NYSACRA Learning Institute on Innovation in Individualized Supports

Contents

The cover image, by Kim Brooks on behalf of her Change Team, depicts Orange County AHRC's journey. The desired future, on the right, is an organization with the maneuverability and grace of a fleet of world cup sailboats. Current reality, on the left, is a steam powered liner that is inadequate to navigate the new waters of individualized supports and endangered by the white water of fiscal austerity. Several generations of prototype vessels mark the stages of organizational learning yet to come.

INTRODUCTION

The NYSACRA Learning Institute on Innovation in Individualized Supports grew out of the work of the Individualized Supports Think Tank, a multi-stakeholder group that gave shape to the idea of individualized supports. NYSACRA's investment in creating the Learning Institute reflects its strategic goal of *Exploring a New Service Paradigm* by assisting providers' efforts to develop individualized services and supports. The Institute is administered by NYSACRA, funded by the Developmental Disabilities Planning Council, OMRDD, and NYSACRA, and strongly supported by the Self Advocacy Association of New York State.

The first phase, from April, 2007 through December, 2008 engaged 15 provider agencies from around the state to increase their capacity for creating innovative, individualized supports for 10 people, initially using OPTS proposals. The second phase, from April, 2009 through June, 2010 engaged 11 provider agencies from the Hudson Valley region of the state for the same purpose, but with modifications to the process based on experiences of the first phase. Each phase of the Institute culminated in gatherings of those involved in individualized supports from around the state, to build connections and think about pathways to the future.

One June 11, 2010, nearly 100 people from Phase One and Two providers, DDSO portal liaisons, site visit host agencies, Central Office OMRDD staff, and others came together to share the successes of what's working, face the obstacles of what's not, and commit to learning together how to think differently. The results of their conversations are posted on the Learning Institute website at http://www.nysacra.org/nysacra/li/PhaseIICurriculum_Materials.htm.

Lessons learned from the two Institutes are chronicled in two "Learning History" papers written by John O'Brien, consultant to the Institute, both available on the website. In Phase One, he noted that change was harder than many expected, even though committed people struggled to deepen their understanding of individualized supports, to find ways to increase organizational commitment to generating innovations, and to discover effective ways to negotiate with an OMRDD whose leaders were in the midst of an effort to re-align its administrative structures to better match its strategic commitment to individualized supports.

 In Phase Two, which follows, he highlighted "turning points" or shifts in a person's understanding of possibilities for change: learning journeys to sites of innovation, meeting people with developmental disabilities who are living with individualized supports, involving people with developmental disabilities directly in their learning experiences, being active in a network of people on similar journeys, being part of a strong change team, and incorporating new practices into work routines. Overall, the Institute provided a pattern of encounters, relationships, and realizations, which together allowed the participants to make sense of the concepts and challenges in the curriculum.

The NYSACRA Learning Institute Phase Two project is officially complete, but the strategic goal remains and so the effort will continue.

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Ann M. Hardiman

Executive Director

July 9, 2010

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Perspective

Part I of this Learning History* describes the purpose of the Learning Institute, defines its conceptual framework, and presents what those responsible for guiding the process learned about the systemic challenges of developing the capacity for individualized supports in New York state's developmental disabilities service system in Phase I.

Phase II of the Learning Institute, which engaged a different set of organizations from October 2009 to June 2010, had the same purpose and conceptual framework as Phase I (outlined on the next page) but the process was modified in light of reflection on Phase I.

- The term of Phase II was shorter (9 months rather than 21 months).

- Phase II participating agencies were geographically concentrated in two OMRDD Developmental Disabilities Services Office (DDSO) areas (Taconic and Hudson Valley) rather than drawn statewide. This was intended to engage DDSO staff as active participants
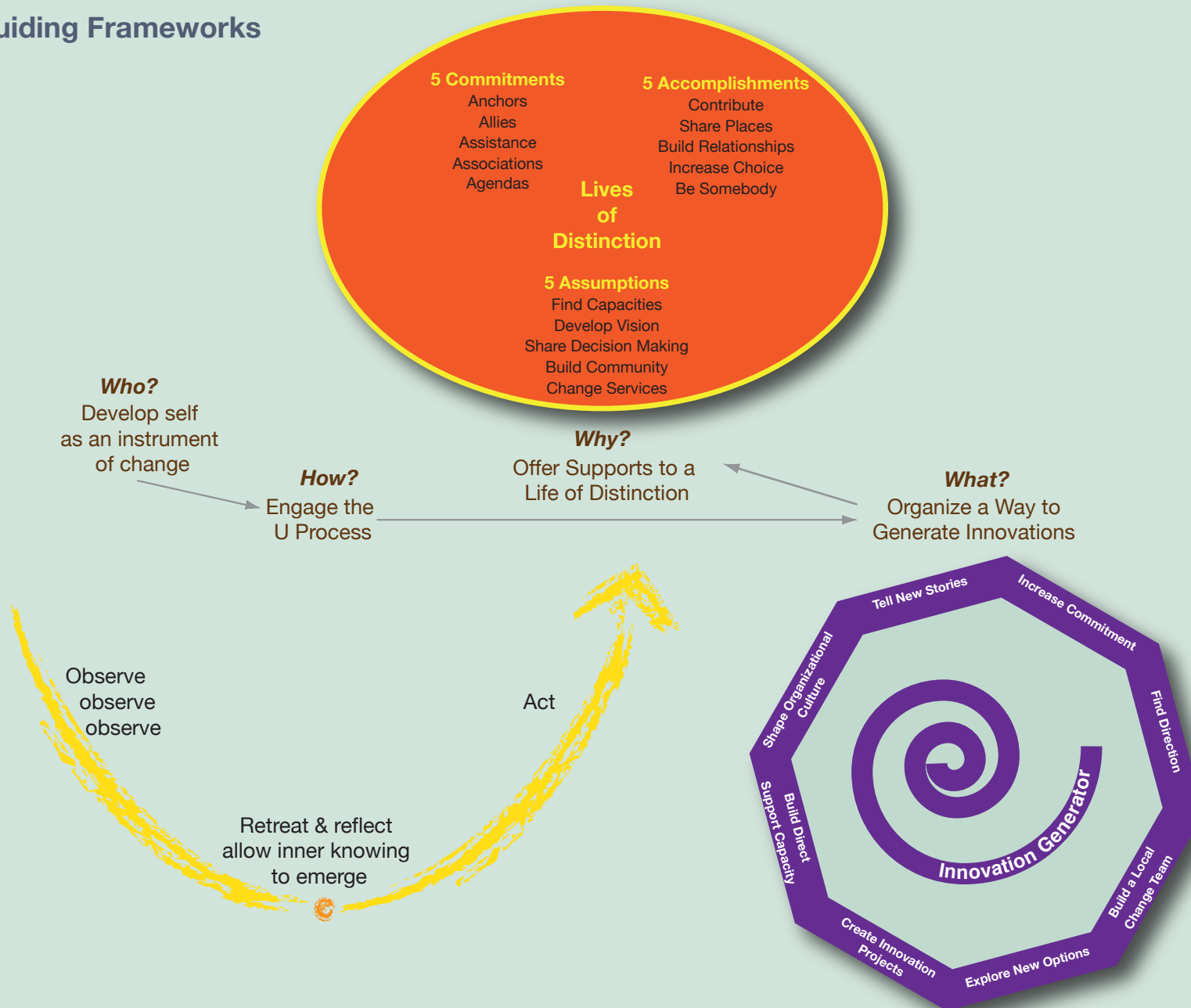
Learning From Phase I

- Offering individualized supports calls for transformational change. It is not simply a matter of attracting additional money and solving technical problems.

- Transformational change calls for people to engender commitment to supporting people to compose a life of distinction, develop themselves as instruments of change, engage in a creative process, and design and implement an increasingly subtle and reliable process for generating the social innovations necessary to respond to a variety of particular and changing individual circumstances.

- Fully realizing individualized supports is impossible unless the whole system evolves into a person and citizen centered pattern of operations. This requires a different mind-set and different approaches to control than is current.

- In order to develop its capacities for individualized support, the system needs to make thoughtful and substantial investments in creating platforms for change. These platforms are built to contain but not extinguish risk. They offer capable innovators significant degrees of freedom to build collaborative relationships with people with disabilities and their families and community members and learn from taking action on deep listening.

- Moving toward a system capable of offering individualized supports will conflict with important commitments and big assumptions that shape current reality. A good strategy will support productive discussions about immunity to change.

