2016

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

A Learning History

John O'Brien

Cover Images
In the final session participants created images that express the intention they are taking from the Learning Institute into their future.

Learning Institute on Innovation and Individualized Supports for Persons with Complex Needs
May–December 2016

Advocates, Heritage Christian Services, & NYS OPWDD
AHRC Nassau
Arc of Monroe
Aspire of WNY
Family Residences & Essential Enterprises
HeartShare
Independence Residences
Mountain Lakes Services
People Inc.
Richmond Community Services
The Arc of Westchester
The Resource Center, Unity House of Cayuga County
Wildwood
YAI

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.

The Learning Institute supported change teams in four ways:

• Workshops brought agency representatives together to explore essential aspects of person-centered work.
• 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.
• Webinars offered useful information on topics that influence the implementation of new approaches to housing, support and employment.
• A network of mutual support that formed as people connected in workshops and on the learning journey.

17-19 May
Transformational Change • Right Relationships in Support of the Good Life • Person-Centered Planning
Beth Mount, Hanns Meissner, Michael Kendrick & Carol Blessing

30 June – 1 July
Beyond "Behavior": Supporting Confidence, Competence & Wellbeing
David Pitonyak

28 July
Addressing the Physical Environment
George Braddock (webinar)

29 July
Transforming Organizations From Congregate to Individualized Supports
Jeff Strully (webinar)

7 September
Addressing Risk & Liability
Chris Lyons
The Role of the Direct Support Professional
Joe Macbeth

8 September
Reflection: What We Are Learning
Beth Mount

5-6 October
Learning Journey to Family Lives, Westborough, MA
John O'Brien

7-9 December
Self-Advocacy Perspective • Generative Stories Prototypes • Lessons for Our System
Michael Kennedy, Beth Mount, Hanns Meissner & John O'Brien

Learning for transformation

The Transformation Panel guides OPWDD's response to meeting the changing needs and expectations of the growing numbers of people with developmental disabilities and families who want sustainable services. Their recent report, *Raising Expectations, Changing Lives*,[*] identifies three accomplishments that demand transformation rather than just improvements on more of the same services and administrative practices.

- *Community: People with developmental disabilities will be accepted as part of our communities, living the lives they choose while experiencing good health, growth, and personal relationships.*
- *Outcomes: The focus is on the quality of the person's experience and the outcomes the people we support have told us they want, which includes living and working in the community while directing their own services and supports.*
- *Flexible Service Delivery Platforms: Integrated, quality services must be supported by networks of high performing providers with the flexibility to meet people's needs. All service delivery platforms, including managed care, should measurably further this vision. (p. 11)*

The Panel crystallized these three dimensions of transformation in a set of essential questions to test any new OPWDD initiative (quoted in the right column).

* *goo.gl/ZksG0q*

Because transformational change shifts the fundamentals of current structures, it creates uncertainties that can't be resolved by expert opinion alone. One area of uncertainty concerns people who are identified as presenting complex needs.

- To what extent are the outcomes of living and working in a community that accepts them while directing their own services and supports possible for them?
- How will high performing providers develop supports that give people at the higher end of need the best possible opportunities for integration, active involvement and independence?

Only learning through action that moves beyond current boundaries will produce the knowledge necessary to reduce these uncertainties.

The Transformation Panel's commitment to change that shifts relationships to community, outcomes and service delivery platforms in a way that takes account of people with complex needs frames the work of this Learning Institute. It's focus has been on learning by engaging people that participating agencies identified as presenting complex needs to co-develop better supports. Much of their learning validates a conclusion the Transformation Panel reached and identifies elements of our system in need of transformation.

> *If individualized supports are the goal, we need to acknowledge that our current system lacks that kind of flexibility. (p.7)*

**Essential questions** to ask of OPWDD initiatives:

- Does it help promote the integration of people and services in the community?
- Does it encourage the active involvement of people with disabilities and their families?
- Does it broaden the range of choices and options for individuals?
- Does it foster independence?
- Does it take those at the higher end of need into account?
- Does it use data to measure and evaluate quality and satisfaction?
- Is it clear and realistic in its language?

–Raising Expectations, Changing Lives (p. 12)
goo.gl/ZksG0q

Disclaimer 1 of 2. Based on experience and study, I, like the rest of the people who designed and delivered the Learning Institute, have strong and distinct views about effective support to people with complex needs. These views may not be shared by experts with different experiences or perspectives. The Learning History reflects, as best I can, what participants heard and their reflections on the action they took.

People's lives are more important than paperwork. It's how you look at people and what you do together that really matters.

~ Michael Kennedy
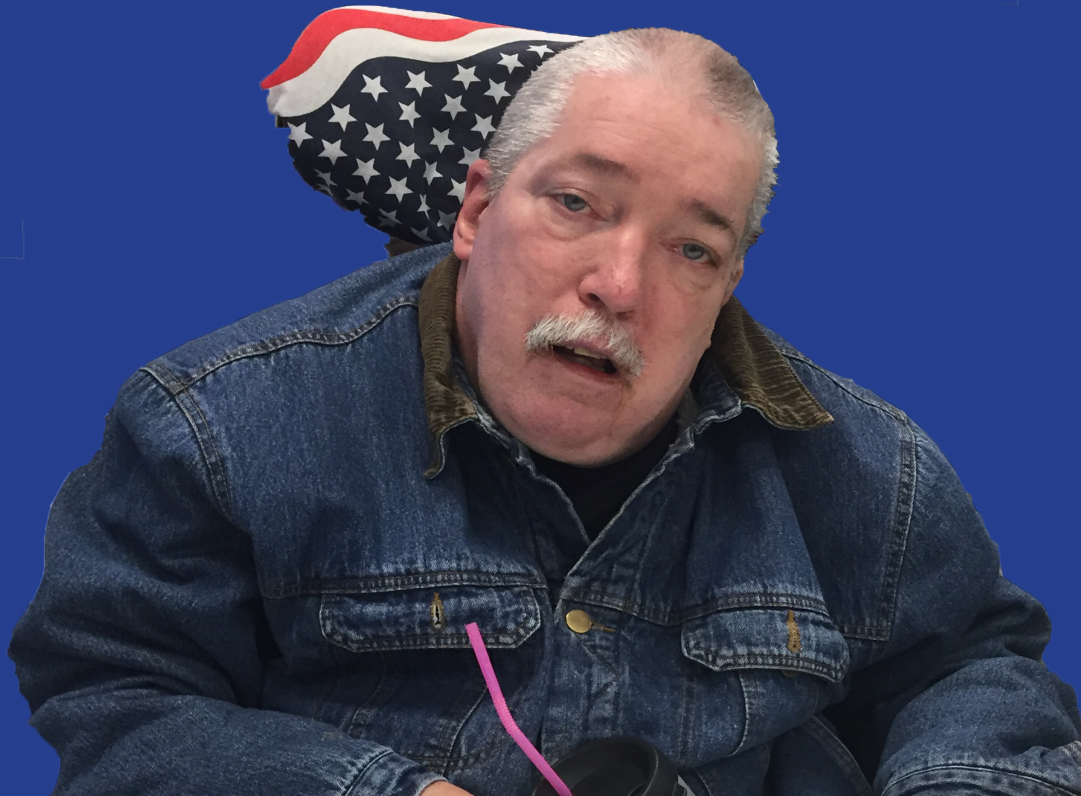
Presentation to the Learning Institute, 7 December 2016. Read the first volume of Michael's autobiography, *My Life in Institutions and My Way Out.* goo.gl/fWautu

