



## Contents

Perspective	3
Results so far	4
Project design and resource assumptions	4
Institute activities	5
Important changes in the environment	6
A slow pace of implementation	7
Guiding Ideas	8
Where did these ideas come from?	10
Opening space to learn	11
Had we but world enough and time...	12
A challenge to the system	17
New ways to see and think	20
Launch platforms for change	21
Listening Practice	22
Next steps 1: A searching discussion about overcoming immunity to change	24
Next steps 2: Strengthening communities of practice	27

## Perspective

The NYSACRA Learning Institute on Innovation in Individualized Supports (from here on the Institute) grew out of the work of the Individualized Supports Think Tank, a multi-stakeholder group that gave shape to the idea of individualized supports in a clear definition, discussions about how to practice in a person-centered way within the constraints of the New York State system,<sup>1</sup> and the implementation of the Institute by some of its members. 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. Since the Institute was designed, the Think Tank's understanding of individualized support has been clearly reflected in OMRDD's Comprehensive Plan, along with other key ideas strongly associated with Think Tank leaders and explored through the Institute. Think Tank members' vision provides the vocabulary of aspiration for OMRDD's Comprehensive Plan: lives of distinction, person-centered work, self-direction, homes of people's choice, working and contributing to community life, and having meaningful relationships.

This alignment between the central themes of the OMRDD strategy, the Institute's agenda, and the commitments and work of those who designed, supported, and facilitated the Institute makes the lessons that come from the Institute about encouraging fundamental change in service provider organizations especially relevant. The Institute has served as one forum in which those responsible for influencing and implementing the system's strategy and those whose daily work it is to plan, manage and deliver support can explore the meaning of the central themes in the system's policy in the context of service provision.

Everyone who has invested in the Institute could reflect on their experience and share important lessons. I have chosen to focus this inquiry on the consultants who took primary responsibility for conceptualizing and guiding the work of the Institute's participants, Hanns Meissner and Beth Mount. Their position as

***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*

*OMRDD will continue to strive to support people to have greater choice and control in their lives while ensuring its stewardship of the public's trust and precious resources. The challenge now faced is to go forward in a way that contributes to the shared sacrifice required in the state's current fiscal crisis while still fulfilling goals to deliver high quality supports and services that offer greater choice and self-direction for people who have developmental disabilities, and which are more sustainable in this financial environment. Management assessment strongly suggests that through changes to OMRDD's financial platforms, administrative infrastructure, and business practices, supports and services can offer both equity of access and a better match between what people with developmental disabilities and their families need and desire to live the lives of distinction they deserve.*

*OMRDD believes that lives of distinction for people who have developmental disabilities are achievable when they have plans, supports, and services that are person-centered, individualized, and as self-directed as they choose, and are focused on four basic personal outcomes: living in a home of their choice; working or engaging in activities that contribute to their community and personal growth; having meaningful relationships; and having good health.<sup>2</sup>*

---

<sup>1</sup> Throughout this paper, "system" refers to the whole system 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.

<sup>2</sup>OMRDD, *Interim Report: Statewide Comprehensive Plan 2008-2012*. Albany, 2009, p. 2.

thought leaders and practitioners in developing the capacity to deliver person-centered supports, and their role in the Institute as designers and facilitators of a process intended to produce the kind of organizational change that they and their colleagues in the Think Tank believe is necessary to deliver on OMRDD's commitments, make their reflections useful to those who want to lead transformative change in the whole system.<sup>2</sup>

## Results so far

### *Project design and resource assumptions*

The Institute's designers proposed a two stage, two year approach to change, intended to develop provider capacity to deliver individualized supports as defined by the Think Tank. In the first stage, agencies commit to a person-centered approach to planning and program innovation and form multi-stakeholder change teams. Change teams participate in several sessions with experts and learn to implement models that will improve agencies' ability to deliver individualized supports in a way that assures financial stability. Participants in these sessions constitute a community of practice that provides peer support throughout the change process. Each change team plans with at least 10 people who will benefit from agency innovations. In the second phase, agencies deploy innovations that implement the individual plans. These innovations result in measurable changes for the 10 focus people, such as moving into smaller more independent living arrangements, while they develop agency expertise and culture in ways expand capacity to offer individualized support.

