



NYSACRA Learning Institute on Innovation in Individualized Supports

Learning History • Southern Tier

June 2015 – November 2015

John O'Brien



NYSACRA

The New York State Association of Community and Residential Agencies



Southern Tier Learning Institute

June–November 2015

This Learning Institute was supported by the New York State Office for People With Developmental Disabilities.

The image incorporating Theory U on page 5 is modified from materials licensed under Creative Commons by Otto Scharmer and The Presencing Institute, www.presencinginstitute.com/permissions.



Cover Images

In the final session participants created images that express the intention they are taking from the Learning Institute into their future. At the conclusion of the session they place their images on the *What more is possible?* diagram that pictures one of the themes of the Learning Institute.

ACHIEVE

Broome OPWDD

Broome DDRO OPWDD

Epilepsy-Pyralid, Inc.

Franziska Racker Centers

Herkimer Arc

Southern Tier Independence Center

Springbrook NY, Inc.

The Arc Delaware County

The Arc Otsego

Wayne Arc

Participating agencies developed **change teams** to translate the work they did in Leadership Institute sessions into local action-learning. In the five months of the Learning Institute, the change team's task was to identify a leverage point and, as quickly as possible, begin learning through action how to make that leverage point a focus for creative action that will, over time, increase their agency's capacity to work in a person-centered way.

The Learning Institute supported change teams in four ways:

- **Workshops** brought agency representatives together to explore essential aspects of person-centered work.
- **Learning Journeys**, hosted by agencies committed to deep change, allowed critical reflection on the process or organizational change in the New York environment.
- **Webinars** offered useful information on topics that influence the implementation of new approaches to housing, support and employment.
- **A network** of mutual support that began to emerge as people connected in workshops and learning journeys.

3 -5 June

Chris Liuzzo: Common Life Experiences of Persons with Disabilities

Hanns Meissner: Blue Space

Beth Mount: Applying Theory U

25-26 June Learning Journey

Host: Heritage Christian Services, Rochester

6-7 August

Carol Blessing & Michael Kendrick: Person-Centered Planning

17-18 September webinars

John Maltby: Affordable Generic Housing

Adam Pekar: Labor Law & Individualized Housing Supports

Meghan O'Sullivan: Using Assistive Technology to Promote Independence & Lessen Intrusion

Rachel Pollock & Katrina Roberts: Customized Employment

15-16 Oct Learning Journey

Host: The Arc Rensselaer County

18-20 Nov

Generative stories

Polarities

Prototype for continued learning

A turning point

New York State’s system of supports to people with developmental disabilities is at a turning point. The field has developed new ways to individualize supports so that people can have community lives in their own homes and valued roles as workers and citizens. These developments alone would call for significant change to live up to the vision that OPWDD has embraced, a vision reflected by the visions of the system’s providers and consistent with US law and Federal Medicaid policy:

People with developmental disabilities enjoy meaningful relationships with friends, family, and others in their lives; experience personal health and growth; and live in the home of their choice and fully participate in their communities.

Reforms to the state’s whole Medicaid system increase the demand for substantial change. The US Centers for Medicare and Medicaid Services (CMS) –the co-funder of OPWDD’s services– has become party to a Transformation Agreement that commits OPWDD and its contractors to challenging goals.*

- *Developing new service options to better meet the needs of individuals and families in a truly person-centered way, including allowing for more self-direction of services;*
- *Creating a specialized managed care system that recognizes the unique needs of people with disabilities, and is focused*

* www.opwdd.ny.gov/transformation-agreement/home

on a habilitative model of services and supports;

- *Ensuring that people live in the most integrated community settings;*
- *Increasing the number of individuals who are competitively employed;*
- *Focusing on a quality system that values personal outcome goals for people, such as an improved life or access to meaningful activities; and*
- *Working to make funding in the system sustainable and transparent.*

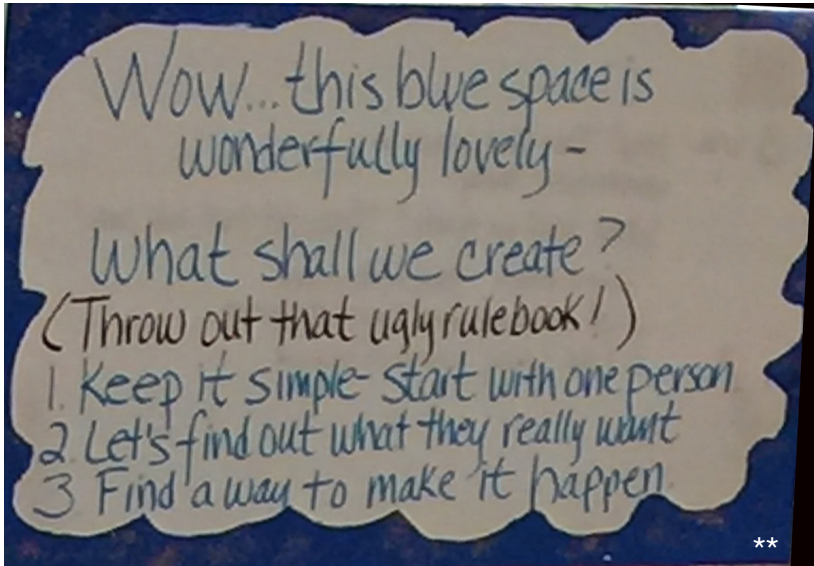
The leverage points that Learning Institute change teams chose align with three of these goals and progress on their action learning prototypes is strongly influenced by the quality system and the implementation of managed care and a sustainable, transparent funding system.