What we are learning

At the final session, participants shared their learning from the journeys they began during the Learning Institute. They have learned strategies and considered new perspectives, but much of importance has come from remembering the qualities of relationship that give meaning to their work and actively renewing these qualities in creative partnerships with individual people with complex needs.

—§—

There is always more to each person than we see. No label or procedure can capture all of who a person is. No matter how long a person has been our client we discover more about who they are and what's important to them when we step beyond our current client-staff relationship, open ourselves to listen and trust grows between us.

—§—

To stay on course we need to continually ask "Does what we are doing give the person a better chance to live their good life?"

—§—

Good strategies are important, but relationships determine whether or not those strategies work.

—§—

If we open our hearts and minds, our relationships with people who challenge, frighten and frustrate us give us good chances to develop personally and professionally.

—§—

We're expected to know all the answers. We need to be humble enough to keep learning. We have to make and protect space to learn.

—§—

We need to notice when fear drives us away from what we know is good. We need to find courage and resilience by strengthening our relationships and our commitment to what we value.

—§—

It's a tough but ethical practice to notice and own the ways that we ourselves impose the disadvantages of clienthood. If we accept that we are part of the problem, that we contribute to people missing opportunities, we have a chance for real change.

—§—

A sense of mission that commits us to making a meaningful difference is essential. It can't just be words, it has to be alive and influence all of our decisions: hiring, organizational planning, and everyday work. If we don't keep checking our integrity in serving our mission we will get lost.

—§—

People don't need our protection, they need our support. People don't need to be managed, they need to be empowered. We need to learn to lead by following and serving not commanding and controlling.

—§—

Concern for health and safety is important but it easily turns overly restrictive if we don't pay equal attention to dignity of risk. Now the balance is tipped too far toward simplistic ideas of health and safety.

—§—

Knowing a person's history is important. Not just what's in the record but what the person has lived. Empathy is the key to understanding the effects of what can be a lifetime of being isolated, controlled, underestimated and poorly supported.

—§—

We may need to build trust, confidence and partnership with people and families. Blaming kills trust.

—§—

We must remember that we and the people we support are part of a human rights movement.

—§—

It's hard but worthwhile work to keep putting the human back in human services.

—§—

Words create worlds. It helps to have multiple ways to look at people and think about what really helps.

—§—

We have to be intentional about thinking outside the box of our current investments in buildings, techniques and staffing.

—§—

We have far too much investment in serving groups and far too little in supporting individuals. Learning to support people one at a time too often loses the competition for attention and resources to group focused services.

—§—

We can trap ourselves into thinking that more staff is always the answer. If we add staff we need to be sure they make the person's life better, not just increase control.

—§—

We can't provide good support to people if we don't support those who assist them. We have to make a consistent effort to improve the worklife of DSPs.

—§—

Reaching out and learning with and from colleagues from other agencies is well worth the time it takes.

The Learning Institute developed an understanding of complex needs…

Complex needs are differences in body, mind and behavior that demand…

…the highest level of capacity to individualize supports in order to reduce a person's risk of exclusion from good opportunities for development, participation and contribution, and

…firm commitment to vigorously and continually champion the person in getting and living the good life.

Participants discovered that:

Current group based living and day program arrangements pose obstacles to effective responses to complex needs and deny people opportunities for community integration and self-direction by design.

These obstacles can only be effectively overcome with a level of individualized, highly responsive support that is impossible in group settings, especially when those settings are designed to maximize control over groups of people who share a diagnosis that signals complex need. People with complex needs need skilled, ethical direct support in homes of their own and in roles that match their personal interests.

Developing the capacity for individualized support calls for transformational change. Modifications to more of the same cannot reach far enough to develop the capacities necessary to support what is possible.

In it's current state, the DD system is poorly positioned for transformation. Policy and practice generate inflexibility, raise the cost of change and introduce delays that inhibit the rapid learning cycles necessary to individualize supports. There is an inconsistency between the call for transformation and the demand for compliance to rules that lock in more of the same.

The biggest barrier to transformational change is a pervasive climate of fear and its effects on the people on whom people with complex needs rely. Fear of liability, fear of penalty for paperwork errors, fear of bureaucratized intolerance for the errors inherent in respect for the dignity of risk, fear contaminates relationships and erodes the quality of support.

Everyone can facilitate transformation by…

…weighing every decision in terms of its impact on developing individualized support for community integration and self-direction and adopting a consistent bias toward individualization.

…working persistently to assure good work for the Direct Support Professionals who must act as allies to people with complex needs as they seek and live the good life.

…advocating vigorously to reduce the costs of compliance.

…opening themselves to learning, especially by appreciating what makes a positive difference in the experience of people with complex needs.

…driving out fear.

A perspective on transformational change • Hanns Meissner

It's helpful to distinguish three types of change: developmental change, transitional change, and transformational change. Each type of change requires different capacities and responses from all key stakeholders.

