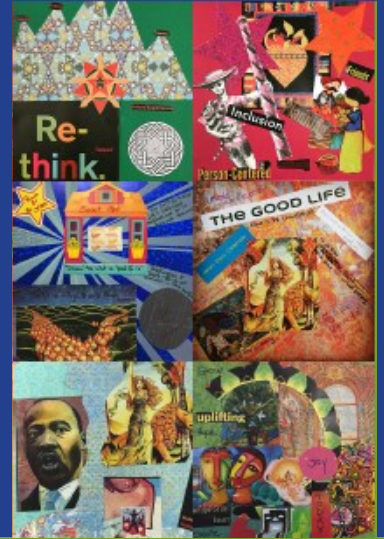


NYSACRA

Learning Institute on Innovation and Individualized Supports for Persons with Complex Needs

Final Report

April-December 2016



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 a clear definition to the idea of individualized supports, and the NYSACRA strategic plan that was developed in 2005. The Institute is offered by NYSACRA, and has been funded by the New York State Developmental Disabilities Planning Council (DDPC), the New York State Office for People with Developmental Disabilities (OPWDD), the Self Advocacy Association of New York State (SANYS) and NYSACRA.

The Learning Institute defines individualized supports as those that are created around an individual's distinct vision for their life rather than created around a facility or a funding stream. These person-centered supports are 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.

There have been five Institutes since their beginning in 2007 involving over 65 provider agencies working as a community of practice; committed participants learning from each other and from experts provided by the Institute, creating new small service designs, testing ideas through implementation, and becoming leaders of change in their organizations and in New York State. The overall goal was for each participating agency to build its capacity to generate innovative supports for individuals with developmental disabilities to allow them to live lives of distinction.

LESSONS LEARNED

from past Institutes on offering Individualized Supports:

- It requires transformational change in organizations and in each individual who attends; it is not enough to say, "we do that" and then find money or solve technical problems
- It requires an interaction of ideas and experiences; especially experiences that allow the learner to see and talk with people with disabilities who are living lives of distinction
- It requires new approaches to relationships with people with disabilities that are not built on control and risk avoidance, but rather on new ways of listening to people
- It takes time, exploration, creativity and letting go of the old without necessarily knowing the answers to all the questions; just a deep commitment to answering them together, using community as a resource.
- Providers face all kinds of reasons not to change the supports they provide (i.e., avoiding risk of harm, security in conformity to the norm, compliance with regulation, and avoiding the organizational disruptions caused by change); the greater system needs to address its immunity to change by investing in ways to encourage change to happen.



The fifth Learning Institute was titled “Learning Institute on Innovation in Individualized Supports for Persons with Complex Needs” and followed the Transformation Panel’s report, *Raising Expectations, Changing Lives*. It was designed to particularly address the needs of people with complex challenges, and living in the community.

Participating agencies developed change teams to translate the work they did in Leadership Institute sessions into local action-learning. In the seven months of the Learning Institute, the change team’s task was to partner with at least one person with complex needs 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 with people with complex needs in a person-centered way.

Participating Agencies:

The Advocates, Heritage Christian
Services & NYS OPWDD

AHRC Nassau

Arc of Monroe

Aspire of WNY

Family Residences & Essential
Enterprises

HeartShare

Independence Residences

Mountain Lake Services

People, Inc.

Richmond Community Services

The Arc of Westchester

The Resource Center

Unity House of Cayuga County

Wildwood

YAI

The Learning Institute supported change teams in four ways:

1. Workshops brought agency representatives together to explore essential aspects of person-centered work.
2. A Learning Journey, hosted by an agency committed to individualized support to people who require intensive nursing support allowed critical reflection on the process of organizational change in the New York environment.
3. Webinars offered useful information on topics that influence the implementation of new approaches to housing, support and employment.
4. A network of mutual support that formed as people connected in workshops and on the learning journey.

An incredible faculty of experts were brought together by NYSACRA and our lead consultant Chris Liuzzo.