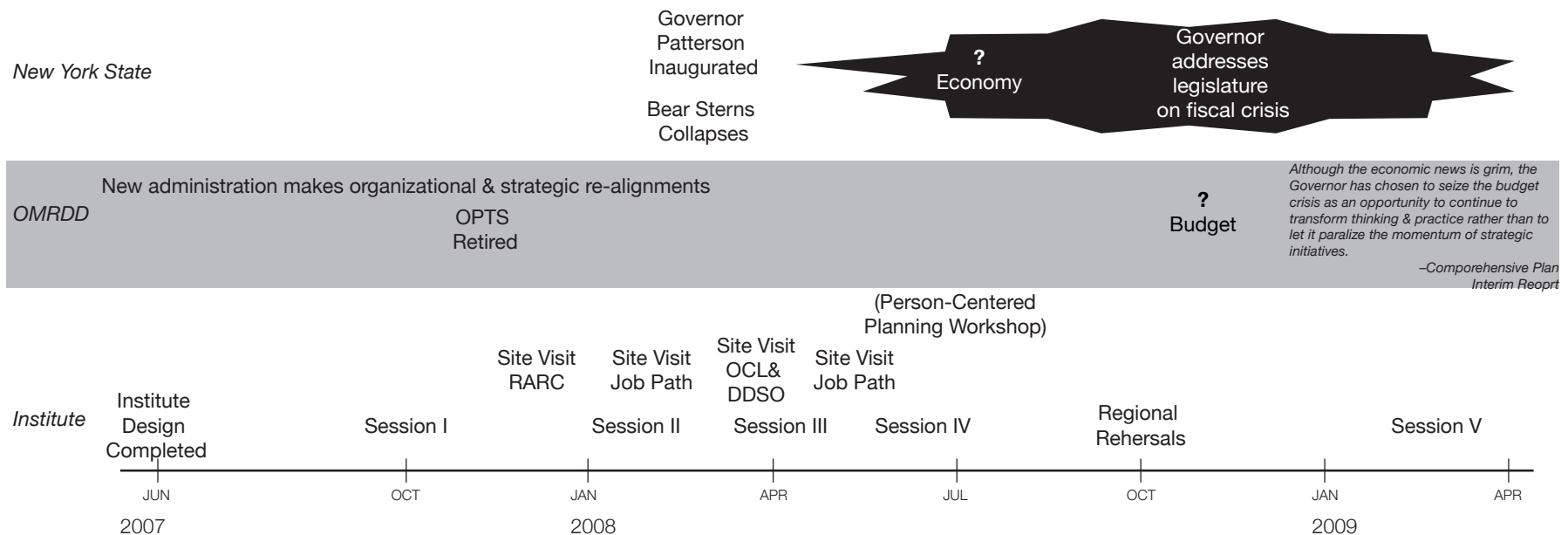
The design assumed that innovations shaped by the Institute would probably form the basis for OPTS proposals, which would provide continuing funding. Participating agencies are supported by small grants from OMRDD of \$2,500 for stage one and \$17, 500 for stage two. Additional resources will be available from the Real Change grant that OMRDD received from CMS. Beth Mount's consulting contract with OMRDD will support her involvement in the project.



<sup>3</sup>Beth and Hanns are my friends and colleagues. I have been an occasional adviser in their work on the Institute and an observer and commentator at two of the sessions. Work on the Institute overlaps other joint projects, some reaching back many years. So this account of lessons learned comes from a conversation among friends. It lacks what a critical outsider would observe or what a researcher would discover by asking participants about their experiences. It benefits from what people who share beliefs and a history of collaboration can bring to their reflections.