Developmental change

Marked trail — Destination
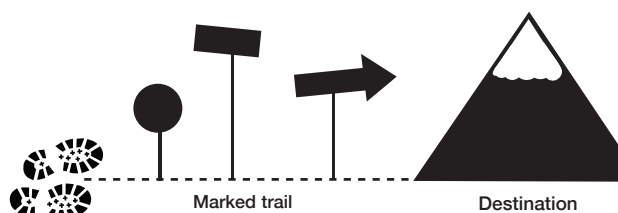
A woods outing typically involves reading the description of the hike in a guide, preparing for the level of difficulty of the trail, and following the trail markers to your destination. This is the sensibility of **developmental change**. Service organizations engaged in developmental changes might offer a new vocational service, open a residence for a specialized population (e.g., for people with Prader-Willi syndrome) or implement a consumer software program. The relevant change tools include process improvement, continuous quality improvement, conflict resolution, role clarification, team building, and staff training and development programs. This type of change identifies a gap between expectation and performance, articulates an improvement objective, and applies a problem-solving strategy to achieve the objective. Developmental change tools and strategies usually work to improve existing skills, processes, and structures.

When trails erode they must be re-routed and cut to a new destination. This reflects a **transitional change** sensibility. Transitional changes involve

Transitional Change

Old Trail — Former Destination — New Trail — New
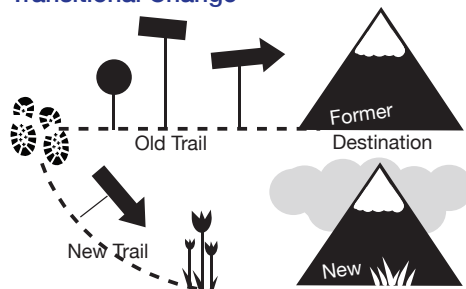
differentiating a new state from an old state, "re-tooling" the system and its practices to fit the new model. Mergers, consolidations, reorganizations, revising systemic financial payment structures (such as moving from fee for service to capitation payments,) re-engineering and/or creating new services, processes, systems and products to replace the traditional one are each transitional changes. The Medicaid Home-and-Community-Based Waiver implemented across the US in the 1980s and 1990s reflected this type of change in the developmental disabilities field. Strategic planning, project management, setting goals and objectives with timelines, developing metrics, and designing new business models are expressions of this type of change. Transitional change is closest to the current energy around re-engineering institutional service forms to managed care. Transitional change, like developmental change, does not seem to produce the kind of evolutionary shifts that occur when relationships between provider and recipient are realigned to partnerships.

First ascents of mountains in uncharted and rugged territory are transformational experiences. The intention to climb some of the highest and most remote mountains in the world has been compared to the quest for the Holy Grail. **Transformational**

Transformational Change

Scoping Out the Terrain — Whacking the Bush — Locating a Vantage Point (Increasing Awareness) — Discovering a Way — Preparing For the Journey — Arriving at a vantage point to scope out the next journey

change, the most complex form of change, involves fundamental reordering of thinking, beliefs, culture, relationships, and behavior. Moving into individualized supports for community life requires a change approach that turns assumptions inside out and disrupts familiar rituals and structures. It rejects command and control relationships in favor of co-creative partnerships.

Disappointment is inevitable when people seek a result that calls for transformational change with the understanding and social architecture suited to developmental change or transitional change –as many DD systems are doing under the heading of "system transformation." Coloring a transitional change initiative with transformational language only increases confusion, and risks setting up double binds by pitting the requirements of the established support model against the effort to create individualized supports for community life.[*]

Complex need as an invitation to transformation

A group of people identified as presenting complex needs[*] are likely to be more different from one another in body and mind than any other diverse collection of people are. In their personal distinctiveness they represent an extreme challenge to our system's commitment to individualization. The stakes are high. When this challenge is poorly met individuality melts into routines of meeting basic physical needs and maintaining externally imposed control of behavior. Being treated as one of a homogeneous group defeats the effectiveness of attempts to support development.

The extent and intimacy of people's need for assistance means that the way that services are designed and delivered almost totally defines their daily life and future prospects. History shows that any person with developmental disabilities in client status is at risk for the wounding experiences identified in the next column, and people with complex needs are at especially high risk.

This Learning Institute was a modest effort to heed and reduce risk of exclusion from higher order values. The Transition Panel report reads as clear about the value of people with developmental disabilities living and working in their communities with services they direct and uncertain about whether this is possible for people at the higher end of need. The Panel leaves the question open and calls for attention to people with complex needs in all OPWDD initiatives. This is wise: assuming that people identified as having complex needs can't be supported in valued community roles risks too much.

By no means does the work of Learning Institute Teams resolve this uncertainty, but participants clarify it by their inquiry into two related questions.

- What do we mean by "complex needs"?
- Which type of change –developmental, transitional or transformational– is necessary to establish a fair test of the possibilities for community integration and self-direction[**] for people with complex needs?

* Disclaimer 2 of 2. This Learning Institute was neither intended nor resourced to produce reliable evidence. This Learning History is simply my way of making sense of what participants reported as they discussed their experience of working in a person-centered way to individualize supports to people they identified as presenting complex needs. For reasons noted in the following pages, none of the teams have fully implemented the desirable changes in support that they have identified, so there is no way at this point to judge outcomes and satisfaction (indeed, delays created by systemic inflexibility have increased some people's productive dissatisfaction). Read the summary of insights and analyses produced by listening to their reflections for what they are: an account of what experienced, committed people learned about their organizations and system from an intentional effort to test their capacity to individualize supports for people they identify as having complex needs.

** Because it labels an OPWDD program, the term self-direction is ambiguous. Unless there is explicit reference to the program, in this paper it means that a person or those who provide decision support have effective control of the services and supports the person is eligible for. It is an aspect of independence.

Risks of Clienthood

- Social & relationship discontinuity
- Loss of freely given & natural relationships
- Discontinuity with the physical environment
- De-individualization
- Symbolic branding
- Impoverishment of experience
- Segregation & congregation
- Having one's life wasted
- Exclusion from higher order value systems

Learning Institute materials based on the work of Wolf Wolfensberger

What do we mean by complex needs?