This alignment makes what Learning Institute Participants have discovered relevant to the whole system’s work for change.

Self-direction of person-centered services**	●	•	•	•	•	●	•		
Living in most integrated community setting	•	•			•	•	•		•
Valued outcomes, meaningful activity	•		•	•		•	•	•	
Competitive employment									

** Nine projects submitted written descriptions of their prototypes. The columns map each prototype’s focus onto the Transformation Goals. In the top row, large dots identify use of the option to self-direct an individual budget. Smaller dots indicate customized arrangements within typical funding categories.

A simple approach reveals complexity



The Learning Institute starts with a simple theory of change. 1) Begin in relationship with one person. This is not only consistent with the idea of working in a person-centered way, it also limits the amount of uncertainty a change team encounters by keeping the effort focused within a manageable boundary. 2) Discover what more the person wants of the good things of life (a home of their own; purposeful work; participation in community learning, leisure and civic life; good relationships). 3) Take action, reflect and revise to create opportunity and support to experience those good things. 4) Use the learning to repeat with another person. Do this one-at-a-time with as many people as capacity allows.

This sequence typically surfaces necessary organizational and system changes as the effort encounters obstacles to positive and direct action. By making these changes the organization and the system increase their capacity to individualize supports. As capacity grows so does momentum and scope for change because the path grows smoother as positive changes accumulate. The change cycle moves faster and includes more people.

Change teams typically find themselves in complex situations by following this apparently simple sequence. They find inflexibilities that limit individualization from staff schedules to billing codes. Some people with developmental disabilities may lack the trust, knowledge of possibilities or confidence to jump into steering the change. Important disagreements about what can or should be done surface as people discover the different meanings they assign to words like community, self-determination and person-centered planning. Negotiations with regulators and funders are more time consuming and difficult than can be predicted from their mission and vision statements. Attempts to explore new opportunities surface a need for cultural change (the ugly rule book the poster makers had to throw away). Organizations are stable in a way that shifting any aspect of the situation involves the whole structure. Dealing with the interaction of forces for and against person-centered work becomes like playing the game of Jenga that the Springbrook change team made.

Blue Space, adopted from Learning Institute consultant Hanns Meissner's book of the same name, identifies the social field that allows change teams to



Hanns Meissner (2013). [Creating Blue Space](#). Toronto: Inclusion Press. Download a summary at <https://www.nysacra.org/docs/Blue.pdf>

**Participants in the final session presented stories of what they have learned during the learning institute that generates a better understanding of how to do person-centered work. This is a frame from the ACHIEVE change team's storyboard.

You can dance in a hurricane
 But only if you're standing in the eye
 –Brandi Carlyle lyric
 played by a participant



act creatively and persistently in situations where trying new ways of supporting people is complex because of competing priorities and uncertainty. The image is of the cloudless sky at the eye of a hurricane, a place of stillness that allows a change team the freedom to attend to what more is possible and discover how to bring the new into being.

Blue space is an intentional and disciplined co-creation. The Learning Institute has adapted a way for change teams to generate this social field and invent new supports from the work of Otto Scharmer and his colleagues at MIT's Presencing Institute (www.presencing.com).^{*} The process follows a U shape from sensing new possibilities, to discovering what new story wants to be told through the team's work, to creating that story by trying and refining

^{*} For an easy-read introduction, see John O'Brien (2015) *Theory U: A Way to Change Services for People with Intellectual Disabilities* www.nysacra.org/docs/Short.pdf.

prototypes of the new story in action. When teams reach the point of co-creation they need **resources for invention**: time to take action and reflect; negotiated flexibility in the roles and schedules of direct support workers; real shifts in typical approaches to risk management and compliance with regulations and protocols; and investment of money in trying new things.

The Learning Institute approach to change serves a distinctive and challenging understanding of person-centered work. This understanding is expressed in the service design principles that follow.

Co-initiating
uncover common intent
 stop & listen to
 what life calls you to do

Co-evolving
 extend new capacities
 to discover what more is
 possible

Co-sensing
observe, observe, observe
 connect with people & places
 of potential

Co-creating
prototype the new
 develop living examples to
 explore the new by doing

Presencing
connect to sources of inspiration & will

Design Principles for Individualized Supports

Chris Liuzzo*

During the Learning Institute, I compiled this set of Service Design Principles to guide participants as they developed their prototypes.

These Design Principles apply to the design of individualized supports in any context, but my primary interest is in employing them to reinvest resources now bound up in congregate services in more individualized and self-directed supports.

These principles are not presented as exhaustive.