- Investing in the formation of cross boundary, voluntary communities of practice around individualized supports will make an important contribution to change.
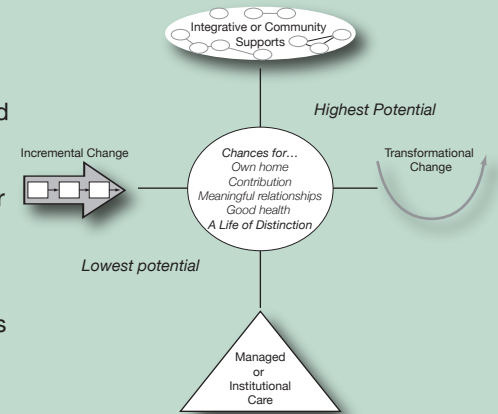
*John O'Brien (2009) *NYSACRA Institute on Innovation in Individualized Supports: A Learning History. Phase I: April 2007 – 2008.* Albany, NY: NYSACRA. www.nysacra.org/nysacra/li/A_Learning_History.pdf

	October	November	December	January	February	March	April	May	June
Learning Journeys	Rensselaer ARC		Job Path Another Step						
Focused Workshops		Patti Scott on Individualized Supports Awakening the Spirit	Theory U at Garrison		Design for Discovery	*local discovery process*	Wheel Power with Self-Advocates	Webinar with MD Community of Practice	
Institute Sessions	Innovation for Lives of Distinction	Increasing Commitment		Prototyping				(Group Reflections)	Final Session

Guiding Frameworks

5 Commitments
Anchors
Allies
Assistance
Associations
Agendas

5 Accomplishments
Contribute
Share Places
Build Relationships
Increase Choice
Be Somebody

**Lives
of
Distinction**

5 Assumptions
Find Capacities
Develop Vision
Share Decision Making
Build Community
Change Services

Who?
Develop self
as an instrument
of change

How?
Engage the
U Process

Why?
Offer Supports to a
Life of Distinction

What?
Organize a Way to
Generate Innovations

Observe
observe
observe

Act

Retreat & reflect
allow inner knowing
to emerge

Tell New Stories

Increase Commitment

Shape Organizational Culture

Find Direction

Build Direct Support Capacity

Innovation Generator

Build a Local Change Team

Create Innovation Projects

Explore New Options

with agency Change Teams in Institute activities, however this proved very difficult for DDSO staff.

- Phase II participants had no additional resources promised from OMRDD because of their participation in the Learning Institute and, while some agencies have pursued funding through their DDSO before or while involved in the Learning Institute, there was no commitment of OMRDD funds to Learning Institute initiatives. The uncertainty about dedicated OMRDD funding that occupied considerable attention in Phase I did not affect Phase II.

- Phase II Agency Change Teams gathered as a whole group fewer times for longer sessions. The processes and materials for these sessions were refined and participants had the opportunity for more extensive exposure to Theory U than Phase I participants had (see www.nysacra.org/nysacra/li/PhaseI-ICurriculum_Materials.htm).

- Phase II put an even stronger emphasis on Change Teams (or Learning Circles as some agencies named them) than Phase I did. Two of the 11 agencies withdrew from the Institute because of internal changes that made it difficult to sustain their Change Teams.

- Agency Change Teams were encouraged to match themselves and other people from their organizations to a series of Learning Journeys and focused workshops. Many of these activities were scheduled in the first quarter of the Learning Institute to accelerate Change Team learning and provide opportunities to engage other people from their agencies.

- Phase II included an opportunity for group reflection on the Learning Institute convened by John O'Brien and Beth Mount. Three different groups of Change Teams members and their guests met for a day long session to consider their experience of the Learning Institute.

Part I of the Learning History gathered lessons about the whole system from the perspective of the Learning Institute's designers. This Part identifies themes in the experience of the Learning Institute from the point of view of its participants by considering Reflection Group members' discussion of two open ended questions:*

- What have been some of the **turning points** as you have moved through the Learning Institute?

- Which Institute ideas or activities have had the greatest positive impact on your ability to work for change in your organization?

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*This Learning History simply recounts what I have learned by reflecting on what people said during the three group meetings and the Learning Institute's final session on 10 June. In the group meetings, I listened carefully, made notes during the meetings, frequently summarized my understanding to check accuracy, and asked groups to identify common themes and resonant ideas. I reviewed my notes, identified key points, and sorted to identify the themes and messages I have written about here. While I have tried to preserve the sense of what people said, I have summarized, linked similar ideas across groups, slightly modified some examples to make them anonymous, and paraphrased freely to create a narrative from participant's comments. The turning points that people identified are moments of individual learning and I have not tried to weight them in terms of the frequency of their occurrence or in any other systematic way. Some points are made with quotes from my notes, set in italics; most of the points have been combined into the narrative. I have supplied the overall context in my reflections after the meetings; this might shift the meaning that people intended. This is by no means a complete summary of Phase II of the Learning Institute, an account of its accomplishments, or a complete record of participant evaluations of the Learning Institute. It will serve its purpose if it stimulates further conversation about the complex, fascinating, and frustrating process of realizing the vision of individualized supports.

Notable results*

For organizations

- Greater visibility & growing commitment to individualized supports
- Increasing board support
- Renewed mission through an extensive process of discussion of the meaning of a full life
- Adopting quality of life measures to drive the mission
- Recognition of the scope of cultural change required
- Greater numbers of staff actively involved in change process
- Stronger change team with greater organizational support
- Direct involvement of people with disabilities in change team
- Cross department involvement in changes
- Investment in Innovation Developer position
- Changes to hiring & orientation that better reflect the values of individualization & give people & families a more active choice of who supports them
- Strong connections with efforts to strengthen direct support professionals' contribution (Everyday Heroes, Dreamcatchers)
- Learning more about non-traditional housing options
- Seeking resources outside the OMRDD system (CDBG, housing counseling, First Time Homebuyers Club)

For working relationships

- A new & stronger connection with people
- Stronger partnerships with people & families in developing supports
- Listening more openly to people & so a deeper understanding of people's dreams & preferences
- Staff thinking differently about people
- Positive changes in behavior planning
- More staff seeing new possibilities
- Acting with people to take steps toward what they want

In people's lives

- New roles in community life, more focus on membership, jobs, learning (one person earned her Nursing Assistant Certificate)
- Active engagement of person in Learning Institute & Learning Journeys
- Increasing autonomy
- A greater sense of hope & ownership of a positive future
- More people leading their own planning
- Emerging sense of independence & freedom
- Parents starting to consider investing in new possibilities
- Many steps closer to actualizing the dream of independent living

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* This is a compilation of the results reported by the Change Teams participating in the final session on 10 June; each agency accounts for some of the results reported in the lists here.

Another Mountain

Think of the top of the mountain on the left as the system's destination for the past 30 years. Legislators and executive officials, other state agencies, OMRDD managers, providers, and advocates have become remarkably good at their jobs and have attained a summit they can be proud of. Generous allocations of state funds have leveraged a high level of federal financial participation. The number of people in institutions has declined very significantly as has the number of people on waiting lists for services. Provider agencies are for the most part successfully meeting increasingly complex and stringently enforced regulations. Community and political support is high.
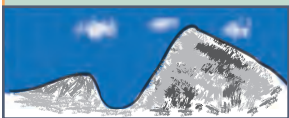
As a number of Learning Institute participants have come to a deeper understanding of what is possible, a wider vista comes into view. They see that building competence in individual supports means climbing another mountain. At the moment this looks like the mountain on the right of the picture: a steep learning curve presents uncertainty and different risks. New sorts of equipment and new techniques will need to be invented to make the ascent. High functioning teams are essential to stay oriented and maintain courage.

Scaling the mountain of individualized support requires coming down from the summit the system has worked hard to achieve and maintain. It means descent from hard won capacity to solve the routine difficult problems that arise on familiar ground and finding a way in territory that demands more innovation. Transformational change depends on noticing that it is possible to be too good at our jobs, so well adapted to our current system that we try to hold on to the familiar even if the ground is shifting under our feet and the important opportunities lie on the next mountain. At-tachment to practices and structures that work well on the current mountain top can inhibit exploration. An important part of the work involves carefully reviewing cherished assumptions, systems, structures, and practices and choosing what to conserve and what to leave behind.

For most of the system, the scale of what is possible on the next mountain is unknown. It's prudent to send out teams of explorers to survey and invent new techniques and tools. It's important not to weigh them down with the paraphernalia that seems necessary to survival on the current summit.

This storyboard presents Crystal Run Village's journey from the point of view of a Change Team member with a developmental disability as she increases her knowledge of alternative ways to arrange supports and use technology, expands her circle, discovers new connections and capacities, gains confidence and refines her plans.