One common understanding of complex needs comes from our field's medical tradition. It begins with expert focus on differences in the person's body and mind as they are revealed through medical/nursing or behavior analytic/psychiatric language and practices. Complex needs result in multiple diagnoses and detailed, usually symptom focused, treatment plans that demand close professional oversight and control. Conformity to nursing or behavior plans takes unquestioned priority over personal choice and opportunities for community integration. Due to the extent of perceived disease or impairment prognosis is usually guarded if not grave. Interacting conditions demand professional skill. Evidence based interventions are assumed to be available. This understanding often leads to grouping people with others perceived as clinically similar to themselves in settings staffed, often intensively, to offer nursing care or behavioral intervention. In short, complex needs are understood as characteristics of people's bodies and behavior that call for intensive professional intervention.

A Learning Institute based on this perspective would contribute to developmental or transitional change (page 8). The destination –symptom control or reduction– is clear and the path charted by specialist knowledge. It would train participants technically, improving their diagnostic skills and increasing their repertoire of tools and strategies. It would introduce adapted approaches to person centered planning and new models for operating residential and day programs suited to the population. It would provide technical assistance on how to finance and implement these strategies and models.

There is no question that applied professional knowledge can be of great benefit to all people with impairments. It can be as important to good support as a GPS can be to a mountain hike. The techniques of positive behavior support and augmentative and alternative communication have made life better for as many people as the new designs and controls that provide good positioning and mobility. For most people these technical supports, once established, work in the background as they get on with life. Professional interventions serve developmental or transitional changes in people's lives.

Some people have more complex responses to technical interventions. Their differences in body, mind and behavior test available skill and knowledge past current limits. Techniques that usually work smoothly don't move helpfully into the background of life but occupy the foreground of people's days. Indeed there is a real risk that a person's diagnoses will become life defining. When this happens, the purpose of support can come unstuck from helping a person discover and live a good life and stick on delivering more of the same sort of interventions. Those with power focus more and more on eliminating or coping with perceived difference and less and less on capacity.

Absent good relationships with people mindfully committed to support a good life in community, control of symptoms or behavior becomes an end in itself. This can justify deployment of increasingly life limiting or coercive measures that compound the impact of the person's impairments. At the extreme, people become hostage to compliance
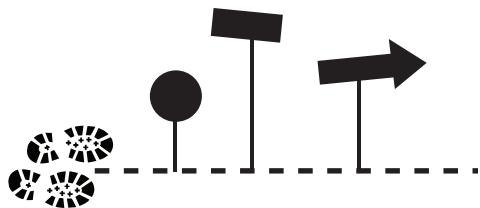
with professional will; professionals inadvertently become people's masters. Pessimism collapses expectations and standards as a person's failure to respond to interventions justifies endlessly delaying access to valued community roles. The potential to blame and devalue the person grows and some people become untouchable by service providers afraid of the risk they are imagined to pose. Chances to realize the system's values of actively promoting human and civil rights and supporting community integration and self-direction crash. **In practice "complex need" can come to mean, "no real chance of community integration and self direction."**

Widening focus to account for a person's experience of service design and delivery, provides a pragmatic understanding of complex need, which can be summarized this way. **Complex needs are differences in body, mind and behavior that demand the highest level of capacity to individualize supports in order to reduce a person's risk of exclusion from good opportunities for development, participation and contribution and firm commitment to vigorously and continually champion the person in getting and living the good life.***

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*Michael Kendrick presented a multi-dimensional idea of *the good life* to the Learning Institute. Many teams adopted it to express their purpose in planning and providing support and as a standard to assess their efforts. See www.youtube.com/watch?v=fPRzj_-B-bw

Making a fair test

The Learning Institute took the question of access to meaningful community integration and self-direction for people with complex needs as an invitation to **transformational change.**

Teams found it useful to think of their work as a shared journey into new territory where opportunities and threats must be discovered, the path forward must be discerned and maps must be drawn based on action-learning. Several teams found a metaphor for their journey in *The Wizard of Oz,* as this artifact from a team's account of its learning shows.

Transformation at the intersection of person and provider produces learning about what it takes to build organizational capacity. Some of this work is affected by the relationship between the organization and the system that funds and governs it. This makes person-centered work with people with complex needs a high leverage site for learning what it takes to make the changes envisioned by the Transformation Panel.
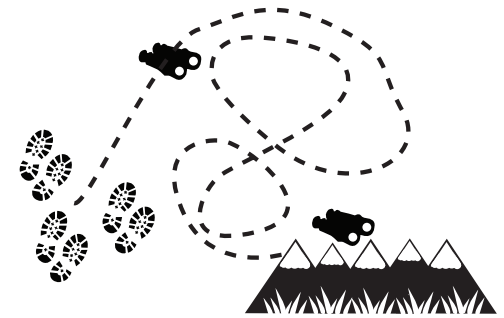
An invitation to transformation
(Never go alone!)

How might we...

Reflecting on the Learning Journey to Family Lives, an agency providing nursing support to people with complex health care challenges in their own homes (*familylives.us*), participants adopted a **design thinking practice** and de-fined challenges of transformation with these *How might we... questions.*

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...find blue space to innovate amid the daily chaos?

...open up new community opportunities, including jobs?

...better balance safety with dignity of risk?

...strengthen people's voices by listening with more empathy & acting with people on what we hear?

...drive out fear & reduce anxiety?

...decrease learned helplessness in everyone?

...move from group homes to support for people living in own home?

...move from control over people to caring action with people?

...empower people to experience joy? ...avoid being an obstacle to joy?

...strengthen natural supports, especially for people without family contact?

...diversify funding sources?

...do better at matching DSPs to people & support-ing their relationships?

...make stronger partnerships with families?

...make our mission alive in our HR process: hiring people with passion for mission?

...support DSPs to act on the recognition that their work is enabling the Good Life?

...move from doing for consumers to support-ing active citizens?

Meeting inflexibility

Relationships in which trust and confidence can grow, especially with the direct support professionals that a person counts on every day, are the foundation for good support. If community participation and self-direction are to be a meaningful possibility for people with complex needs, the capacity to individualize supports must reach all the way down from the design of their living environment to moment-by-moment adjustments in interactions. They will have the best chance of a good life when those who plan and manage services celebrate the challenge of their needs for extreme flexibility as opportunities for creative action consistent with the field's highest values.

Change Teams met three interlocking sources of inflexibility in the system, in the structure and culture of services, and in themselves.