I offer profound appreciation and gratitude to many others who have influenced my thinking over many years, including Wolf Wolfensberger, Hank Bersani, John O'Brien, Beth Mount, Michael Kendrick, Tom Nerney, Derrick Dufresne, Mike Mayer, and David Pitonyak. Their thoughts and contributions are evident throughout the principles.

* Chris organized this Learning Institute and contributed to each of its workshops and learning journeys. These principles are based on his practical experience of shifting resources from group based services to individualized supports. Download a booklet of these principles from www.nysacra.org/docs/Liuzzo.pdf

Get design questions in the right order

This is not so much a principle of design, but one of process. If the first questions are *how will we pay for it* and *what regulations will apply*, then the process will already be compromised.

Hank Bersani stressed how important it is to not *draw the bullseye* before the planning has even begun.

Of course, understanding who the people served are and what they may need in their lives is a primary source of guidance for service design. The measure of this should, at a minimum, be what most people consider the elements of a *good life*.

Start with the values you want to guide your design. Then, the other pieces will begin to fall in place.

Increase the likelihood of persons attaining valued social roles.

Successful supports result in the immediate attainment of a valued role: home owner or tenant, employee, club member. Just as important, it should set the stage for and increase the likelihood of people enacting other valued roles over time. One may move from being a tenant to becoming a valued neighbor, member of a tenants' association and a host of tenant get-togethers.

Honestly address vulnerabilities of concern, with careful attention to real vulnerabilities, not those projected onto people by human service systems.

Real vulnerabilities are those which truly place the person at consequential existential risk of physical, social or developmental harm but for which insufficient compensating or offsetting intentional safeguards are not yet in place. These vulnerabili-

ties of concern are identified by understanding and then addressing the primary sources of vulnerability, such as poverty, loneliness, the absence of voice and so on.

Human service systems tend to perseverate on low probability and often quite unspecific risks, such as fire, crime or general physical safety and on ostensible safeguarding interventions of low or questionable value and practical relevance, such as mandatory annual physicals, over staffing and over protection, filing of bureaucratic reports etc. While consideration of these risks and interventions have value, they are much more oriented to reducing the perceived risk and liability of the service provider. Intentional safeguards should not divert resources and attention away from more fundamental vulnerabilities of the people being supported and fool providers into thinking that they have adequately addressed real risk.

Address real needs, not those invented by human service systems.

It is not difficult to identify fundamental human needs, which include love, friendship, safety, security, association, contribution, belonging, and so on. These are the things Wolf Wolfensberger calls *the good things in life* and what Aristotle and many others since call the *good life*.

Human service systems are not adept at addressing these needs but are skilled at inventing and occupying people in *working on* more superficial needs such as *needing* to keep one's room clean or learning to cook a meal or to make change of a dollar. Prioritizing these superficial needs amounts to a subtle form of coercion, requiring persons to address needs that are not really the person's priorities but distractions imposed by system routines and practices.

Decouple the supports provided to any one person from those provided to others.

Many, probably most, support designs are predicated on resources (such as staff support) being shared by more than one person. A staff member may be required to visit numerous people in several apartment settings over the course of a work shift. In a group home, staff are constantly allocating their time among the people who live in the house.

Support designs should maximize the dedication of resources to a single individual such that the support one person receives is not dependent upon the supports provided to others.

Here is a simple test. You will know you are approaching satisfaction of this design principle when a person you support expresses a desire to go to a movie tonight and your answer is not *we'll see*, but *which show?* Patterns of resource use should reflect the priorities of the person not the most expedient way of staff managing their work.

Minimize social distancing & improve relationship.

Typical staff-client relationships are tightly prescribed. Human service systems tend to impose strict social boundaries between recipient and provider by law, regulation, policy and procedure. Service disciplines, such as social work, counseling, nursing and so on, have long traditions of teaching boundary management as a process of keeping distance from *the client*. Yet at the same time, they teach about the importance of relationship itself.

While boundary management may have laudable objectives, such as role clarification and prevention of abuse, it inhibits, in fact, often forbids many authentic forms of bonding and connection between

staff and clients and unwittingly promotes an “us and them” mentality.

Good design promotes an enriched quality of relationship between the persons in provider and recipient roles while ensuring the ethical conduct of supportive developmental rather than custodial relationships.

Good design promotes relationship between provider and recipient while insuring the physical and social safety of both.

Promote & Nurture Right Relationship.

The concept of ethical partnering or *right relationship* is easy to intellectually understand yet profoundly difficult for humans to enact. It can be understood as the Golden Rule. If one simply started with the principle that people should relate to the people served honorably that would set the stage for much more ethical consciousness in how people are with others.

Many human services place little value or importance on *right relationship*, consciously and unconsciously. Treatment plans, service plans and behavior plans are replete with examples of providers identifying what service recipients should learn and do, in the eye of the provider. They are notoriously light on partnering, shared and respectful decision making, obligation, negotiation and mutuality. Good service designs disrupt this norm of indifference to ethical partnering and instead nurture the seeking of *right relationship*.

Minimize organizational and governmental intrusion while promoting transparency.