## Institute activities

As the chart on the facing page shows, stage one Institute activities have run to plan, but over a longer time period. Representatives from participating agencies engaged in five large group sessions (three were for one day, one for two days, and one for one and a half days), and a one day rehearsal of proposals held for regional clusters of participating agencies. In addition, representatives from most agencies made at least one site visit to one of four organizations who have made considerable progress on providing individualized supports and maintaining fiscal stability, and people from several agencies participated in a one day session on person-centered planning that was held in response to several change team's requests. There has been continuous support from Pat McKay, NYSACRA's Associate Executive Director and Institute Liaison, who, among other important contributions has tracked project activities and gathered relevant materials on a web page which chronicles the Institute at [www.nysacra.org/nysacra/learninginstitute.htm](http://www.nysacra.org/nysacra/learninginstitute.htm). Representative from Self-Advocates of New York, Developmental Disabilities Council staff, senior OMRDD staff, and Ann Hardiman, NYSACRA Executive Director, have advised on the design of sessions and participated actively in Institute activities



Agency change teams varied in composition and position in their organizations. Few brought board member or self advocate members to the larger gatherings and only some teams brought senior agency staff.

According to summaries of the session evaluations, those who attended generally found them helpful and many participants report significant personal learning about individualized supports and what it takes to deliver them.

#### *Important changes in the environment*

The environment for Institute participants' change work was powerfully affected by change from two sources. OMRDD leadership is restructuring the whole system to offer supports that better live up to the principle of *Putting People First*. And, the world economy is in a crisis which powerfully affects New York State's revenues and the incomes of many of its citizens while it generates great uncertainty that touches everyone in the state.

OMRDD restructuring, which holds the promise of greatly improving the system's capacity to offer individualized supports, had the immediate effect of invalidating the Institute's resource assumptions.

A month after the first Institute session, OPTS was retired. Participants then had questions about procedures for accessing funds to implement their plans, and a strong current of uncertainty about sustainable funding for proposed innovations has continued until this writing. Some participants report that this uncertainty increased stress on Change Team's work. Three agencies decided to leave the Institute, in part because of doubts about continuing funding for their proposals.

Shifts in OMRDD structure, strategy, and style resulted in adjustments to roles, relationships, and procedures. A common understanding of shifts in strategy and procedure takes time to reach from the center to districts. Some participants reported that proposals that seemed consistent with the messages they received through the Institute about OMRDD's priorities did not find the acceptance they expected when they began working with their DDSOs. Usual patterns for getting things done can be disrupted. Beth Mount, a key resource person, worked without a contract with OMRDD until well into the term of the Institute.



The CMS Real Change Grant has focused on developing Information technology and other infrastructure for refocusing the system on offering more options for self-direction. While these changes are critical to the long term capacity of the whole system to deliver its strategy, they have not provided resources directly to the Institute or its participants in the short run. OMRDD is re-designing Consolidated Supports and Services (CSS), the system's mechanism for people who chose to self-direct their supports, and offer new options for self-direction by amending the state's HCB Waiver, but the time for implementation is indefinite. These necessary and promising streams of work raise important timing questions for participating agencies: does it make sense to implement changes now, or is it better to wait until HCB waiver amendments introduce the Agency of Choice option or make self-directed supports easier to use.

Well into 2008, plans for change moved forward under the assumption that OMRDD would continue its long-standing pattern of purchasing change with new money. As clouds gathered over New York State's economy, uncertainty grew and, when OMRDD froze expenditures on planned improvements in order to align its budget with new fiscal realities, uncertainty spiked and waiting to implement innovations seemed prudent to agency managers. A renewed leadership commitment to proceed with new investments in change was welcome news early in 2009, but the system as a whole remains under significant pressure from those interests that see the financial crisis as a good reason to protect existing services and postpone significant change until better times. Moreover, just at the time when Institute gatherings could have been a valuable forum for making sense of environmental changes, it had used almost all of its resources for sponsoring meetings and participating agencies travel budgets were constrained.

#### *A slow pace of implementation*

As of 30 March 2009, no Institute proposals have been approved by OMRDD. Of the 12 agencies remaining active in the Institute, 9 have drafted proposals.<sup>4</sup> Four agency proposals combine some level of person-centered planning with par-

---

<sup>4</sup> These conclusions about agency plans are based on my reading of proposals and prep-sheets for practice presentations. The focus on the results expected from the project says nothing about individual learning or what change teams have done while working inside their organizations.

particular people with the design of an innovation intended to develop the agency's capacities to deliver individualized supports. Two proposals intend to individualize supports in accordance with person-centered plans but do not include plans for agency level development beyond a try-out of more individualized supports for particular people. Three proposals identify programmatic improvements but do not connect these improvements to plans made with specific people either before or during the first 17 months of the project. Project participants were selected on the basis of a proposed project judged to meet the criteria for increasing agency capacity to deliver individualized supports. Most of the proposals to OMRDD that will start the second phase of the project very closely track the agencies' original applications to the Institute.