Self The first move in transformational change is finding a vantage point. The first step in finding a vantage point on individualized supports is to recognize the power of culture –what is taken
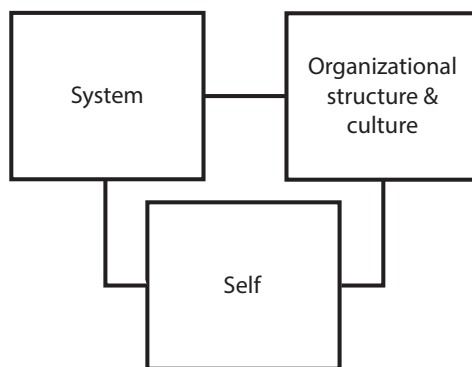
for granted as *the way things are*– to shape perception and action by forming blind spots. Blind spots lock in more of the same by obscuring the possibility that new support capacities could open new opportunities for self-direction and community integration.

Blind spots receded as participants renewed their connections to what they value in their work and considered different perspectives on complex needs. They opened their assumptions to inquiry and recognized that, like the back wards of the old institutions, the category "complex need" sweeps together people with singular bodies and minds into a single "specialer than special" grouping.
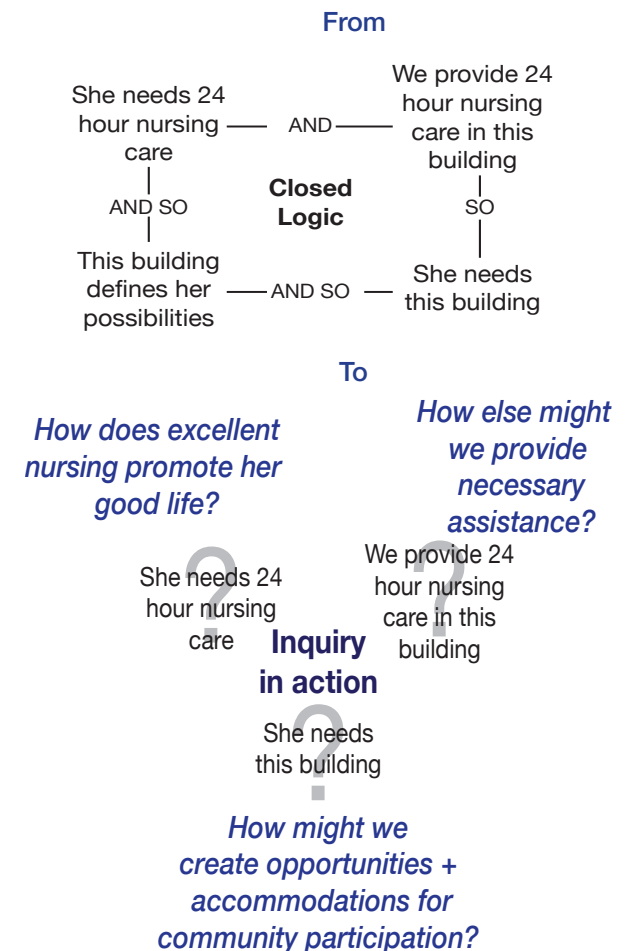
Assignment to the status, complex need, can overshadow individual identity, generate pessimism and justify false and rigid conclusions about how a person must be served. One safeguard against this error is to notice when thought and action are trapped in closed logic and intentionally open minds to inquiry in action that takes the values our system espouses –community integration and self-direction– seriously enough to learn through inquiry in action. This means putting a question mark over current assumptions, pursuing new questions that open those assumptions to test, and trying other ways. New questions lead outside settled boundaries to new sources of knowledge.

Integrated, quality services must be supported by networks of high performing providers with the flexibility to meet people's needs.

–Raising Expectations,
Changing Lives (p. 11)
goo.gl/ZksG0q

From

She needs 24 hour nursing care — AND — We provide 24 hour nursing care in this building

Closed Logic

AND SO

SO

This building defines her possibilities — AND SO — She needs this building

To

How does excellent nursing promote her good life?

How else might we provide necessary assistance?

She needs 24 hour nursing care

We provide 24 hour nursing care in this building

Inquiry in action

She needs this building

How might we create opportunities + accommodations for community participation?

13

	Perspective
Beth Mount & Hanns Meissner	Creating Blue Space as a condition of Transformational Change • Stages in the history of services & current organizational challenges • Theory U as the guide for Learning Institute & Change Team process –*Blue Space* goo.gl/5M1ifm and *Pathfinders* goo.gl/gtZGj6
Michael Kendrick	The Good Life as purpose & measure of quality • Critical perspective on the conditions necessary for individualized supports • Right relationships • Lifestyle development –kendrickconsulting.org
Carol Blessing	Person-centered planning as a way to guide people to live their full citizenship as contributors to community life –cclds.org
David Pitonyak	The neurophysiology of much of what is often labeled challenging behavior • Anxiety, trauma, stress & isolation as causes; creating and supporting good relationships as a way to move toward healing & development • Transforming the architecture of support dimagine.com
George Braddock	Creating physical environments that work for people with complex needs: what does self-direction look like in the kitchen? Environmental modification as a support for people with cognitive and sensory processing differences • Person-centered planning must consider both the human and the environmental design – *Making Homes That Work* goo.gl/EQFXWX
Jeff Strully	20 year perspective on the transformation of group homes & day services for people with classic autism into individualized supports for people to live in their own homes & work & inhabit other valued community roles • The powerful, mostly positive effects of individualized supports on the lives of people, family & staff –jaynolan.org
Chris Lyons	Demonstration that managing organizational risk and liability and providing individualized, self-directed supports are not mutually exclusive
Joe MacBeth	Direct Support as an emerging profession with an Ethical Code and process for certification whose members are essential to individualized supports. • The benefits & worth of investing in DSPs. –www.nadsp.org
Learning Journey to Family Lives	Values driven individualized supports to young people with complex needs for nursing, most of whom live in their family homes • How nursing care actively & intentionally supports valued & contributing roles & relationships • Mission & values sustained by clear principles and rigorous expectations communicated through hiring & continual learning requirements –familylives.us
Michael Kennedy	The impacts of institutionalization • The perpetuation of the institutional experience in group homes & day programs • Making the move to your own home and job –goo.gl/3nbV8o

Learning in action must be a collaboration between a person and those who support them. It can't be done to the person, it must be done with them. It happens through repeated cycles of trying something different, reflecting, and then amplifying what works and revising what does not. Delay in these cycles limits the adaptation to individual difference necessary to individualize supports for people with complex needs. The longer it takes to formulate and implement adjustments the less effective support will be.