Turning Points

We define individualized supports as an array of supports, services and resources that are person-centered, based on the unique interests and needs of the person, afford the person as much control over their supports as they desire, and are adaptable as the person's life changes. This means that supports are created around an individual's distinct vision for their life rather than created around a facility or funding stream.

–Individualized Supports Think Tank

Reality check. As part of the discovery process, Change Team members at one agency invited a person to join them, along with their Service Coordinator, for an intentional but informal meeting in a neighborhood coffee shop. The Change Team's purpose – which they shared with the Service Coordinator– was to listen carefully in order to get to know the person better, continue to build collaboration, and gather some more ideas about what individualized support might look like in this situation. The meeting delivered a reality check as Change Team members noticed the behavior of the Service Coordinator, who had not been involved in any Learning Institute activities. The Service Coordinator listened only until the person indicated that they had been wondering about a potential change, jumped in to interrupt the person with a judgement that what the person was thinking about was not realistic, and rapidly proposed an alternative that seemed to Change Team members to have little connection to what the person had been wondering about.

To Change Team members, this everyday moment signaled that a capable colleague has a very different sense of the way that individualized supports emerge than they have. They recognized that the journey that they have taken with the Learning Institute has brought them to approach the people their agency serves from a different place than this Service Coordinator does. The reality check demonstrates that they need to significantly increase the number of their colleagues who listen in the way that they have come to appreciate makes a positive difference to people's responses to questions about what matters to them.

Turning Points. It is not uncommon for people committed to a change to say that people like the Service Coordinator in the preceding vignette "don't get it". This phrasing usually implies a negative judgement. Often, it is spoken in a tone that expresses a frustrated desire for change, asking what can we do to make this person get it. At any rate, it points to an observed difference that makes a difference to the success of the change effort. What might be the sources of this kind of difference and what does this suggest for developing the capacity to offer individualized supports?

A person might not get **the words**, or not get them in the same way that the change agent does. Individualized supports or person-centered planning might be unfamiliar words whose definitions people need to learn or terms that people define differently. If this is the source of not getting it, vocabulary instruction and perhaps a source of authoritative definition will increase the numbers that get the words.

A person might not get **the process**. For example, the discovery phase of person-centered planning follows a set of steps and a logic. A person unfamiliar with the process might impatiently sidetrack it. If this is the source of not getting it, study, guided practice,

and apprenticeship will increase the numbers that get the process.

A person might not get **the dance**. The Learning Institutes' designers understand the good qualities of individualized support as emerging from relationships in which people are open to a form of sensing capacities and possibilities that generates new support arrangements that fit individual circumstances. This sort of relationship reflects a distinctive way of being together in a specific community and service system environment. It is a particular sort of dance.* Someone who operates from the assumption that they are in a dance of professionally assessing deficiencies and prescribing solutions from a formulary of existing programs will look very strange indeed to those who are moving to the rhythm of individual possibilities for a life of distinction. When both share the same dance floor things may seem weird indeed. If contrasting dances is the source of not getting it, people will need to choose to join a search for new patterns of invitation, expression, and response. Because much of the dance of individualized support happens beneath and before procedures and words, learning takes place by experiencing familiar things, like conversations with people who receive support, in new ways.

The Learning Institute offers its participants opportunities to update and extend their vocabulary through a series of conceptual frameworks, images, and stories that define its designers' current understanding of individualized supports. It provides chances to learn and practice some of the arts of planning with people, organizing supports, and developing a capable organization. And it invites people to join in the experience of a journey of discovery.

One way to look at the journey that the Learning Institute orchestrates is to identify turning points, moments when participants sense an important shift in their understanding and their power to innovate. From this perspective, those who seem not to get it have passed through fewer turning points than those who feel a different energy and direction for change.

The turning points that participants in the reflection groups identified are personal and arise from their individual histories and their differing organizational roles and contexts. Because these shifts are developmental and depend on people's openness to them in the moment, turning points can't be programmed and delivered in a curriculum in the same way that words or procedures can. Because these turnings are fundamental to joining the dance, and thus to understanding how to engage people with developmental disabilities and their allies to enact individualized supports, the Learning Institute can best be understood as offering its participants access to a variety of experiences that can bring them into a more vital contact with their highest future purpose and the highest future purpose of their field.[†]

Expressing these turning points in written words dehydrates them. Moments of insight are more often accompanied by a shift in a person's sense of understanding, or clarity of direction, or an increase in
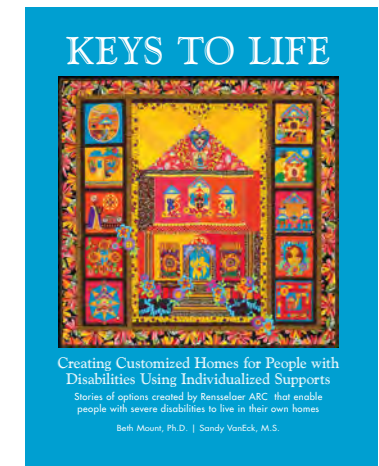
*For a fuller exposition, with examples, see this account of the work of Rensselaer ARC, one of the Learning Institute's Learning Journey sites. Contact SVanEck@renarc.org to order a copy.

†This way of thinking about the Learning Institute continues my effort to understand the work of Otto Scharmer and his colleagues at the Presencing Institute. While I gladly acknowledge my debt to them, they are in no way responsible for the limits of my understanding. Those who want to follow my advice to learn more should consult the resources collected at www.presencing.com rather than relying on this paper.

Insight into Turning Points

The standard English translation of the Chinese classic *I Ching or Book of Changes** names its twenty-fourth guiding image *The Turning Point* and offers counsel about moments of turning. A few points from this guidance are paraphrased here to identify an infrequently discussed form of change that is necessary to generating greater capacity to individualize supports.
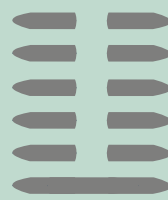
The turning point comes naturally after a time of decline, just as greater daylight begins to return, almost imperceptibly, the day after the year's darkness reaches its greatest depth at the winter solstice. Something old, that has passed its time, is left behind and the new is introduced. Movement toward what is new occurs because the turning is devoted to the possibilities of the moment. It brings those who sense it into harmony with the time. One may fail to recognize the turning; this leads to misfortune.

The turning always calls for decision and self-mastery. This is easier when a person is in good company and chooses good examples to follow. It will be easier to stay the course when there is a connection of the spirit with a good friend.

When a social group shares the same view of the turning and makes their knowledge public, selfishness and separation decrease, the way becomes more clear and easier, and the chances of fatal mistakes decrease.

The turning is not forced and so there is no risk of serious harm as long as its path is followed and the inevitable early missteps are detected and corrected quickly.

In the moment of turning energy for change is just at its beginning. It is strengthened and reinforced by a period of rest. Everything related to the turning must be treated with care at the beginning and not dissipated so that the turn can lead to a flowering.

Wilhelm, R. & Baynes, C. (1969). *The I Ching or Book of Changes*. Bollingen Series XIX. Princeton: Princeton University Press. Pp. 97-100.

energy for action than in streams of new and persuasive words. The words and images that people chose to express important changes often sound familiar, even cliched, but in context these common words take on new meaning and open new possibilities for the person whose sense of things has shifted.

"Listening" provides an instance of the feebleness of written words. A number of participants reported turning points around a new kind of energy for change invoked when they practiced a deeper quality of listening. It is from this deeper place that they can see that they had previously been listening in a less powerful way without knowing that deeper is possible. To those who have not been through this turning point, hearing that listening matters in person-centered work will not seem anything like news and the report of the possibility of greater depth of listening may not register at all.

This Learning History, then, risks looking like a rehearsal of the obvious. That is a good reminder that there are no substitutes for what can be learned by setting out purposefully with good companions, opening mind and heart to new experience, embracing what arises on the journey, sharing its benefits with those who stayed at home, and reflecting on its lessons.

We don't get out much

The call of possibility guides and energizes leadership for transformational change. Despite public commitment to individualized supports, New York's developmental disabilities system* muffles this call.

The system works as it is, so agencies experience little immediate demand for change. Both locally and statewide there is substantial civic and political support for agencies and services as they are. Most of the people and families currently served seem satisfied with the overall design and logic of current services. Complaints are more likely to be framed as failures to implement existing policies or scarcity of placements than as demands for fundamentally different forms of support and many react negatively to proposed changes that might interrupt current patterns. Crucially, the system has been spectacularly successful at attracting funding through a cycle driven by maximally leveraging Medicaid. Much advocacy effort goes toward preserving what the system has in the face of fiscal crisis.