As these results show, organizations participating in the Institute have not moved smoothly through the process designed before big changes in OMRDD and then in the State as a whole created great uncertainty about money for new initiatives and structures for innovation. We can't yet point to people who have moved into life with more individualized supports and organizations that have instructive accounts of significant changes in capacity and culture

Shifts in the OMRDD system and the state's economy provide good reasons for slippage on the Institute's proposed timeline, but the experience of those involved in Institute has much more to offer a changing system than the lesson that reorganization and high economic uncertainty slow the pace of change. Reflection on the Institute's work so far can inform the development of a system transforming to offer supports that put people first.

## Guiding Ideas

If the Institute has had a shortage of certainty about money, it has had an extravagance of ideas. The concept map on the facing page selects four clusters of ideas that seem to me to form the core of the Institute curriculum.<sup>5</sup> The logic of this curriculum is straightforward, though each component is demanding. It can be summarized by answering four process questions.

## Plan for Agency Development

Based on Person-Centered Plans	Plan for Agency Development	
	No	Yes
Yes	2*	4
No		3†

Intended Number of Person-Centered Plans	150	Actual Number of People or Families Involved in Planning Proposals**	34
--	-----	--	----

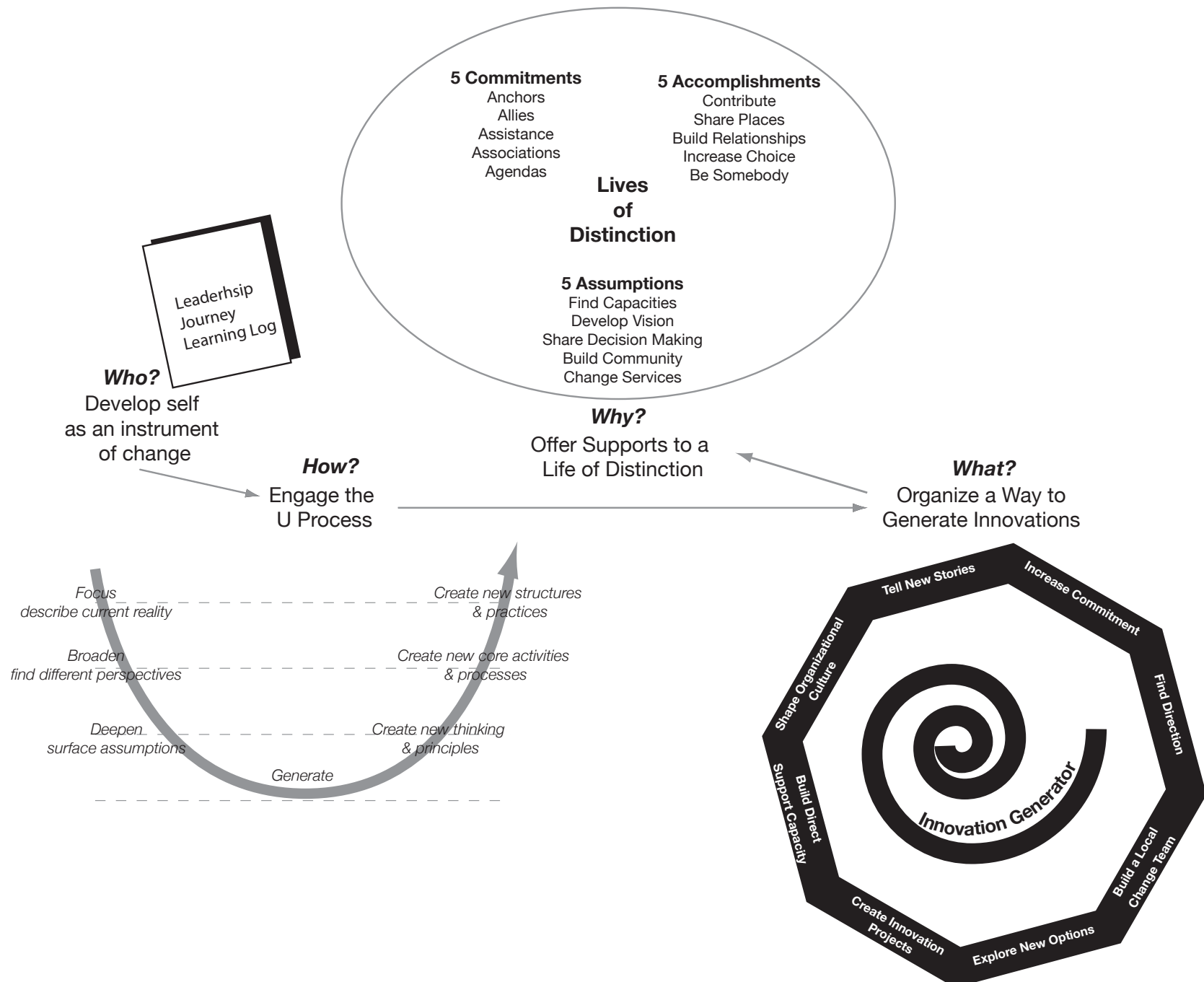
\*Though these proposals don't refer explicitly to the agency developing new capacities, they do suggest innovations at the individual level such as the possibility that focus people will have a central role in hiring their own staff or use CSS funds to direct their services.