Due to their reliance on other people for support and on public resources, people with disabilities experience bureaucratic intrusions most citizens would find invasive. For example, in regard to

personal privacy, staff persons may have read their personal histories and know intimate details about them, often before even meeting them. Staff can often routinely impose demands, rules, sanctions and so on in an arbitrary manner. Clinicians decide what they will attempt to change about a person, sometimes even deciding that a person's inherent self needs modification (e.g. “so and so is too bossy with her housemates. We need a plan to address her bossiness.”). This level of intrusion, manipulation and coercion is all too common and not recognized for how invasive and controlling it is.

Good service design is about thoughtfully balancing and resolving apparent contradictions. In this case, balancing transparency with the human needs for respect, privacy, autonomy and control is the designer's challenge.

Reinvest existing resources away from congregate services.

We can expect little in the way of transformation from congregate to individualized services if we do not move resources from the congregate settings in which they are currently bound up to self directed individualized supports.

Absent intentional reinvestment, providers will continually seek new funds for individual supports while still maintaining congregate settings. It is better that there be a conscious decision to disassemble our congregate models and thoughtfully replace them with *one person at a time* lives in the community that are suitably individualized in how they are supported.

Maximize control over use of resources and selection of support persons.

There is a positive correlation between this principle and the others already identified. The more control people have over their resources, the more likely the other principles can be achieved. Even where people may need support with the control of these matters, the presence of support should not undermine the primacy of the person's own authority to direct their life and supports.

John O'Brien has written that part of our work is to *make hope palpable* for persons receiving supports. Control helps to do just that. Let us be sure to give people their lives back that they lost when they became clients.

Enhance the perception of persons with disabilities.

Over 40 years ago, Wolfensberger identified the common role perceptions of devalued persons, including persons with disabilities. Among others these include the eternal child, the object of pity and the sub-human. He not only identified these perceptions but provided ample evidence of their universality.

Good service designers are conscious of the danger of these negative role perceptions and are intentional about addressing them by emphasizing and nurturing normative perceptions of people to counter this danger

Be flexible to change with changing needs.

Standardized or *fixed* service models and practices, such as group homes and day programs do not have sufficient flexibility to change with a person's changing wants and needs as do "stand alone" self directed individualized arrangements.

They are, by design, fatally inflexible. If a person's needs change, there are two typical responses...

...fix the person so that the standardized model can continue to be employed or

...move the person to another standardized model ostensibly designed to address this new need (think, *medically frail house* or *behavioral house*).

In contrast, quality service design results in resources that can be shaped and reshaped around a person as his or her needs change over time without recourse to disrupting adaptive social and physical environments. Resources can be thought of as akin to the Gumby toy: able to move and bend with a person. This flexibility must arise not only from new models and structures but from an ethic and attitude of committed responsiveness.

Be efficient.

The current human service system expends an almost unimaginable amount of resources while achieving relatively little in the way of meaningful outcomes.

And little if any data demonstrates that congregate services provide the elusive economy of scale so sought after by planners and managers.

With attention to good design principles, it is possible to spend resources more wisely, achieve better outcomes and to reinvest away from segregation and congregation.

Support valued social roles

Address real vulnerabilities

Address real needs

Individualize supports

Minimize social distancing

Promote right relationship

Minimize intrusion

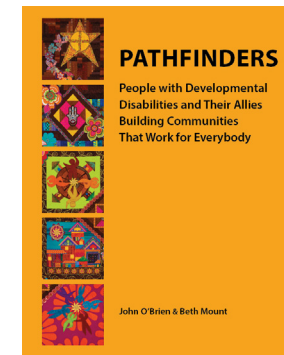
Reinvest

Maximize the person's control

Enhance perception of the person

Be flexible

Be efficient



For more on person-centered support see John O'Brien & Beth Mount (2015) *Pathfinders: People with Developmental Disabilities and Their Allies Building Communities That Work Better for Everybody*. www.inclusion.com

Change is personal

The leverage points that change teams select are consistent with OPWDD's Transformation Goals and they are straightforward: living arrangements that suit people better; support to those who choose to self-direct individual budgets; more satisfying participation in community life.



However, from the first step – joining the person to co-initiate the change by finding out what the person wants- some change teams discovered that their own assumptions and history with the person they are joining creates obstacles. One team found that their assumptions limited what they could hear.

We have learned that you really need to LISTEN to the person. We tend to have a lot of ideas of what we THINK the person wants or needs and that may not be the case.

Organizational culture can be understood as what is taken for granted as *the way we do things here*. Thinking about listening raised questions about the kind of listening that people with developmental disabilities, their families and direct support staff experience.* The belief that all of a person's

* Learning Institute Workshops introduced ideas that help people take a critical look at their culture and alternative ways to proceed. Some participants raise awareness of blind spots by using the distinction introduced by Michael Kendrick between real needs, shared by all people, and needs invented by service systems. Recognizing the effects of wounding experiences presented by Chris Liuzzo provided a new perspective.

needs were already well addressed was tested as teams listened and discovered people's previously overlooked desires for reasonable changes that allow them greater opportunities to develop new roles and new capacities. Teams have questioned the balance of power between clinical judgment and personal freedom. They have recognized that person-centered planning can energize more creative action than their current practice does. They have noticed that such simple things as an unquestioned practice that residential support staff will only work from nine-to-five outside group homes closes off many people's access to their own homes.