There is a high degree of homogeneity in the system. The history of New York's deinstitutionalization efforts and concurrent growth of Medicaid funding has elaborated a tightly coupled system of administrative mechanisms, labor agreements, and regulatory processes in which there is relatively little variation in program design, service practice, and organizational structure. Agencies are much more likely to distinguish themselves with innovations in practices within

a common service model and occasional incremental changes to that model than by generating the kind of new forms of support that advocates of individualized supports have in mind.

The system is large enough to supply most of what it needs in the way of personnel from within itself, so there is a limited flow of people across state and system boundaries. Many in senior management positions have grown up in the system or closely related agencies, and sometimes within just one or two organizations; most managers have a repertoire that is sufficient to deal competently with the opportunities and conflicts that the current system presents.

The system runs on continual compliance with a regime of expanding detail complexity that rivals a NASA shuttle mission. Staff at every level devote a significant portion of their time to documenting, checking, justifying and correcting their agency's conformity to rules dedicated to safeguarding health and safety, assuring the correct delivery of authorized services, and maintaining a steady flow of funding. Because rules govern very fine details, strong agency norms develop around avoiding punishment from auditors and regulators who scrutinize their work frequently and minutely.

Demands for action are constant and for many managers over-commitment is a way of life. An in-box with more than 50 unanswered messages is not uncommon, routine meetings necessary to keep orga-

* Throughout this paper, "system" refers to the whole set of advocacy organizations, service providers, and state administrative agencies that shape the use of public funds to support people with developmental disabilities and their families in New York State.

nizational wheels turning take substantial time, crises demand resolution, the unexpected arrival of auditors has become routine, work often accompanies people home. Time for thinking, reflection and renewal is a luxury that seems so hard to afford that even the desire for it disappears.

What makes this system profile interesting are the turning points at which some Learning Institute participants sensed the effects of these everyday contours of their culture on their ability to work effectively for individualized supports. They noticed themselves **enclosed in a sort of cultural bubble** that makes it difficult for them to notice and learn from positive differences between their current understanding of individualized supports and what other organizations are doing. These turnings shift a catalog of obstacles to action into a series of invitations to listen and connect in a deeper way.
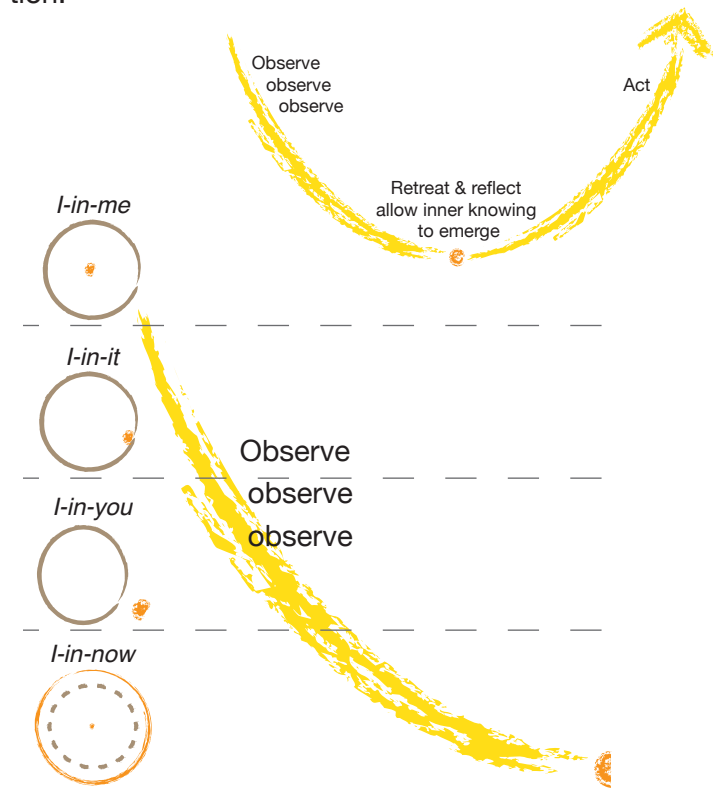
Many change team members participated in a two day workshop, *Theory U: Learning from the future as it emerges*, presented at the Garrison Institute in early December 2009 by Katrin Kaeufer and Arawana Hayashi of The Presencing Institute. This workshop involved Learning Institute Participants with interested staff and managers from other agencies in the experience of listening more deeply to self and others to sense the highest future possibilities in their situation and design actions that embody those possibilities. The experience of dialog, social presencing theatre, journaling, movement, reflection on case examples, and design of prototypes led some Learning Institute

* For a description of these practices, see the *Theory U Toolbook* at www.presencing. com/docs/tools/UToolbook_ v1.1.pdf

†See a brief video of Otto Scharmer summarizing this perspective, *Leadership Is to Shift the Inner Place from Where We Operate,* at www.youtube.com/ watch?v=XMPOf4iMDe8&feat ure=related For a fuller exposition, see Otto Scharmer (2009). *Theory U: leading from the future as it emerges.* San Francisco: Berrett-Koehler Publishers. Chapters 8–11.

participants to turn toward a continuing investment of time in deeper listening and reflection. Some have adopted the Case Conference method that they learned at the workshop as a regular practice, others have seen the importance of making time for relationship building as a foundation for person-centered planning efforts.*

The workshop also offered an understanding of leadership as an intentional shift in the inner place from which we operate.† Each shift into a deeper mode of listening brings people closer to the source of a direction and energy that powers meaningful innovation.

I-in-me

I-in-it

I-in-you

I-in-now

Observe
observe
observe

Act

Retreat & reflect
allow inner knowing
to emerge

Observe
observe
observe

From certainty to admitting new evidence

Learning Journeys gave Learning Institute participants the option of visiting and learning from agencies that have worked within the same system constraints as participating agencies do and have generated viable innovations that provide individualized supports to some of the people they serve. The visits offered more than a chance to see what people's lives begin to look like when they experience individualized supports. They also allowed a look into how the host organizations have adapted to the demands of offering individualized supports.

During their visits, some participants noticed that they were using **strategies for not learning** about individualized supports from their hosts and decided to suspend these strategies in favor of more open inquiry.

- Focus on similarities and miss differences. *I was busy saying to myself, "This is nothing new." And, "We do this too." when I saw that they were doing something very different from what I even thought was possible.*

- Attribute greater ability to the people their hosts support. *Our guys are just too low functioning for this to work for them.*

- Assume that the risk to people supported individually is unmanageable, accidents waiting to happen.

- Assume that no one that they serve would want to deal with the uncertainty and responsibility of change and that family members would resist overwhelmingly.

- Assume that the risks to their organization are unacceptably high.

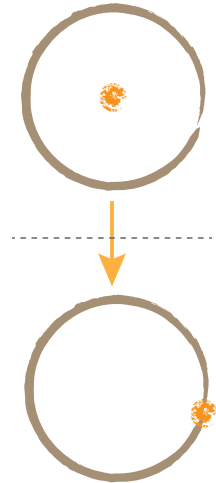- Assume that their hosts somehow work under fewer system constraints.

Of course any of these things might be true. The turning came for those participants who became conscious that these assertions amount to a stream of judgements based on untested assumptions and that this stream restricted what they saw and heard.

Some participants decided that these strategies reinforce the cultural bubble. Even when people leave home, they carry the bubble with them, ignoring or discounting differences that might disturb current practice more than a comfortable little bit. The way out of the bubble is simple but not always easy. *When we let go of the chatter in our heads and just look, listen, and question we can learn from each other.*

Suspending internal judgements that support more of the same can be disorienting because it disconfirms settled beliefs. *I was so sure that a person who needs a lot of support could never live outside a certified home that I almost missed seeing that it was working. But when I really saw what was actually happening, I kept going back and forth between "It can't work" and "It does work." I decided that individualized supports can benefit a lot more people than I knew. So the job is even bigger than I thought.*

Some new possibilities come at the cost of sacrificing comfortable assumptions.

From stuck inside my own cultural bubble…

…to looking around me for evidence of new possibilities that challenge my current assumptions.

* For a brief description, see the
video clip button, *Wheel Power*,
at www.wehavechoices.org.

From new evidence to new possibilities

Focusing attention and discussion inside the cultural bubble preserves certainty that current plans for change are based on a complete understanding of the possibilities and limits of individualized supports and the interests and capacities of people served. Recognizing the power that our certainty has over what we see and think shakes that certainty and opens up space for deeper listening and learning.

The Learning Institute offered Change Teams two opportunities to collaborate with people they serve in a person-centered planning process: *Awakening the Spirit Within*, co-sponsored with Onondaga Community Living, and *Wheel Power*, a discovery process and workshop co-sponsored with the Self-Advocacy Association of New York State (SANYS).* Each of these experiences brought people together in a way that contrasted with typical ISP meetings in the use of time, the images of planning together and the questions that shaped the inquiry. Resource people who are living or supporting people to live a more self-directed life with individualized supports were available to participants to encourage better listening and a longer reach.