Adopting a posture of person-by-person inquiry doesn't guarantee success. It simply substitutes curiosity for unquestioned certainty and converts what has been taken for granted into questions that can be searched by asking new questions and doing something different to discover individualized answers.

Learning Institute sessions, identified on the facing page, introduced participants to multiple perspectives on differences of body and mind. Each perspective has a good chance of revealing actions that decrease the risk of exclusion from community and deprivation of meaningful control. Considering the options for action that appear when a person and their change team look at their situation from these different angles breaks the spell of more of the same.

As Change Team members connected with participants from other agencies, developed relationships with the people they selected as partners in change and considered those people's individual situations from the different vantage points introduced in workshops and webinars three things came into focus.

One. People's group living arrangements and day services make individualization difficult, especially when the horizon of expectation includes active support for a good life with community integration and increasing self-direction. In many instances people's daily routines included little attention to developing competence and capacity for choice and few if any opportunities to extend relationships. Sometimes design features, particularly group size and concentration of people with similar impairments, limited the effectiveness of prescribed interventions and made assisting the person to pursue their good life very difficult. An example, a person who becomes extremely dysregulated in response to noise was trying to live in a specialized home with other people who are frequently very noisy. Another, no action had been taken on a person's expression of interest in a job although the p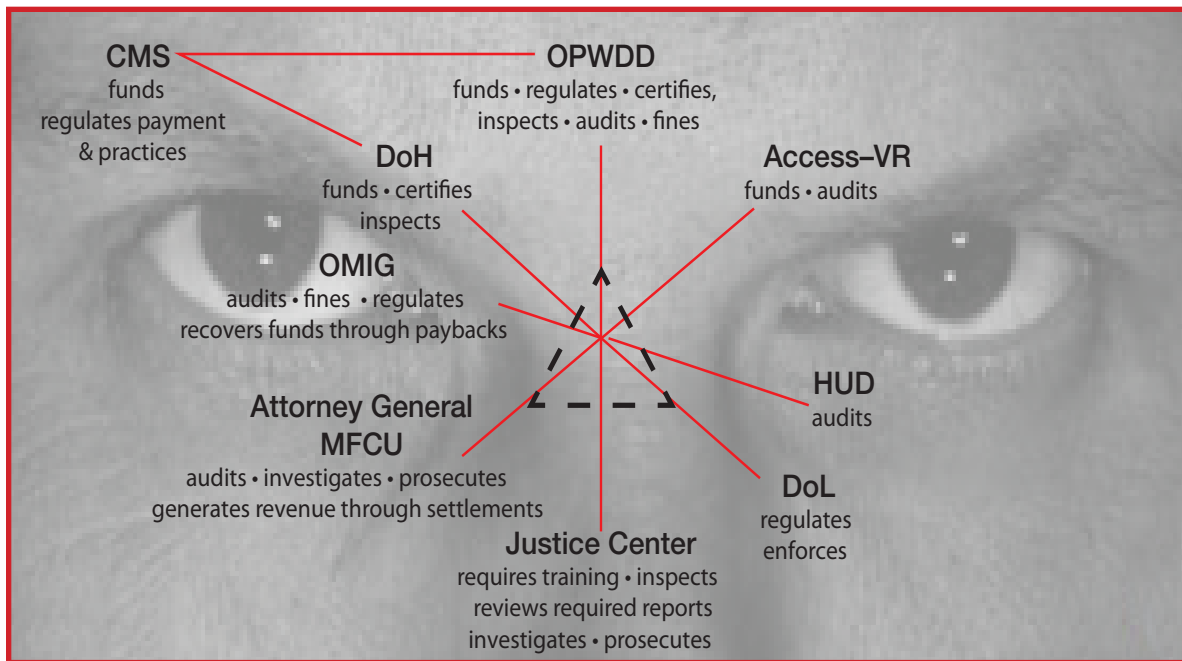erson expressed interest repeatedly. **Organizational inability to adapt and respond without long delays and complicated negotiations is, in itself, an important source of the complexity that impairs people who require highly individualized and flexible supports.**

Two. Changing undesirable living arrangements is very difficult. Participating organizations and OPWDD itself have considerable **room to improve their capacity for the learning in action** necessary for transformational change. Participant organizations, and the OPWDD system, seem to have at least implicitly assumed that significant improvements in support to people with complex needs is achievable within people's current or easily available living and day service environments. Decision makers did not seem to have considered that better meeting the needs of people with com-

plex needs would call for new forms of individualized living and employment support arrangements and that risk management, human resources, rate setting, payment and regulatory functions would all need to become active sites of transformation. Most organizations apparently assumed that progress is possible when Change Team membership is added on to existing duties and that momentum for transformational change can grow without investment much beyond time to attend Institute meetings.

Three. As trust grew in the Institute group, many participants acknowledged the erosive effects of a **climate of fear** on their work. Some expressed a sense that their work unfolds under the constant, hostile gaze of many eyes alert for errors. They notice how much time they invest to defend against

enforcement mechanisms that, as they experience them, assume that errors in documentation are evidence of fraud or that staff are presumed suspect for neglect or abuse. Repeated appeals to accountability as justification for weakening organizational boundaries and strangers who never meet people intruding into people's lives seem hollow. Not one of the authorities who scrutinize and regulate demonstrate an effective way to take the side of people with complex needs and their allies as they struggle for a good life. They don't acknowledge limits to the righteousness of their demands on organizations or humility about the rightness of their judgments about people's lives. The costs to relationships necessary for good support of avoiding imagined liabilities, dealing with redundant inspections and conforming to increasingly complicated and restrictive payment mechanisms go unaccounted. OPWDD managers seem resigned. Organization managers seem to see no choice but to do whatever it takes to comply and avoid the risk of bad audits or judgments of neglect or abuse by inspectors, investigators or jurors in liability suits. Committed people are increasingly alienated from the relationships and action with people that give meaning to their work. The moments of blue space necessary to create flexible, individualized supports get harder to claim even as they become more necessary.[*]

CMS
funds
regulates payment
& practices

OPWDD
funds • regulates • certifies,
inspects • audits • fines

DoH
funds • certifies
inspects

Access–VR
funds • audits

OMIG
audits • fines • regulates
recovers funds through paybacks

HUD
audits

Attorney General
MFCU
audits • investigates • prosecutes
generates revenue through settlements

DoL
regulates
enforces

Justice Center
requires training • inspects
reviews required reports
investigates • prosecutes

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* As Hanns Meissner presents it in his book of the same title goo.gl/5M1ifm *blue space emerges in safe, appreciative places, in dialogue and engagement with others, in generative action, and deep inside our self.*

Organizational structure and culture. It has been common practice to reserve living in your own place and holding an individual community job for people capable of managing with modest and fading support. This is often called "independent living", which misdirects attention away from those who will benefit most from individualized supported living . Excluding people from individualized community environments on the basis of their perceived skills erases options for the people who will benefit most from because of the complexity and highly individualized nature of their need for supports capable of rapid adaption. They need independence from being managed as one of a group in order to have the best chance at a good life. Well supported individualized living and work settings are much better able to respond to self-direction than group settings are.