When change teams recognize and accept the shortfall between the values their organization espouses and its practices, the space for meaningful change opens if they are willing to step into it.

[We realized that] we need a mechanism to translate our philosophical commitments into tangible services for the individuals we serve.

Some teams recognized that over-focus on eliminating risk has created a state of learned helplessness among the people they support and unreasonable timidity on the part of staff. They have slowed down to renew their relationships with people they had assumed that they knew well in order to establish a deeper foundation of trust. Time for a slow process of shared discovery and reflection has made imagining better far more satisfying.

A service coordinator identifies a change in practice based on experience with co-initiating:

I [will] dig more when someone wants to move to the community, take more time with the individual and really help them figure out what they want.

Review questions adopted by a change team

Are we taking a critical look at the situation?

Is this person living “a good life” in their definition?

Are we doing the best by this person?

Are we limiting the individual because of our own experience/viewpoint/bias?

Are we asking the right questions and being patient with the answers?

Are we rushing the process and rushing people to make decisions?

Shared awareness of the power that fear exercises in the system as it is and the effects of fear among staff as a limit on people’s chances for a better life frames a personal and organizational challenge. Fear multiplies *no*’s, *what-ifs*, *but*s, and *can’t*s and drains energy from the pursuit of the positive goals set by the Transformation Agreement.

Co-sensing through workshops and learning journeys allowed recognition of new possibilities for action and time to re-connect with the purpose of the work that lies beyond avoiding punishment by the enforcers of the system’s complex demands for compliance. This has given some teams renewed courage.



The mutual support that developed among the network of change team members helped clarify and encourage efforts to expand the sense of possibility and ability to take action. Reflection on their experience led participants in the Learning Institute to generate their own design principles and action guides (on the following page) that keep courage and fidelity in person-centered work clearly in view.



In our day to day work, the words we use encompass various concepts and ideas: standards, regulations, audits. We know these things have been deeply ingrained as we live in a world that runs like a machine. In our day to day work with individuals with developmental disabilities we

often [overlook] the obvious, which is that people are not concepts or ideas or machines who fit into a nice, neat package.

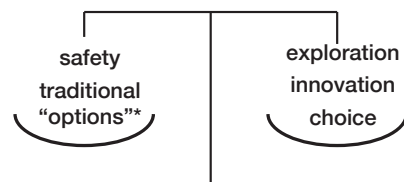
During this Learning Institute is was amazing to see how we as the participants were initially puzzled yet inquisitive about how to begin reshaping our automatic downloading: to really begin focusing on what possibilities emerge when you become open to blue space. Working in partnership with individuals focusing on what factors can and need to be explored can shape how we think about getting the good life. Looking at the actual application (how to do it) appeared to be a struggle for most of us. The what ifs, the risks, the funding, the buts continued to emerge as the Learning Institute progressed but then the lights within each of us came on: the excitement, the possibilities. “Now is no time to think of what you do not have –think of what you can do with what is there.” -Ernest Hemingway

Identifying and disclosing during this journey what within ourselves and within our agencies impedes our abilities to create and how to conquer those things within oneself that need to change has been enlightening.

Design principles & action guides

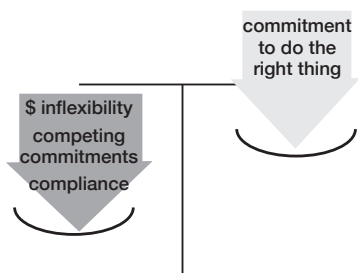
Do what is right

Find balance

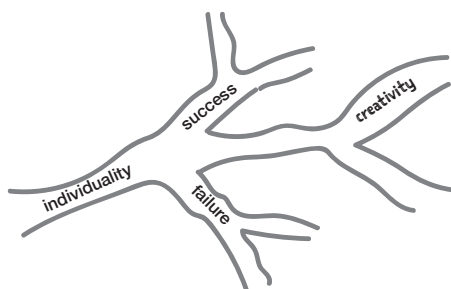


* Choosing among available vacancies in legacy services.

It isn't easy.



The person is the creator of their own journey



Keep learning more ways to put the person in control of the services we provide.

Increase people's own contributions to their journey.

Recognize basic human needs & rights

dignity•love•friendship•wellness•participation•choice•meaning•contribution•freedom

Honor voice & choice

Respect choice as a human right, for ourselves and the people we support.

Don't care for, care about. Don't do for, do with.

Enable safe, supportive environments that encourage growth & innovation. This applies to everyone involved: people with DD, families, staff.

Create opportunities for meaningful relationships

Welcome life experience

Risk is part of innovation. Take reasonable risks together.

Support people through negative experiences as occasions for growth & learning.

Don't get stuck in "what-ifs".

Life is a garden; dig it.

Minimize social distance

Encourage natural relationships to grow.

Promote independence

Don't predict. Encourage & actively support people to try new things that are meaningful to them & learn together from the experience.

Support voice by creating a culture of openness.

Promote self-advocacy.