For some Learning Institute participants this process was a source of disconfirmation of unquestioned certainties. As one Change Team member put it, *The person has been on my caseload for three years. I thought I knew all I needed to about her. In just a little while, I learned so much I didn't know about her.*

Some who shared these planning opportunities recognized the positive effects of straightforward practices like bringing people together with others who are living individualized support, dedicating time, and devoting respectful attention to open questions about capacities, relationships, and desired opportunities. A turning point came for some people when they realized that **they can create an atmosphere that allows empathic listening**, a kind of appreciation of other's experience that provides a new and stronger understanding of the person, a better focus, and a greater desire for change.

There are disturbing suggestions in this discovery. The level of energy and knowledge that shapes individualized supports does not depend primarily on proficiency in implementing procedures. Especially in its early stages, it depends on the internal state of those involved: where inside themselves they listen from, their capacity to create sufficiently trusting relationships, and what they believe about what is possible and desirable.

The tension grows when it becomes clear that the planning process underpinning individualized supports is not a form of magic open only to a few. It does not require great artistic talent or extraordinary charisma. A number of different approaches seem to work. What is essential is bringing people together in respectful way –including the differing voices of people themselves, family members, friends, community members, direct support workers– and listen-

ing together for the possibilities that emerge from a committed search for a valued future.

From this point of view, individualized supports are not a programmatic offering that an agency constructs and then offers to people, making small adjustments to suit individual preferences like a housing developer offering the option of granite counter-tops. Individualized supports are created when people join together, listen to one another and act in their communities in a purposeful way. This leads to the sorts of personalized innovations that are required to provide good support. The agency role is to support these collaborations not to hold an inventory of placements.

Direct experience of how much routine ISPs leave undiscovered –and how accessible and ultimately beneficial a better alternative is– raises awareness of how tightly the time and behavior purchased by Medicaid can be bound to less productive activities. Those who make this turning face a demand to actively make time and space to listen empathically.

Since you ask: A listening dilemma

Most people and families who receive extensive services report overall satisfaction with their lives and supports. However, some other stories are possible when the context changes and people feel that their perceptions are welcome and will not be met with disapproval. The box on the right summarizes the change agenda that one self-advocate defined through several contributions to a Reflection Group. (I

Can we get the message?

A person with a lifetime of experience receiving services acts as a paid advisor to one organization's board and actively participated in a Reflection Group. Her key messages:

- Expectations for employment are way too low. Not only are many people not expected to be able to work outside of a sheltered setting, services just get a few kinds of jobs and people have no opportunities to take up trades or other occupations. Staff ignorance of better job possibilities keeps people in the dark or makes staff discourage people who want good jobs. This expectation that people can't learn to be more self-sufficient means that people are less able to manage on their money than they need to be, so poverty bites harder.

- Ways to back people up when they hit rough times are lacking. When things fall apart, people find themselves back in a more sheltered setting and sometimes they lose their chance to get out.
- People face discrimination at every turn and staff could do more to support people to fill their responsibilities as citizens. Two examples: Access to voting is poor and many people don't learn about alternatives like absentee ballots. Many people are excluded from serving on juries by poor access or professionals judging that they are not able.
- We need to survey people to see what they understand about their rights and find out what they want to do to exercise their rights and their responsibilities.
- Lots of people have spent many years out of place, separated from their families and other people because of service responses to disability. Sometimes people have big dreams, like anybody else, but their dreams get shot down, even by their own family. My family shot my dreams down from when I was a little kid and it still hurts and makes me angry. When people have been separated and had their dreams shot down they need help and support to stand up, break the stigma, and move on with their lives. Nobody should be surprised if people are angry about this or if the anger comes out when some-one really wants to listen.
- The names and the history of services are stigmatizing. They associate people with retardation. This insults the people who use the service, some of whom do not even have intellectual disabilities. It also sends the message that people aren't capable of being rehabilitated into a more independent life. The "R" should stand for rehabilitate.
- Staff don't always provide people with services that really match their individual condition and help them grow. More people could learn literacy, take control of their money, and learn to figure out how to do things and when to ask for help if staff would start with what people can do and move on from there instead of doing for them and just telling them what to do. Instead we should expect people to learn to solve problems and have the tools to figure things out for themselves.
- Too many staff have a "look down on you" attitude. It doesn't matter what questions they ask with that attitude, people won't be able to give them good answers.
- Staff say they are too busy, running all the time and not having time to work on these things. I wonder if they are always running with the ball or if sometimes they are busy running away from something. I think we should ask what they might be running away from.

assume that these are ideas that this advocate has developed and shared in her role as an advisor to the agency and that the agency has taken good account of them. What follows is a more general reflection.)

What is striking about this agenda, besides its perceptiveness, is the dilemma it poses. Addressing it is a massive task, even to the extent of discovering how many of the people the organization serves would agree with its picture of their services or its priorities for change. It is hard to hear these things without feeling drawn to do something about them, but it is hard to figure out where to find the resourcefulness to act on them. There is a temptation to let this call to action be simply a speech a self-advocate is occasionally indulged to make.

This would miss the strategic insight in this agenda. Exactly like progress on individualized support, making progress on its items calls for a turn around in organizational culture: higher expectations based on stronger belief in people's capacities and more capable assistance; assistance more precisely matched to individual circumstances; more powerful and practical back-up when things go bad to underwrite greater risk; more focus on valued community roles, especially employment. This underlines the importance of approaching development of individualized supports as one aspect of creating an organizational culture with the capacity to innovate in response to what all its members hear when they listen carefully to each other.

Clearing the space for learning

Simply finding time and material resources to collaborate with people to generate individualized supports is challenging indeed. Some participants in the Learning Institute have discovered that they also need to clear mental space for learning.

I've discovered that to make real change I need to learn new things. To learn new things **I need to get to a new place in my relationships** *with the people I serve*. For some participants in the Learning Institute, the route to that new place of learning leads through a greater awareness of what they see and how they think. A shift in how they perceive and make sense of things makes room in their thinking for the new voices, new perspectives, and new information that will shape innovations.

Though this may seem like the sort of mental contortionism that would paralyze action, some participants have found it practical to notice what they have previously ignored or dismissed, as well as the ways that their organizations reinforce the ignoring. This leads to experiments in widening awareness.

Narrowing perceptions

Fear narrows both the scope for action and the possibilities that people are willing to even discuss seriously. Defensive risk aversion routines are understandable when news of agencies undergoing minute scrutiny and significant penalties for non-compliance with Medicaid regulations circulate through the system. This creates a bias toward usual patterns that affects the capacity to imagine innovations. The effects of systemic defensiveness on the transaction costs of innovation came clear to participants in Patti Scott's workshop on individualized supports when they compared the simplicity of an individual budget that meets New Jersey's requirements with the detail complexity of the budget forms required only a few miles away in New York.

Desire to maintain a sense of competence and consistency shapes the way that people make sense of possibilities. Success in individualized supports can look threatening if it casts a shadow over existing programs. People want to do what's best and they understandably resist knowledge that could reduce their estimate of the merit of their current efforts. One participant noticed that his defense of the large group homes his organization operates sounded similar to the resistance he encountered from institution staff when he helped people move from the institution. *I don't like thinking that what we are doing is anything less than state of the art. But when I really listen, I know that what we do now really doesn't suit a lot of people. It's more important to keep doing the best that we can think of than to hold on to the idea that we got it right forever when we built what we have got.*
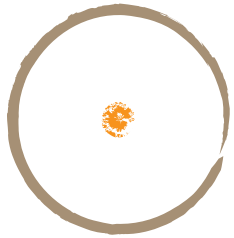
Awareness narrowed & possibilities for action biased toward more of the same by…

… a climate of fear & defensive avoidance.

… unconscious desire for consistency

… emotional memories

… restrictive ways of framing situations

This way of thinking about consistency values a continuing effort to imagine and do better over efforts to justify whatever the agency has done historically. It challenges a common idea that individualized supports are a new offering to meet a new demand, mostly arising from some of the families of younger people who have grown up with the benefits of family support and educational programming. This understanding assumes that congregate living is the best imaginable option for most all the people currently experiencing it. This assumption limits the demand for change but it may not stand the test of listening to people who have a chance to see how more individualized alternatives work for the people who experience them.