Once they leave their family home, people with complex needs are very likely to live in settings intended and sometimes purpose built as sites for the delivery of nursing care or behavioral intervention to a group selected as if a single professional attribution makes them suitable housemates. If the aim is to increase community integration and self-direction, service's delivered through this group based design work poorly for most people and only with the most heroic effort for people with complex needs. People have the best life chances when organizations have the capacity to individualize supports and make them portable and adaptive to a wide variety of community settings. As Institute workshops and webinars affirmed, these are not theoretical constructs. The possibility and desirability of living in your own place and contributing to your community has been demonstrated

within reach of (nearly) everyone with access to flexible, individualized supports.

Money is not always a barrier, most people with complex needs are in high cost settings. The difficulty lies in making money flexible enough to flow in sufficient amounts into new, more individualized forms of support.

Some Institute learning partners have very substantial numbers of staff around them. But staff occupied by design inside the walls of a program (and its associated vans) in delivering and supervising routines and managing incidents are placed in a position of power over people. What matters to people with complex needs is staff members who exercise power with them to seek good lives in everyday places and events.

There is a challenge in matching and retaining capable Direct Support Professional who understand and are committed to the ethical principles of offering person-centered support to self-direction and inclusion.[*] The continuing devaluation of the skilled nature and critical importance of direct support work re-creates a chronic workforce crisis that leaves people with complex needs particularly vulnerable.

There are cultural and relationship issues that organizations that operate hierarchically have difficulty managing. The ways that people with complex needs show up in group settings specialized around low expectations for community integration and self direction can get baked-in to staff (and family) member's sense of people's identity and possibilities. Those Direct Support Professionals and managers with genuine concern and affection

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[*] *The NADSP Code of Ethics* goo.gl/ezeGjC

√ Commitment to drive out fear

√ Individualized settings for living, work & community participation. Freedom from being managed as one of a group.

√ Sufficient, flexible money through channels that recognize the holistic nature of necessary support.

√ Capable, ethical, well supported
Direct Support Professionals committed to sticking with the person & learning with the person to increase self-direction and community integration.

√ An organizational culture that promotes respectful relationships & supports people in negotiating transformational change.

√ Skillful management of polarities: e.g. dignity of risk – safety.

for the people they assist and supervise cannot imagine the person surviving, much less thriving, outside their current setting. When rooted in relationship, these beliefs can't be changed by command or a few days of training. Many good people come to see how much more is possible with respectful invitations to join in the action; some do not. All those invested in current arrangements face some real loss of familiar roles and routines and some may experience guilt for underestimating people and unintentionally holding them back.

It would be absurdly dangerous to discount the real vulnerabilities that come with extreme differences in body, mind and behavior. People who require skilled and intensive assistance in a group setting will also require skilled and intensive support in their own home or as they connect to valued roles in a more diverse community. Those who design and deliver individualized supports must be even more capable because they need to be able to skillfully and rapidly adapt to changes in the person as their environment changes from moment-to-moment. Personal commitment, knowledge, prudent foresight, good judgment and skill keep people safe with far less compromise to living a good life than counting on regulations and routines behind walls can do. Ethical relationships keep people safe and healthy.

Managers' competency is on the line. Given all of the external pressures on the organization, can they create a safe space for transformational change and invest sufficient time and talent for real change to emerge through meaningful involvement of people with disabilities, family members and

Direct Support Professionals? Does the organization have sufficient depth of skill to effectively frame and manage polarities, for example the polarity between safety and dignity of risk. Can managers create ways that work to build, deepen and renew commitment in daily work to the values of community integration and self-direction?

System. The following section identifies opportunities for OPWDD to make efforts for transformational change more effective.

As Learning Institute participants have come to understand it, transformational change depends on trust and tolerance for multiple trials and adjustments on the way to greater capacity. It calls for space to try new approaches and so for ways to suspend rules and practices that lock in more of the same.

OPWDD could make Learning Institute partnerships more effective

Three broad themes stand out from discussions throughout the Learning Institute. None are revelations, but each has come into sharper focus as Change Teams have struggled to make timely progress.

Learning Institute participants recognize that OPWDD is one actor among many in a system being re-shaped by federal and state Medicaid reform, CMS dictates of conditions for federal financial participation, the presumption by outside powers that there is significant amounts of fraud or abuse for them to uncover and penalize, external political limits on OPWDD's autonomy, and hyper-vigilance to negative media coverage. They realize that there is no magic wand for OPWDD administrators to wave that will dissolve the obstacles that block or slow progress in Learning Institute partnerships. There are no easy fixes.

Increase flexibility

The first way OPWDD could make Learning Institute partnerships more effective is by making steady progress on increasing flexibility, reducing the barriers to individualization that the Transformation Panel recognized…

> If individualized supports are the goal, we need to acknowledge that our current system lacks that kind of flexibility[*]

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[*] *Raising Expectations, Changing Lives*, goo.gl/ZksG0q

Individualization of residential and day supports and flexibility refining support arrangements by real time learning and adjustments are essential to good support to people with complex needs. No amount of pre-planning can anticipate changing circumstances. The alternative to greater flexibility is acceptance of the inevitability of restrictive measures and exclusion from the possibility of increased community integration and self-direction.

Apparently the current state of relations between CMS and OPWDD is a significant source of inflexibility. Learning Institute participants would be encouraged to know that…

…OPWDD is part of an effort which includes advocacy organizations and provider organizations to actively engage CMS in finding a better balance between the values expressed in its 2014 Rules for HCB Waivers and the demands it imposes as conditions of waiver funding.