Anything is possible

Listen, don't pre-judge

History doesn't have to define the future.

Maybe the only reason we can't do something good is because we have been told we can't.

Keep it simple & transparent

The question isn't "can it be done?" The question is "how can we do it?"

Know the rules inside & out.

Negotiate with conviction.

Persistence beats resistance.

We don't always have to have the answer. We learn by doing.

"No" is not an answer. Find reasons to say "yes"

Be in the now. The "what-ifs" will be.

Make it financially viable & sustainable but think outside the box.

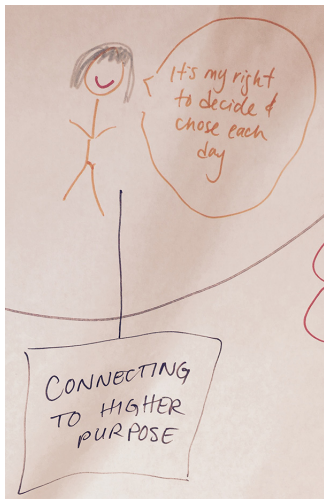
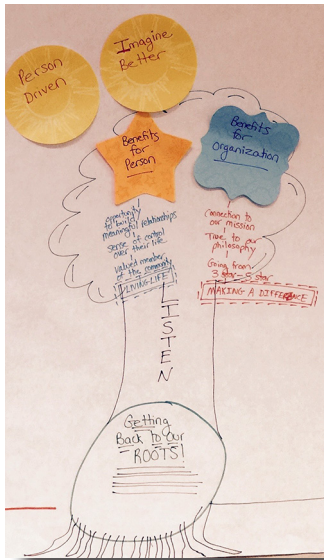
Figure how to bill for it when you know what you want to create.

Be open minded & flexible

Expect plans to change.

Participants in the Learning Journey to The Arc of Rensselaer County developed these principles. For a copy of the booklet: www.nysacra.org/docs/Participant.pdf

Cultivating the new



The Learning Institute asserts that the point of the Transformation Goals is a deep change in the form of support for a whole system, not just the addition of an option for a few eligible people. Self-direction, inhabiting one's own home, competitive employment, meaningful participation in community life and person-centered assistance will be typical, not exceptional. The task is like converting a vacant lot into an organic community garden. The ground must be cleared, the soil rebuilt, and new seeds planted and cultivated. To enjoy a new harvest, people must commit to organize and faithfully do the work from month to month.

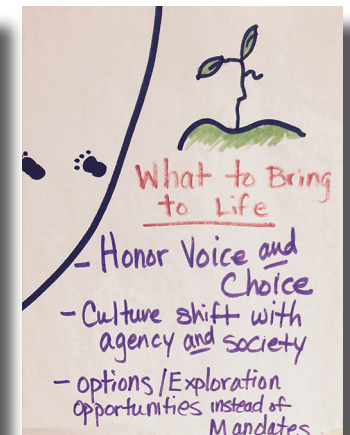
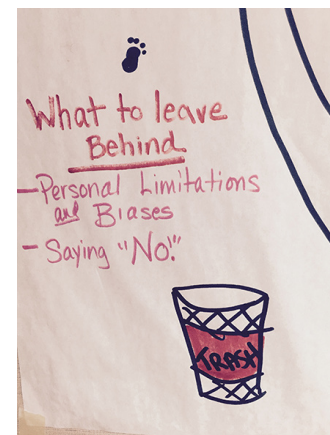
Like the Cooperative Extension's Master Gardener program, the Learning Institute offers its participants seeds, connections to others with similar interests, advice and encouragement. There is no need to wait for the discovery of new plant varieties. There are already a variety of robust practices that can grow into effective supported living and self-directed person-centered assistance, many already growing in New York's climate. But seeds are no use without living soil and the will to tend the garden.



Real change takes sustained work. Technical problems of funding, real estate and job roles need solutions. Deep disagreements about people's capacities and best interests must be addressed. Fear of risk and loss threatens focus and creative action at every stage. The energy for this work comes from connection

to the highest purpose shared by the change team. The images on the left show the ways two change teams represented the purpose that their work serves.

Clarity of purpose allows a change team to decide what they must let go of and what wants to grow with their help.



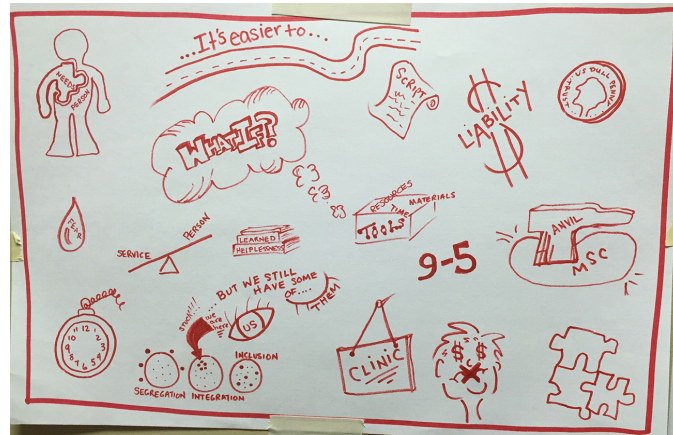
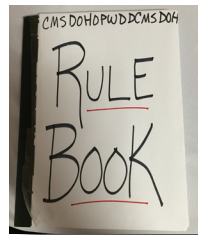
Clearing the ground

Before a vacant lot can flower and bear fruit the ground must be cleared and tilled.