Emotionally changed memories block noticing changes and thinking about their implications, especially when a person's understanding of holding a professional role includes the idea of maintaining an objective, unemotional distance. One participant was assigned to plan with someone who had physically hurt her and noticed that, in this situation, her professional demeanor was a cover for bad feelings that restricted her ability to respond to the person. She brought up the past experience with the person, and in talking it through felt forgiveness and a new energy to act as the person's ally. Another participant took responsibility for mis-perception and updated her understanding of a person who had the courage to confront her in the course of a person-centered planning workshop and say, *You still look at me like I was*

exactly the same person that got in trouble seven years ago. You don't see I'm different now.

The way a topic is framed shapes thinking. During a discussion which had fallen into a very familiar pattern of complaint about family members' resistance to change, one Learning Institute participant noticed another way to understand the situation. *It dawned on me that we have systematically distanced families. We've told them in many ways that we can do what their sons and daughters need if they will just trust us and let go. Individualized supports will work better with their involvement, so we have to stop the same old complaining, take responsibility for our part of the problem, and figure out how to work together.* As long as a Change Team has framed a problem –uncooperative families who won't let go to let go– discussion is likely to be caught in an unproductive loop. Noticing the organization's role in creating the situation that needs to change opens the way for a more productive understanding.

Systemic preoccupation with health and safety is a prime example of the power of framing to shape what people in the system imagine, talk about and decide to do. Some reflection group members noted that the understanding of health and safety that influences decision making in their agencies is likely to be a source of reasons not to do something or reasons to impose restrictions or increase staff supervision. This leads to a defensive bias that makes it difficult to even imagine possibilities like a person spending nights without staff with the support of

an on-call paid neighbor. *We sometimes talk about dignity of risk, but we **do** compliance and risk avoidance almost all the time.* Another participant thinks that talk that demonstrates agency compliance with health and safety related regulations and procedures takes precedence over discussion of the ways that a particular, whole person can best be assisted to live a good life. *Its almost like we believe that following the rules is a magic ritual that makes people safe. So we don't confront the messy balancing acts that are part of real life, and we don't encourage people to try new things that might work out better for them.* The system as a whole would benefit from dialog that demystified and renewed understanding of health and safety.

Awareness expands

Theory U alerts its students to blind spots, the most important of which is missing the effects of the ways people perceive on what shows up in action. Awareness of a blind spot doesn't eliminate it, otherwise it would not be necessary to continue to check carefully when merging into traffic. Awareness does alert us to a limit in what we see and encourage us to compensate for it.

Realization of a new way to view a situation doesn't always require a dedicated time of reflection. Sometimes recognition comes in the midst of action. One Change Team member was assisting in a search for a suitable property for people who are the focus of a local learning initiative. *I was thinking what a great house this was when it came to me that I wasn't looking at the place through the eyes of the people who might choose to live there. I was ready to try to sell them on it because of how it looked to my eyes. I was making it all about me, all the while thinking I was doing it for them.*

Learning Journeys gave several Learning Institute participants a chance to **notice themselves restricting what they allowed themselves to take in** and consider. *It sounds weird, but there was a moment in the visit when I could see myself dismissing what was right in front of me. I saw myself reinforcing my own doubt that people could live this way. I decided I want to break out of this because I don't want to put my limits on the people that we serve.*

This is not a decision to just accept whatever someone else says and exactly imitate what they do. It's a resolution to be more open and curious in gathering knowledge and more appreciative, self-aware, and imaginative in making sense of the ways others' work can inform and energize the journey of individualizing supports.

Expanding awareness gives rise to new questions. One Learning Journey host, Rensselaer ARC, has taken every opportunity the system has offered to downsize its programs and assist people in more individualized ways. One visitor made noticing this difference from her own agency's practice the occasion for reflection which led her to think about this sequence of questions.
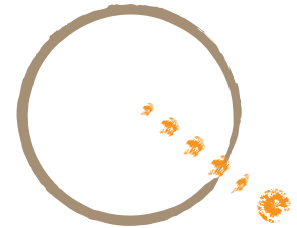
Awareness expands as we recognize that we only see part of what we want to change & correct our limits by reaching out to engage & listen deeply with others who have different gifts & points of view.

- *How was our organization thinking when we didn't do what they did when they did?*
- *What kind of blinders did I have on then that let me miss even thinking about this possibility before now?*
- *What kind of blinders do I have on now?*

Compensating for inevitable limits in perception and imagination doesn't require super-human feats of individual self-awareness. It's more than enough to simply broaden our gatherings to include people with differing perspectives and capacities and create occasions of dialog to sense what a desirable future calls us to do together.

This collage sets Ulster-Greene ARC's participation in the Institute in the context of a longer journey that began well before the Learning Institute with recognition of the limits of demanding compliance to standard service offerings and aims to develop a continually improving capacity to support people in the range of valued roles that constitute a full life. This means exercising leadership to move through a middle zone of re-thinking, developing commitment and reinvesting in learning better ways.

Planning to be surprised

Transformational change happens when people create the social conditions necessary for surprise. (*Why*, one participant wondered, *do we so often think that a surprise must be unpleasant?*) This insight came when they **accepted responsibility for the uncertainty** inherent in working with people to create individualized supports. This contrasts with their previous assumption that competence means having the answer to every problem imaginable and always being able to predict and control what will happen. Since predictability decreases as people move away from well worn routes, a predictable journey into individualized supports would not stray from well traveled, well mapped roads. The future would look very much like more of the same rather than disclosing customized assistance for good lives. Avoiding uncertainty is a prescription for repetition. Learning to move creatively in uncertain conditions is the way to innovation.

I had learned my job until it was a complete routine. Anything that came up had a black and white answer. Every week went the same way. It pulled the rug out from under me when the changes started and we went into getting to know people all over again by exploring new things outside together. I was scared at first. But the people I support have shown so much more of what they can do that it's more than worth it. My week is more diverse, more creative, more interesting. The job is growing into the kind of person I want to be.

A better image of competence pictures a team that learns to put action motivated by purpose in the foreground and move avoiding possible errors into a less prominent position. *First we decide what's worth doing; then we figure out how to do it responsibly.* Descriptions of the vulnerabilities that come in consequence of a person's disabilities reveal constraints that the invention of individualized supports for that person must account for. They should not be reasons to refuse to participate in a person's search for the personalized assistance they require to live a good life. *It's easy to get caught up in the mechanics of real estate. We have to remember, that's not the final point. It's a step along the way. The real point is the life that the person gets to live in that new place.*

One participant noticed a tendency to treat the possibility of failure to satisfy a preference –like finding an affordable apartment in a particular neighborhood– as if it were a risk to be avoided or a vulnerability on a par with difficulty swallowing or the need for timely seizure meds. This reflects a paternalistic attitude, an attitude that assumes that the staff's job is to protect people from disappointment. Surfacing and challenging the culturally reinforced assumption that people with developmental disabilities are delicate and incapable of resilience to failure when they have good relationships leaves more room for

I like the idea of practicing serendipity through intentionality.

collaboration than perpetuating the idea that it's the provider's job to protect people from disappointment.

Many participants in the Learning Institute like the image of a shared journey to describe their efforts. The journey invites people to seek a life of distinction. It is completely predictable that along the way they will meet unexpected difficulties, but exactly what will come up is unknown, so teams work on cultivating the sensitivity and honesty to take early responsibility for difficulties and the resourcefulness to figure out how to keep the journey going in the face of them. A core group of reliable and trustworthy companions make the journey possible and meaningful. Connections to a network of other explorers who can share the learning from their similar journeys provides knowledge and builds confidence and commitment.

This is true at each level of change. People with developmental disabilities have the best chance of a good life when they have a strong circle of allies and a broad network of people to learn with. Change teams have the best chance of influencing their organizations' competence to offer individualized supports when they have accepted responsibility for a shared purpose, constructed a common understanding of the culture they are changing, and developed shared practices for learning from action.

A strong Change Team

Reflection group members identified characteristics of a strong change team.

People with developmental disabilities and families are active partners in developing individualized supports for themselves. People and their families are actively involved in the work; they are not just waiting for the agency to come up with a new service for them. Members don't think that their task is simply to talk generally about individualized supports. Real people experience the consequences of the team's work.

The Change Team is a place of dialog on difficult questions. Collaborating with people with developmental disabilities to develop individualized supports is not a matter of following the steps in a recipe. Especially in early efforts, difficult ethical questions can arise. Often these issues are resolved by applying a familiar understanding of policy to the situation and moving on. But sometimes, it's in the complexity of the questions that the opportunities for the most positive change hide. One team noticed that hard work to create a good working relationship with parents had left their sons' voices largely unheard. Devoting some time to thinking about this situation can improve both the quality of the next step that the Change Team takes and what the team learns. Some issues are matters of philosophy, for instance working out an understanding of equality between staff and the people they support that doesn't simplistically ignore real differences.