† These proposals to develop new program capacity include the intention to use person-centered planning in their implementation.

\*\* Some of these people and families have not yet had person-centered plans. Agencies have shaped their proposals by consulting them about their interest in change, but are waiting for their proposals to be accepted before proceeding with planning so that people won't face a long wait between the promise of a change and its actualization.

<sup>5</sup> These ideas are presented in *Innovations in Individualized Supports*, the Institute's handbook, and a number of supplementary handouts and worksheets, all of which are available at [www.nysacra.org/nysacra/learninginstitute.htm](http://www.nysacra.org/nysacra/learninginstitute.htm). Throughout this paper, I have summarized, paraphrased and sometimes interpreted Institute materials in order to clarify my reflections on the process. Participants did not use the versions in these reflections.





<b>Who</b> creates organizational change?	Each participant develops self as instrument of change so that they can work as members of an change team and ...
<b>How</b> , by what method will the change happen?	–engage the U process to build...
<b>What</b> will be created through the change?	...an organization capable of generating innovations in response to changing individual situations and therefore able to...
<b>Why?</b> What benefits will these capabilities deliver; what purpose does the change serve?	...offer supports that give people with developmental disabilities the best chance of a Life of Distinction

*Where did these ideas come from?*

The Institute's facilitators have committed years to collaboration with people with developmental disabilities and their families as they have directed the creation of more individualized supports. They have also worked hard to develop organizational capacity to reliably deliver individualized supports, and made themselves students of organizational and leadership development methods. The Think Tank that germinated the Institute is a forum that has clarified the lessons of collective experience with offering individualized supports for organization development and policy reform. The facilitators approached the Institute as an opportunity to test and improve their understanding in action as participating organizations made changes.

As a group, the organizations that chose to join the Institute offer a good opportunity for testing the facilitator's assumptions about change and thus for informing the system's planned change to individualized supports. Participants are a reasonable cross section of service providers: they are distributed from the eastern end of Long Island to the Capitol District to Jamestown; they serve urban and

rural communities; they are small, family governed organizations and large service providers; they are close to start up and long established; some offer a comprehensive set of currently funded services and others focus on service coordination or the individualized supports that are feasible within current system constraints.

### *Opening space to learn*

At the end of the second session, a participant said, “When I came, I just took it for granted that I knew what person-centered planning and individualized support were. I’ve learned that there is a lot more to learn than I thought.” Un-learning –or recognizing that there is more to learn than one knew– proceeds best when people who feel a sense of possibility have sufficient opportunity to develop trust and a sense of safety that allows them to explore and revise their mental models.

The Institute opened five questions about individualized supports in a way that challenged the understanding that some participants and their organizations brought into the Institute:

- What does it mean to provide individualized supports in a way that enables people to live a life of distinction?
- What organizational capacities and service designs give people the best chance of living a life of distinction?
- How are these capacities developed, especially in a mature organization?
- What system conditions support the development of organizations capable of supporting lives of distinction?
- What qualities of leadership do those who want to develop individualized supports need to cultivate?