In the final workshop change teams shared generative stories: experiences along their way to co-creation that connect their efforts to higher purpose and embody important lessons about creating the capacities to offer more person-centered support. Reflection on these stories produced accounts of what change teams must find ways to move out of the way in order to create the space for person-centered work to thrive.

Fear is pervasive. Continual audits and inspections have sensitized staff to the risk of rule violation (“getting dinged”) and to the statistically remote possibilities of liability for negligent death. Rule consciousness drives out direct perception of complex situations and judgment about what will safeguard people. Organizational hyper-vigilance about rule violation discounts to almost zero the costs of loss of people’s freedom of choice, movement and association, the costs of segregation, the costs to learning of living without the dignity of risk and failure, and the costs to equal and trusting relationships created by reflexively putting the details of people’s lives under staff control.

Organizations tend to recoil from **uncertainty**. At the system level, the slow and shifting pace of moving Medicaid toward managed care makes



managers unsure of what will happen to new initiatives. A wait-and-see decision rule puts a brake on investment in making and broadening the shift to individualized supports. At the personal level those who are trying new ways have no guarantee that everything will go smoothly. Indeed the odds that new problems will demand solutions are very high. Insisting that there will be no missteps or failures not only locks in inaction, it also leads to underinvestment in the means to make resilient adjustments when the unexpected does happen.

Current structures are **inflexible** and it takes a good deal of work to re-purpose their assets. Changing staff schedules and work sites disrupts settled routines. Stretching stable funding arrangements seems risky and demands negotiation. Unquestioned interpretations of regulations within organizations can reduce the space to try new ways.

Silos that separate organizational functions work well enough to maintain current efforts, but collab-

Everyone wants people to have good lives, but that doesn't mean we are always doing the best possible job of helping people to live their best lives. We can hide our need to improve under a blanket of benevolence and good intentions.

We asked Nicole, *What is the good life?**

Being on my own

Getting a job

Visiting my boyfriend whenever I want.

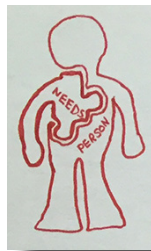
Being out and having responsibility.

orative effort across boundaries can be a key to innovation. It is especially important to bring people responsible for finance into the change team as active members. When most working relationships are internal to the organization and the DD system, creating effective connections with local landlords and employers demands extra effort from over-committed people.

There are **competing priorities**. The goal of moving the whole organization away from congregate housing and into individualized support for people's use of typical housing competes with the demand to maintain a stable supply of available beds.

Change team members regularly experienced the demands of their responsibility to manage settled services as a limit on the time and energy for innovation. For several years, organizational leaders have had to devote substantial attention to the implementation of managed care and changes aimed at making funding sustainable and transparent.

Many organizations act **overconfident in their current stories** about people. Stories about people are partial, focused on "special needs" that are



captured with disability labels that predict where the person will live. This mutes attention to the whole person's needs for freedom, relationship and meaning. Overemphasis on clinical descriptions and prescriptions can overshadow people's capacities and interests. The story becomes managing deficiencies and matching existing services to assessed needs rather than developing gifts

and valued social roles. The effects of wounding experiences are dismissed with more labels. Unquestioned assumptions about what people can't do bias thinking and decision making. Simple questions about what people want in a good life go unasked. The notion that readiness for one's own home or job can be reliably determined based on the way people act in congregate settings not only leaves out people judged unready, it leads to complacency. Staff neglect learning how to assist people to develop relevant skills in community places that matter and fail to make the best of assistive technology and environmental adaptation. People's accommodation to the services they receive, including the restrictive aspects of those services, is taken as satisfaction and a good reason to avoid creating more individualized supports.

There are some signs of **us-them relationships**. It can be easy for staff to assume that they know people well enough to speak for them rather than supporting people to develop and use their own voices. It can be easy to presume people's trust rather than strengthening equal relationships by humble inquiry and shared action. It can be easy for staff to act as if they are justified in restricting people's choices because they know best. Staff mindlessly impose the bias of *high and low functioning* labels on people as if these were valid indicators of their potential. Service-speak distances people from common life: a person's own home is spoken of as a *non-certified housing option*, a term that no one outside the orbit of New York's developmental disability services could recognize.

* From *This Is My Life*, a video produced by the Franziska Racker Centers change team.

Building good soil

An important aim of the Transformation Agreement and recent CMS rules is to substantially increase capacity to support people in their own homes and jobs in ordinary community workplaces. If this is to be done in a way that promotes self-direction the making the necessary change will be like learning to grow an organic garden. Self-direction requires equal and collaborative relationships with people with developmental disabilities and their families. Developing new opportunities calls for different relationships to landlords, housing developers and employers. If the development of these capacities is to be organic and sustainable it will take time and care to build up the soil in which new plants can thrive. In doing so it's important to avoid the depleting effects of quick fix chemical fertilizers and pesticides.