Members see themselves working for the good of the whole agency. They have a strategy for building capacity for individualized supports in the whole

organization. Their strategy is based on continuing identification of leverage points for strengthening a culture that supports innovations based on careful listening to particular people. Members don't see themselves as simply doing a small project as Learning Institute homework. They see small projects as one aspect of organizational transformation. Change team members look for and make the most of opportunities to encourage practices consistent with individualized supports in their organizational roles.

Core membership is influential because it includes people with the relationships, knowledge of agency and system workings, and (access to) authority to make decisions and take action at a pace that builds momentum. The Change Team can enlist help from others in the agency when their expertise is required. Members don't feel powerless.

Work as part of the Change Team has priority. It is not members' top priority, but Change Team assignments are important enough to claim regular and consistent attention in busy schedules. Change Team membership figures in members' performance reviews and responsibility for Change Team assignments are explicitly identified as opportunities for professional development. There are regular, well facilitated meetings to check in on action and occasional longer sessions to review learning and refine local change strategies. A least one member treats the Change Team's work as one of her or his highest priorities. There is visible interest by agency executive management in what the change team is doing and learning.

They have time and resources to invest in learning. This includes going out on learning journeys and participating in workshops and conferences, coming back to make sense of and share what they have heard and seen, and trying out ideas and practicing approaches and skills they have learned about. The Change Team can sponsor other people important to their work to participate in learning activities.

They are resourceful in looking beyond usual sources and methods. In one participating agency, a person faced loss of a job she valued because an agency could no longer afford to have staff drive her to and from work. This created the opportunity to look outside agency boundaries and assist the person to use the dial-a-bus service that is available to all people with disabilities in her community. This has saved her job, made her more mobile and, along with a second person who has followed her into becoming a dial-a-bus rider, has helped a bit to reduce the agency overtime use.

At least one Change Team had a member who receives services from their agency who participated in Learning Institute activities, including a Learning Journey. This Change Team member is willing to be very open with her questions and her worries as well as her desires for the life she believes will open up for her when she receives more individualized supports. This has provided the team with valuable guidance and kept their work grounded.

The people we met through the learning institute have given us a clear picture of where we stand, the knowledge that others are in the same boat, and the confidence to deepen our investment in individualized support.

Larry appears in *We have choices*, a DVD released in 2010 by the Self-Advocacy Association of New York State. www. wehavechoices.org.

Links to a well supported network

Networks multiply a Change Team's power by offering multiple options for people to exchange information, knowledge, encouragement, and challenge. Networks happen and have positive effects when people accept responsibility to participate and reciprocate. Active engagement, paying forward, and giving back strengthen networks. Passivity and preciousness about information and other resources kill them.

Some participants have found the people they have met through the Learning Institute an important resource in their work. By meeting and exchanging with others in Learning Institute sessions, some participants noticed that their jobs have confined them to the boundaries of a particular role and department within their organization, that their cross-boundary encounters tend to be routine, somewhat competitive, and somewhat defensive, and that they had few strong relationships with others in the field but outside their familiar group. Some people have become more purposeful in reaching across boundaries to diversify their personal networks.

One effect of membership in the Learning Institute has been to give some people a chance to remember the intentions that brought them into work with people with developmental disabilities. Sharing their stories renewed awareness of what has real meaning for them in the work. For some, this has created a productive conflict. *I've realized just how far away what I do with my time now is from what really satisfies my sense of purpose. I came to this work to help people who lived in institutions to get new lives and I got a lot of satisfaction out of being directly involved with people. Now I have very little time to spend with people with disabilities and most of my energy goes to maintaining things that do benefit people, but in ways that are more restrictive than necessary. The changes that we are working on now are a new chance to do what I believe is the right thing.*

Network relationships provide peer mentoring that supports seeing and hearing more. Confidence in the possibility of change grows as people see others who are living differently. *Before the Learning Journeys, I thought that individualized supports were just for a few people who are so capable that it's a sure thing. Now my criteria have changed. I think we should work with people who will challenge us and go with us over the edge of what we are comfortable doing now.*

A Change Team included a member with a disability on a Learning Journey to Rensselaer ARC and the whole team experienced what the reflection group labeled *The Power of Larry*. The Change Team member and Larry both have mobility impairments and both need very well organized and capable assistance. As Larry spoke to the visitors about his life, and answered questions about his supports, the effect was visible.* The Change Team member came away from this meeting with information about how individualized supports might work for her and, more than that, confidence that it is possible for her to live as she desires if she and her team work hard together.

Magical thinking about networks is too common. Because networks emerge from reciprocal exchanges, it is easy to think that networks don't require real work to create and sustain them. Just exchanging contact information doesn't create a network. People need to take responsibility for keeping the network alive, as many dead Facebook pages attest. Meetings and Learning Journeys are far more successful when care and attention go into arranging schedules, logistics, and hospitality. This work of making and supporting connections is often invisible and seldom valued sufficiently, but without it much is lost.

The diagram below maps the first weeks of an experiment by Pat McKay, NYSACRA's Associate Director, who serves as a connector in the Learning Institute network. Early in May, Pat received an e-mail request from a Change Team member who wanted to learn how other agencies assess people's capacities to spend time without staff present. Pat could have answered the question herself, or referred the questioner to someone specific who might have an answer. Instead she chose a networking strategy. She created an e-mail list of Learning Institute contact people and broadcast the question to the list. In three days, three list members had shared assessment instruments and further leads. Three other people expressed their support for Pat's effort. On the 26th of May, there was a request to identify opportunities for a new staff person to learn about person-centered planning. By the next day, there were seven concrete offers of help.

The connections in this experiment complement a variety of face-to-face contacts that the people in the circles have had through the Learning Institute. Whether this e-mail network will grow from this beginning depends on whether the people on the list find it worth their investment. But without someone willing to think and act in network terms, as Pat has, this potential resource would remain simply a list of recipients of e-mail notices.
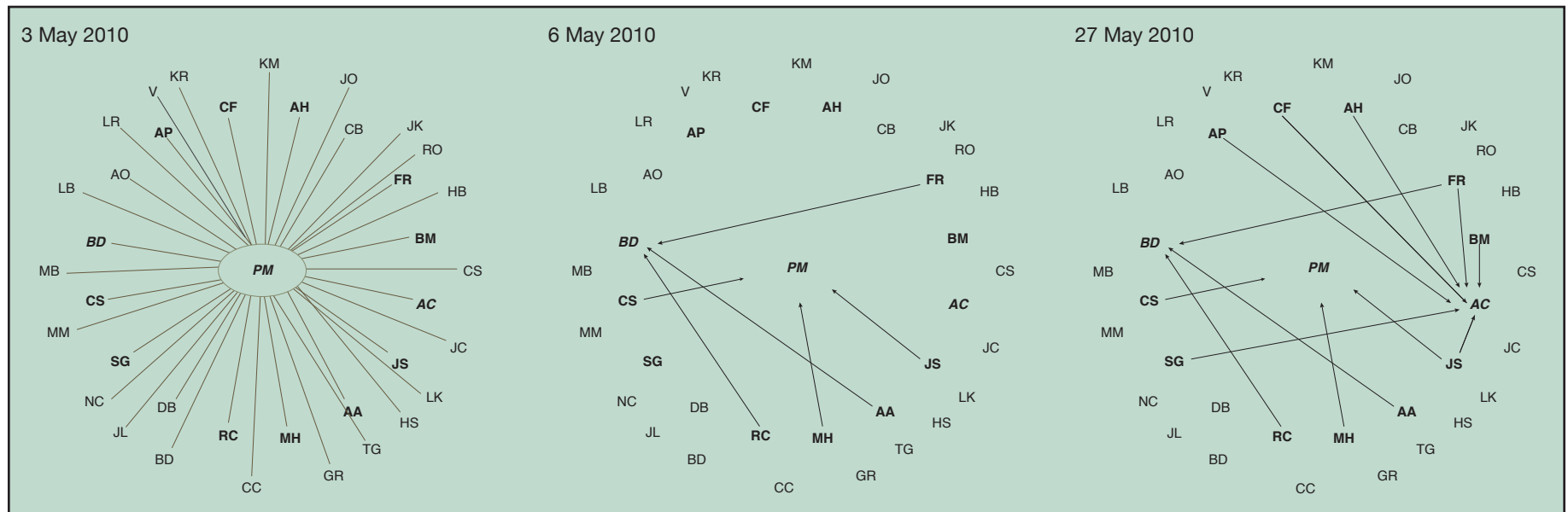
The contributions of authority

*Things shifted when we decided that **regardless of what OMRDD does, we are going to move** toward individualized supports.* Some agencies in this round reached this turning point before the Learning Institute began. They joined because they thought that participation would support commitments they have already made. And some participating agencies are still considering this turn.

