in the areas of banking, housing, childcare, elder care, LGBTQIA supports, and healthcare as well as supports and services within the umbrella of OPWDD.

We hope that these connections will help with absenteeism, lack of drive and turnover rates, but we also want to enhance the culture of East End Disability Associates and strengthen the community that we live, work, and take an active role in.

We're anticipating that more members of our workforce will join us at the Culture Club and help drive us forward as we enhance our culture.

- Co-creating a book in multiple languages for parents that guides them in discovery of what more is possible for themselves and their children.
- Dialogue to explore the relationship between our staff's personal mission statements and our agency mission.
- Trainings for Support Coordinators that build clarity and commitment to being person-centered. These will draw on experience in dealing with complex situations and adapt ideas and practices from the Learning Institute.
- Piloting ways for people who receive support and DSPs to share in experiences that promote wellness.
- Some managers come into their roles from career paths that have given them little direct experience of person-centered supports. Co-developing ways they might learn in relationship with people who receive supports.
- Co-create learning opportunities for people and families who choose self-direction to develop person-centered approaches to their own support in their role as supervisors of their staff.
- Involve the people involved, especially the people we support and have supported, in creating and sharing a timeline that tells the story of our 15 year journey of developing supports to employment.
- A video presenting the internal capacities of social innovators that we have identified.

- Our system is over-controlled and under-imagined.
- Many people 's gifts are hidden, sometimes even from themselves and their families. Trusting that there are hidden gems to discover and build on is a key to good support.
- Direct support work is awesome when it helps to build bridges to valued roles in community life.
- Much needs to change if people are to claim their rights to choice and community life. Along with teaching the art of individual advocacy we need to organize a collective voice.
- Language differences, cultural and family customs, legal status, and fear hold people back from claiming resources they have a right to. It takes generating many different forms of communication to effectively transfer knowledge of how to get what's needed from systems.
- There is a long history that distributes benefits toward people who seem more "ready" and appear less impaired and away from people whose needs are more complicated to meet. Many useful innovations can result from reversing this thinking, turning around and purposefully engaging people who challenge capabilities and demand personally tailored support. Such a turn-around will lead to seeking, adopting, and extending innovations in individualized supports.
- Looking outside the world of services can stimulate innovation. For example, experiencing well designed supports to wellness available to people with greater privilege can motivate the design of a small scale innovation that would test the effects of a similar experience on people who receive support and those who provide it.
- The identity of the workforce is changing. A growing number of staff require more, better customized learning opportunities if they are to do the work in a way that involves them in support for meaningful change in people's lives. The more meaningful a worker's contributions are the more likely they are to stay in the work.
- As the long-term care system is increasingly identified with and managed as if it were health care, more executives and administrators move from managing hospitals, clinics, and managed care organizations to replace managers who have come up through careers that include direct experience with people who rely on long term support. It's worth considering how those new to the field can get a feel for what is distinctive about supporting choice and community belonging.
- Continuing conversations about the values that define being person-centered and focused on valued community roles and relationships are critical to good decision making. Drawing clear lines that define what we want less of and defining compelling images of what we want more of set boundaries for innovation.

- Acting from conviction that *there is enough* to take another step into co-creation, however small that step may be keeps positive possibilities alive. This attitude encourages a careful search for assets and careful thinking about what makes a good next move.
- Good moves into being person-centered are intrinsically motivated. Aware of incentives to compromise, we choose to do what in our best judgment is the right thing for the sake of our values. We pay the system what it is due in ways that leave space for new ways to emerge.
- Our system tends to see person centered work as a matter of procedures. But we understand person-centered work as a way of being in relationship. A way to free all those involved from the burdens of low expectations, social exclusion, and exerting power over people. In the first place, social innovations are shifts in relationships that bring connection between gifts and opportunities for contribution to light.

Two kinds of work are necessary to use HCBS waiver funds to support access to community life.

- **Transactional work** is necessary to draw on HCBS funding. Through this work, administrative requirements are met: eligibility is established; services matched to assessed need; funds accounted; compliance with policy documented; inspections and audits completed. Objectivity, control, correctness, timeliness, and efficiency are prized.
- **Relational work** facilitates access to community life. Investment in relationships builds trust, develops personal knowledge, and activates discovery of what more is possible. Relational work shapes a culture that provides and promotes conditions for social innovation. Deeper listening and co-creative action strengthen voice, make assets, gifts and interests more visible, test limiting ways of seeing and thinking and support opening paths to community settings, roles and relationships. Relational work is valued for serving the art of co-creation through respectful curiosity, compassionate imagination, and the courage to invent new forms of support.

Transactional work is defined from above by administrative systems that pay and regulate. Relational work grows from a sense of right relationship, as people turn to one another to build trust and personal knowledge and then turn outward into more diverse and inclusive community roles and relationships.

Transactional work extracts and files data to construct an Other, a statistical creature that lives in databases that certify deficiencies, track the flow of billable units of service, report incidents, and document compliance with regulations. In this context “person” is a means to the end of drawing funds. Relational work aims to co-create shared stories of breathing people living well together in their own neighborhoods, workplaces, and civic settings. In this context funding is a means to support a person in pursuit of their purpose and life projects.

These two forms of work compete for attention. Because transactional work is well defined and defects in documentation attracts penalties, there is considerable risk that it will eclipse relational work. This risk grows in situations stressed by workforce difficulties and overcommitment. Inflation of transactional work blocks the relational sources of innovative action.

Keeping the two forms of work in a proper relationship is a key challenge in public administration and a major leadership responsibility in socially innovative organizations. A culture that cultivates the qualities named in the “Harvest: Internal conditions of social innovators” (page 13) significantly improves the chances of meeting those challenges and responsibilities with integrity.

An indicator of the potential for greater access to community: according to a 2024 [CQL study of personal outcomes](#) for people with ID/DD, about 39% participate in the community and 34% perform different social roles.

BJ Stasio on being treated as a source of billable units [\[page 15\]](#).