Participants in the Learning Institute have found that these practices build fertile soil. They **create blue space** in which social innovation can flourish.

Listen with the expectation that there is more to learn. New interests and possibilities show up when people experience deep listening. Appreciation of silence and letting go of the idea that staff always have to have the answers makes space for listening. Learning to let go of certainty about what is possible and what is not deepens listening. Letting go of a sense of powerlessness that delegates responsibility for change to somebody who is not present deepens listening. Letting go of fear deepens listening. The test of listening is the emergence of a shared choice to take a step forward



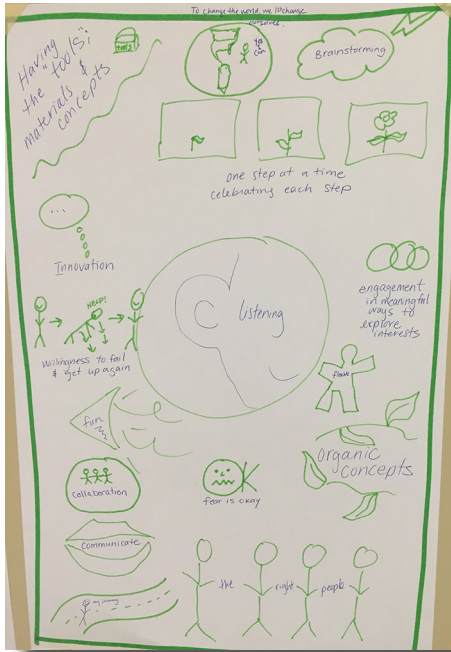
together. The size of the step matters much less than that people discovered and took responsibility for it together. In fact, a steady pace of small steps beyond familiar territory and into the new often produces more substantial results.

Make time and space for shared experiences outside the usual.

Spending time with people in the places they are most themselves (with their permission) can fill out a sense of who people are and strengthen the foundation for collaboration. Experiencing a variety of places and activities with a person allows better knowledge than meeting around a table does. Exploring with people is more powerful than exploring for them. Discussing the pros and cons of visits together to several apartments is a different experience than making an abstract list of criteria on a flip chart.

Notice limiting assumptions and question them.

People with developmental disabilities are vulnerable to the ideas that those who have power over their life circumstances have about what is possi-



ble for them. Real limits do exist, but it is important to test them and clarify their source. Compliance with rules or conditions of funding may close off some pathways. A common mistake is to assign incompetence to the person rather than the policy. *The way we fund this service doesn't allow this person to earn money becomes he isn't capable of work.* Any smell of risk triggers restrictive reflexes. The cure is thoughtful discussion of the person's real vulnerabilities in particular circumstances and the custom design of safeguards. This discussion will distinguish between the chance that a good try might fail (a form of failure that is necessary to growth) or a person might have an unpleasant experience (such as being told "no") and the potential for actual harm to the person (which calls for safeguarding).

Try new perspectives. The Learning Institute introduced a variety of different ways to understand the experience of developmental disability, the most effective ways to develop and provide support, and the process of change. Each of these perspectives provide a potential route of escape from the everyday boxes that shape organizational routine. By considering the right questions to ask to make a real shift in practice, change teams gain leverage and reduce the risk of simply re-labeling more of the same as major change. Further study and application of these ways of thinking is a worthwhile investment in keeping change teams conscious and flexible in their sense-making.

Go and see. Learning journeys allow for sensing, provide practical information and stimulate critical thinking about the meaning of such key ideas a supported living and self-direction. Learning journeys can involve a road trip or they can happen within an organization.

Connect with change makers in other organizations. Local efforts benefit from the mutual support, encouragement, critical friendships and shared ideas that come with personal connections to people working for change in other organizations.

Take responsibility for change. The Learning Institute presents the Transformation Goals as a demand for deep change. This change would be difficult if there were plenty of room for change teams to maneuver. As it is the system shows no sign of easing the imposed constraints that multiply complexity and render public money inflexible. The system seems to imagine that new crops will grow organically in fields that it continues to saturate with the chemicals of regulation and bureaucratic command. Organizations have successfully adapted to provide services that congregate and control people and encounter much stuckness as they try to shift to self-directed, person-centered supports. Most change team members are over-committed and have little time to imagine better, negotiate necessary resources, try new things, and reflect and refine them.

Despite all this the will to create new form of support persists. Making the change calls on change

teams to take responsibility for making space for co-creation. In the first place this means claiming regular time to work together both in meetings and in action outside usual boundaries with people with developmental disabilities. It means setting aside good reasons for withdrawal from the polarities and scarcities that shape their organizations and cynicism at the contradictions and uncertainties that grip the whole system. It means reaching across boundaries to bring more and more people into shaping a strong, clear sense of a future worth co-creating.

The chances that the Transformation Goals will be more than words on paper grow stronger when change teams continually learn from action that engages people with developmental disabilities and their families and support workers with people responsible for finance and compliance in efforts that co-create and support valued roles and relationships in community life.