Authorizing change

Agencies are organized hierarchically. Their managers are authorized primarily by their perceived ability to protect the interests of those who rely on the organization. Maintaining a predictable flow of funds and influence means taking responsibility for the organizations' continuing viability. This makes senior management sanction for change very powerful. Unless executives judge that their organization can find a way to manage the competing interests at stake in creating the capacity for individualized supports, change efforts will be weak, offerings will be small variations on current practice, and any real progress will remain marginal and vulnerable. Change Team members will have to manage uncertainty about whether their agency really wants to engage the conflicts and difficulties that come with real change.

The system's environment makes this a difficult judgement. An extended fiscal crisis reduces confi-

dence in the system's expansion and raises concern about sustainability. OMRDD's Executives have consistently called on the system to develop a much greater capacity to offer individualized supports. However, it is slow and difficult work to translate strategic direction into an administrative architecture that facilitates individualized supports. The Portal initiative has provided some access to individualized funding, but only for small numbers of people in a pilot form. Waiver revisions provide better defined funding streams for more individualized options, especially increased flexibility for in-home supports and investment in some forms of supported employment, but the system is absorbing these changes slowly.

Those people with developmental disabilities who are served by an agency that follows the safety-first norm of waiting for OMRDD to underwrite change with new money are likely to wait a long time. And, in the short run at least, it looks like navigating administrative pathways to more flexible funding will incur high transaction costs and that regulatory processes will adapt slowly to the call for innovation.

The most critical contribution of agency executives and their boards is to make a sober and well considered judgement that their organization has the **capacity and responsibility to generate sufficient means for steady development of individualized supports from within their own resources,** the resources in the communities that they serve, and

the resources represented by the capacities of people with developmental disabilities and their families and allies. As the state level system aligns its administrative and regulatory processes with its avowed strategy, development may move more rapidly and on a bigger scale. In the meantime the agency accepts responsibility to actively look for ways to invest as much as possible in developing individualized supports. Numbers may be small at first, but the intention is to build capacity to collaborate with people and their families to create individualized supports to people who play valued roles in their communities.

Authorization doesn't mean writing Change Teams a blank check. Senior managers remain accountable for the viability of the whole organization and need to make continuing judgements about which conflicts or risks to avoid and which the time is ripe to take on.

A Change Team backed by a consistent message from their board and senior management that the agency takes responsibility for developing individualized supports by making full, flexible and creative use of discoverable capacities has authorization for learning from action.

Modeling

Executive staff exert influence by what they attend to and how they act.

They hold very high expectations of the Change Team. They expect a strategy for transformational change and consult with the Team in its creation. They expect real change for the people the Change Team collaborates with and they expect these changes to inform and add momentum to the Change Team's strategy.

They make it a priority to facilitate the Change Team's work.

They show courage in standing up for what they think is right, facing conflicts and demonstrating principled negotiation with those in conflict.

They make their values clear by what they chose not to sustain and which opportunities for growth they turn down.

They can honestly appreciate what is good in programs that lack the capacity for individualization and resist the temptation to label these efforts as examples of individualization.

They purposefully create forums in which they join people with disabilities, family members, and their staff as learners and dialog participants.

They encourage people to explore difficult questions more deeply. They model not having all the answers and having confidence that the way to a more powerful response begins with deeper listening.

They invest in individual and especially team learning for themselves and for those involved in change.

What invites turning points?

Developing the capacity to collaborate with people with developmental disabilities in organizing individualized supports for a good life calls for transformational change. Transformational change invites people to shift the interior place from which they operate by sensing the demands and highest future possibilities of their situations and learning to embody those possibilities. One aspect of this shift can be named turning points, moments when the will is attracted to new commitments because people see and understand change in a way that alters their sense of what is possible and right to do.

Reflection group members identified the ways that the Learning Institute contributed to their turning points. While many people can identify a particular point in time when a new way of understanding came together for them, most agree that many aspects of the Learning Institute's offerings prepared the way for these moments.

Learning Journeys provided social proof of the concept of individualized supports. Participants could see how others have managed constraints imposed by the system in their design of supports, learn about how agencies have created flexibility by re-configuring and developing their existing resources, and discover how their hosts have generated innovations. Participants appreciated the care that hosts took in presenting their work and its lessons and their hospitality. (Though people did not visit Neighbours in New Jersey, several participants experienced Patti Scott's workshop as another Learning Journey.)

Meeting people with developmental disabilities who are living better lives with individualized supports and hearing their stories.

Involving people with developmental disabilities directly in learning experiences along with Change Team members. The *Awakening the Spirit* and *Wheel Power* workshops created a different context to learn new things about familiar people and imagine new possibilities with them rather than making decisions about them.

Being active in the Learning Institute network of people who are on similar journeys provides information, inspiration, good ideas, and warnings about mistakes to avoid. Active network members develop a sense of accountability to one another, provide one another with mentoring and support, and encourage confidence. The network holds relationships that give its members a place to stand and look at their work from outside their routines.

Belonging to a strong Change Team.

Incorporating new practices into their work routines. Some practices came from exposure to Theory U (the case conference, dialog interviews), some from the way Learning Institute sessions were conducted (the World Cafe, organizational metaphors), and some from the intensive workshops (creating un-

constrained images of possibility for a person, Wheel Power). The practices that people found most useful encourage dialog, deeper listening, clarifying purpose, and reflection. In large part this is because these practices are a strong counterpoint to the rush of short term decisions that define most of their time at work.

While the curriculum is the most obvious way for observers to identify what the Learning Institute offers, reflection group members experience the Institute as a pattern of encounters, relationships, and realizations that has allowed them to extend their awareness, deepen their ability to listen, and strengthen their confidence to act. Without strong change teams and wide network connections they would lack the means to make sense of the concepts and engage the challenges set by the Institute's curriculum.

The Institute's designers offer a number of conceptual frameworks for assessing the degree to which an agency offers individualized supports like the table to the right (www.nysacra.org/nysacra/li/Ind_Refer-

How individualized is the service?

Hanns Meissner

Degree of Individualization	Choice	Decision Making	Control of Resources	Integration into Valued Social Roles
Light (Focus on Modifying Present Practices & Service Environments)	• Person-centered planning leading to individual supports in one's daily routine • Expanded menu of options (universal) • Community outings	• Provides a menu of choices to an individual tabout their daily routine • Choices around participating in individual or group based activity	• Downsizes a home so the individual can have their own bedroom • Opportunity to select their housemates	• Assists the individual in experiencing & being present in the community on a weekly basis • Participates in a small group that visits and/or participates in an activity in a community site.
Medium (Focus on Designing Individualized Service & Supports Environments)	• Person-centered design (may include prototypical options) • Shared living • Alternative staffing arrangements (live-in, paid neighbors) • Supported employment • Life Coach • Agency with Choice (L-1) • Circles of support • Staff assigned & trained for the individual/family	• Provides choices to the individual/family of where & with whom the individual lives, what kind of job they would like, & the kind of life style they want to live	• Assists & supports individual in designing a home situation, finding a suitable location, & setting up the home to the specifications of the individual	• Supports the individual in participating in the community at a job, place of worship, & with associations on a frequent basis.
High (Focus on Supporting Self Determination)	• Supports uniquely tailored to an individual/family • Support-Scenarios (providing a set of unique arrangements to select the option most desired) • Supports provided by a mix of natural & paid providers. • Supports Broker • Fiscal Intermediary • Individual Budgets • Agency with Choice (L-2) • Small Business-Consultation • Home of Your Own • Cash & Counselling	• Supports individual in having choices in key areas of life (relationship, home, health & work)	• Assists individual in owning or leasing their own home.	• Supports individual to play active & primary roles in friendship, marriage, associational life, & employment (outside of paid staff arrangements)

ence_Grid.pdf)While the ideas in this assessment tool are clear once terms like "Agency With Choice Level 1" are defined, a useful assessment of agency performance depends on the internal place from which assessors view the agency's services and the horizon of possibilities that they can see for people with developmental disabilities and their communities. Those who simply look for words like "self-determination" or procedures like "person-centered planning" may grasp no more than superficialities and miss a deeper understanding, mistaking small changes for transformation.

Far more than a mechanism for delivering a curriculum, the Learning Institute functions for those who have made the best of it as a source of connections and the orchestrator of opportunities for new experiences. These connections and experiences have the potential to encourage transformational change by supporting higher expectations and deeper listening.