The Learning Institute agenda was as follows:

DATE(S):	TOPIC:
17-19 MAY	Transformational Change • Right Relationships in Support of the Good Life • Person-Centered Planning with Beth Mount, Hanns Meissner, Michael Kendrick & Carol Blessing
30 JUNE-1 JULY	Beyond “Behavior”: Supporting Confidence, Competence & Wellbeing with David Pitonyak
28 JULY	Addressing the Physical Environment with George Braddock (<i>webinar</i>)
29 JULY	Transforming Organizations from Congregate to Individualized Supports with Jeff Strully (<i>webinar</i>)
7 SEPTEMBER	Addressing Risk & Liability with Chris Lyons and The Role of the Direct Support Professional with Joe Macbeth
8 SEPTEMBER	Reflection: What We Are Learning with Beth Mount
5-6 OCTOBER	Learning Journey to Family Lives, Westborough, MA with John O’Brien
7-9 DECEMBER	Self-Advocacy Perspective • Generative Stories & Prototypes • Lessons for Our System with Michael Kennedy, Beth Mount, Hanns Meissner & John O’Brien

Participant Prototypes

In its description of the Learning Institute, NYSACRA asked participants to conceive a “prototype” of a support design for at least one person with complex needs. The concept of a prototype comes from Otto Scharmer’s “Theory U”, which provides a theory of organizational innovation underlying the entire Learning Institute.

Scharmer poses seven questions to ask as a prototype is conceived:

1. Is it Relevant: Does it matter to the stakeholders involved?
2. Is it Revolutionary: Is it a potential game changer?
3. Is it Rapid: Can it be done quickly?
4. Is it Rough: Can it be done on a small scale allowing for meaningful experimentation?
5. Is it Right: Are the definitions of the project’s dimensions correct?
6. Is it Relationally Effective: Does it leverage the strengths of existing networks?
7. Is it Replicable: Can it be brought to scale?

The prototypes served to help the participating agencies focus their learning on a person. In past Learning Institutes, this has worked to carry an agency in the direction they began with (the person or the project), but very often the agencies dropped that project and their learning carried them in a different direction. In many ways, this reflects the real learning and transformation of thinking that happens during the Learning Institute. On the last day of the most recent Institute, the participating agencies described to their fellow Learners the prototypes they hoped to create. Following is a brief description of them.

NYSACRA Learning Institute

Participant Prototypes

PEOPLE INC.: Supported a woman with physical impairments and medical needs to move from a temporary placement in a Certified IRA to an uncertified, self-directed living environment, using both DoH personal care supports and an OPWDD funded Self Direction plan.

ASPIRE OF WESTERN NEW YORK: Entered into person centered planning with a young woman with profound physical impairments and who does not speak who hopes to “live on my own one day”.

RICHMOND COMMUNITY SERVICES: Developed an agency wide practice of “Strategic Re-Visioning” to implement a “continuous cycle of thinking, learning, planning, innovation, reflection and re-visioning.” It is based on a model of Design, Accelerate, Innovate, Assess, and Re-vision.

ARC OF MONROE: Labeled its prototype “Paving the Way to Home” which is a “process in which we help the people we support, as well as their respective DSP’s, to achieve an individualized sense of home.” Within six months after the close of the Institute, Monroe hoped to have Change Agents trained and engaged, leaders and DSP’s educated about the process and having at least one person “starting their journey.”

AHRC OF NASSAU: Prefaced its prototype with “If you want to change your mind, first change your behavior.” They hoped to make help “Mr. Smith” achieve the “good life” by meeting with and observing him, conducting a POM interview, advocating for him, supporting new relationships, seeking new opportunities according to his wants and listening more deeply to him.

THE RESOURCE CENTER: Identified a 60-year-old man who has lived in institutional settings since age 9. He wants his own apartment. The Resource Center cites numerous barriers, due to his physical disabilities, inability to walk or bear weight and to propel his own wheelchair. The agency wants to develop a “game changer” for this man and created a Change Team on his behalf.

ADVOCATES, INC., HERITAGE CHRISTIAN SERVICES & THE DDRO: Outlined several prototype options to enable different pairs of person to choose to live together and to choose their home. Their options included scenarios for people with and without medications administration needs. All the options are self-directed and include combinations of Agency Supported Community Habilitation, IDGS and DoH funded Consumer Directed Personal Care.

WILDWOOD PROGRAMS, INC.: Focused on Kelly, a 39-year-old woman as the focal person for this prototype. She exhibits severe behavioral concerns and lives with 4 other persons who also demonstrate a high level of need. Through the Institute, Wildwood came to believe that Kelly’s behaviors are rooted in “anxiety and fear” and that a new residential setting is necessary. Wildwood is moving toward reducing “anxiety and fear” by providing Kelly her own space perhaps in a shared living arrangement.