…OPWDD is guided by the Transformation Panel's analysis and is actively revising any inflexibilities under its control. A growing list of policy changes resulting in more flexibility for self-direction would be a sign that the Panel's work is taking hold.

Reduce the costs of compliance

The second way that OPWDD could make Learning Institute partnerships more effective is even more difficult to implement than the first. It is to acknowledge and find ways to engage the high and growing costs of compliance with require-

ments of the multiple agencies that hold mandates to audit, monitor and scrutinize the circumstances of people with developmental disabilities and impose changes without consultation with the people whose lives are affected. These practices, which seem to have become assimilated into the culture, elevate bureaucratic protocol above people's rights to self-directed individual supports and invites skepticism about a growing gap between OPWDD's stated values and the values expressed by the whole system in action. When undergoing and responding to multiple audits claims weeks of your organization's attention it is hard to believe you are part of a system that is aligned with the Transformation Agenda, however serious OPWDD may be about it.

The financial and staff time costs of compliance and disputing imposed sanctions are only the beginning. There are the costs of multiply redundant distractions from the work of developing the new supports necessary if the Transition Panel's work is to be more than a paper exercise. There are costs that arise from loss of meaning, as committed staff feel that a greater and greater share of their attention and talent goes to serve bureaucratic demands, monitors and auditors rather than relationships with the people with developmental disabilities they came into the work to serve. There are the costs generated by a climate of fear.

Real costs are often discounted with appeals to the importance of accountability and health and safety. Thoughtful exploration of both ideals is a condition for progress. Each becomes a source of restriction when it collapses understanding of health and accountability to externally judged compliance with external rules. A better understanding of accountability recognizes trade-offs among multiple interests and seeks a balance weighted in favor of making the changes necessary to live up to OPWDD's commitment to community integration and self-direction. It is contestable that the interests of people with disabilities or public accountability are best served by deploying multiple authorities to search for fraud. A better understanding of health and safety accounts both the risks of taking action and the risks of restricting the potential for positive action. It is debatable that people are healthier or safer when potentially positive changes in their lives their lives can be vetoed by any single, uncontested voice, whether it be a health care professional, a fire marshal or a legal guardian.

OPWDD is only one actor in a complex system, but Learning Institute participants appreciate its efforts to exercise the moral authority that comes from its distinctive responsibility to represent the interests of people with developmental disabilities. Acting in concert with self-advocacy and family advocacy groups and provider organizations to count and work to reduce the costs of compliance is a good use of OPWDD's leadership position. Collaborative effort to advance the transformation agenda with the state Medicaid agency, the Justice Center, the Attorney General, and CMS will demonstrate and strengthen commitment to real change.

Efforts to mobilize encounter significant differences among key actors about what is possible for

people with developmental disabilities and what is necessary to protect the public interest. Leadership will create occasions for people to confront these differences by thinking together about fundamental questions of what keeps vulnerable people safe while respecting their rights to self-direction and community integration. Many Learning Institute participants would appreciate the opportunity to set aside resignation to unquestioned compliance and engage in honest discussion of these issues.

Invest in local transformational change

The third way that OPWDD could make Learning Partnerships more effective is to back its public commitment to Transformation with two direct investments.

The first investment is to establish a **broadband feedback loop** between innovators and system administrators so that the learning of agencies making real change, and initiatives like the Learning Institute, generate face-to-face discussion with OPWDD decision makers. Such a feedback loop would also, over time, produce responses that show innovators that the lessons and questions from their efforts have been noticed and their concerns have registered. When feedback from innovators on the ground can result in changes that open more space and generate more flexibility for individualization this investment will make a return.

The second investment is to adequately **fund a variety of supports** to teams and organizations working on the transformational change agenda of expanding opportunities for self-direction and

community integration for people with complex needs. On the understanding of change used in the Learning Institute **(page 8)**, most recent OPWDD investments have supported developmental or transitional changes aimed at implementing managed care or complying with CMS rules. Such changes are desirable but not enough to make meaningful progress on the transformational change necessary to improve individualized supports, especially when people's needs require the development of new support capacities.

Additional recommendations, based on the experience of particular Change Teams, follow…

Suggested changes to OMRDD policy and practice

In addition to the three critical changes identified above –increasing flexibility; reducing the costs of compliance; and investing in support for transformation– Learning Institute participants identified additional obstacles that some Change Teams have encountered in their journey so far and listed policies and practices that OPWDD could change to make providing individualized supports less difficult for them.

Keep working to make progress on assuring a competent & committed workforce: appropriate wages; opportunities for education; credentialing. Matching people with complex needs with the right DSPs is crucial to good support.

—§—

The option for Self-Directed Services is an important resource for people with complex needs.

• *Simplify & increase incentives to choose it by making it easier to use & minimizing bureaucratic constraints on use of the money.*

• *Assure sufficient funding to allow self-directed supports when, for example, there is good reason for a person with intensive support to be the sole occupant of their home.*

• *Broker fees should reflect the work necessary to arrange good support for people with complex needs.*

—§—

Dealing with risk and fear of liability in a constructive way is at the core of individualization.

• *Strengthen decision support, especially for people with limited family involvement.*

• *Explore policy changes that would allow people legally capable of making informed decisions to override protective oversight.*

—§—

Increase consistency of rules and approvals related to individualized services & self-direction across OPWDD regions & offices. Set the most flexible policies and practices as the standard.

—§—

Work for less redundancy & more consistency among those responsible for oversight.

—§—

Acknowledge the gap between current service offerings & the vision of individualization & community integration and act to close it by…

…offering grants for truly transformational change initiatives.

…aligning billing codes with intensive individualized supports.

…make funding flexible to account for crises.

…calculate PRA to include employment & full costs of individualized supported living.

…encourage flexibility: 3:00 closing time for day services limits opportunities; some interpretations of the Nurse Practice Act limit the availability of supported living options.

—§—

Increase access to relevant technology & environmental modifications.

—§—

Collect, share & promote stories of transformational change.

—§—

Keep working to strengthen partnership between OPWDD & provider organizations.

—§—

Keep working to improve access to competent mental health & substance abuse services from providers who understand & are committed to self-direction & community integration.