WESTCHESTER ARC: Involved a self-direction plan for Bob. He has expressed wanting his own home, to spend more time participating in his community than at his day program and to go to college. The plan includes 24-hour staffing, community habilitation hours, and transition services which will cover alternative college education program offered at a local university. This prototype “will not only challenge the traditional methods of providing housing..., but also show an alternative way to provide a supported housing environment that works for everyone”.

YAI: Focused on organizational change by creating a Department of Person Centered Planning and regional “Blue Space Teams” (a reference to the book by Institute faculty member Hanns Meissner). The goal is to facilitate “a cultural shift” so that “YAI naturally focuses first and foremost on identifying elements of the ‘good life’ unique to a person and then work on figuring out how it can be obtained”.

INNOVATIVE RESOURCES FOR

INDEPENDENCE: Identified a 38-year-old man with verbal, physical and behavioral challenges living in a six-person group home as the focus person. The prototype includes a “smaller, more person centered...setting with...less need for invasive restrictions”. The agency came to be “open to the possibility that we may not be the right organization”.

HEARTSHARE: Calls its prototype “Learning by Letting Go”. The focus person, Patrick, presents behavioral challenges and has lived in an IRA for 22 years. He was living a highly restricted life due to his behaviors. On the “day that changed everything,” Heartshare concluded that “We are the problem” and began a journey toward a “paradigm shift” to “put control in the hand of the people we are serving...”.

MOUNTAIN LAKE SERVICES: Created a prototyped that “involves a deep discovery process” for Michael, who is “continuing to discover himself and how he wants his life to be”. A Change Team was formed that is supporting people to “let go” of the old. Six months after the close of the Institute, Mountain Lake Services hoped that “people are once again developing lives, not developing plans”.

FAMILY RESIDENCES AND ESSENTIAL

ENTERPRISES (FREE): Set its sights on two larger group homes both of which serve persons with mental health concerns and/or are on the autism spectrum. FREE hoped to downsize those homes by a total of three persons and reinvest those resources into a new three person, self-directed setting. At least part of the supports would be provided through a shared living model.





Final Recommendations

The Learning Institute took its cue from the Transformation Panel’s report, *Raising Expectations, Changing Lives*. The experience of participants in the Institute validates a conclusion the Transformation Panel reached. That conclusion is that if individualized supports are the goal and persons with complex needs are included, then the current system lacks the necessary flexibility.

Based on the data from The Learning Institute, participants made the following conclusions:

1. To achieve the Panel’s stated goals and secure the necessary flexibility, change must be *transformational*, not *developmental* (which might be categorized as efforts to improve what already exists) nor *transitional* (which can be described as “retooling” to move from an old to a new model, but does not produce evolutionary shifts). Transformational change “involves fundamental reordering of thinking, beliefs, culture, relationships and behavior”. It is change that “turns assumptions inside out”.¹
2. The greatest barrier to transformational change is a “pervasive climate of fear” pervasive in the system: fear for jobs, fear of making errors, fear of change, fear of audit results, fear of the actions of oversight bodies and so on.

Accordingly, the following recommendations are based on the hope that their adoption will lower the level of fear and, therefore support transformational change. It is important that they be addressed at the three interlocking sources of fear and inflexibility: the personal, organizational and systemic.

RECOMMENDATIONS

1. Begin by reframing what people at the “higher end of need” really do “need” and what their primary vulnerability truly is. If what they need is the Good Life and their greatest vulnerability is exclusion from it, we can, in partnership, begin and sustain conversations to help this reframing to occur.
2. Hold conversations that recognize that there are inherent risks in achieving the Good Life and ask how we can achieve “skillful management of polarities, such as the dignity of risk and safety.”
3. Hold conversations on how to drive out fear and dedicate ourselves to the commitment to drive it out.
4. Strengthen Supported Decision Making and enact policies that allow people to override unnecessary provisions of protective oversight.
5. Acknowledge the costs that a clinically and compliance heavy system, in turn driven by fear, extracts from our resources and ask how we can redirect those resources.
6. Begin conversations to increase flexibility of existing resources and reshape them away from group based settings (identified by participants as one of the major barriers to achieving the Good Life) and into more individualized supports.
7. Increase consistency of Self Direction rules across the state with the most flexible being the standard.
8. Discover ways to mutually invest in local transformational change and establish a broadband feedback loop between innovators and system administrators.
9. Collect, share and promote stories of transformational change.
10. Improve access to relevant assistive technologies and environmental modifications.

¹ Learning History, page 8.