The Institute has been a learning process for the facilitators as well as the participants. As its work has progressed, interaction around these five guiding questions has shaped the facilitators’ understanding of how the guiding ideas work together to facilitate change. This mutual learning doesn’t match the idea that the Institute has ready made answers to operational questions that can be easily transmitted to participants, but it suits the reality of the change the Institute

wants to stimulate. Some participants seemed to find the lack of a blueprint unsettling, at least at first, but many seemed to welcome the opportunity to figure out how to generate the best possible answers to these questions in the context of their own organizations.

*Had we but world enough and time...*

The guiding ideas define a coherent path to the delivery of individualized supports. If people have a shallow understanding of the dimensions of a life of distinction, low expectations will stunt their efforts to make change. Unless participants assume individual responsibility for acting as an agent of change and dealing effectively with the emotions and uncertainties involved, inertia will defeat the effort. If individualized supports are going to match the variety of individual circumstances as they change, agencies need to become generators of a sufficient variety of innovations, not simply installers of the mechanism to bill under one more code. If people are going to come first, disciplines that support deep listening and continual learning from creative, courageous action become relevant.

None of these guiding ideas are just words to discuss and agree or disagree about or indicators of procedural steps to follow correctly. They indicate practices necessary make them meaningful. For example, choice, a much discussed aspect of a life of distinction, becomes meaningful in relationships that take the person's autonomy seriously enough to motivate discovery of opportunities and adjustments that extend the person's freedom to be his or her best self. Benefiting from these practices depends partly on learning their particular vocabulary of words and movements.

A practical grip on any one of these guiding ideas takes concentrated study and supported practice. The conceptual foundation for the U process,<sup>6</sup> for example, is laid out in a 500 page book, and its practices are typically introduced at an elementary level in a five day immersion course. The possibilities opened by the ideas grouped under the heading of a life of distinction have been profitably explored by experienced professionals in multi session courses with practica,

---

<sup>6</sup>The facilitators have drawn on and adapted the work of The Presencing Institute for the use of Institute participants. See Otto Scharmer (2007) *Theory U: Leading from the future as it emerges*. Cambridge: Society for Organizational Learning. In this paper, the U image refers to their adaptation of these ideas.

such as *Everyday Heroes*. Those committed to developing self as an instrument of change often invest substantially in months of coaching and intensive educational experiences.

The Institute met as a group with facilitators for a total of six and a half days in 17 months. Each day was filled to overflowing. The meeting room was crowded. Some participants had long journeys, arrived tired, and faced a return journey at the end of the day. In the time available, most teams did good work, but opportunities to get to know other participants by working closely with them or having relaxed informal conversations were limited by tasks assigned to agency teams, tiredness, and many things to get done.

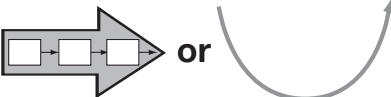
The facilitators designed exercises that ask Change Teams to apply the guiding ideas in their work on the proposals they were preparing for submission. So, for example, in the second session teams were given an introduction to the modes of listening that move the U process and then asked to apply the deepest level of listening in improving the Change Team's proposal. This confronted participants with the challenging of internalizing a new understanding of listening and practicing a new skill while doing real work on their proposal in a brief time. The task might have been more manageable if change teams had facilitators whose practice is informed by a good understanding of the U process and a space and time that would allow trying out and reflecting on the process, but it seemed very difficult for self-managed groups in the time allowed, and most teams seemed to harvest more words about the U process than fruits of its practice.

The Institute materials provided an abundance of study materials and guides to reflection, but opportunities to discuss the sense participants were making with these materials were limited. For example, the *Leadership Journey Log* provides a framework for developing self as an instrument of change by writing and reflecting on a record of the continuing experience of Change Team membership. Those participants who invested in keeping the log undoubtedly benefited from it. However, it was hard to find time to provide review and coaching during sessions and it isn't clear that participating agencies made time and coaching available so that participants could make the most of their logs. As well, the

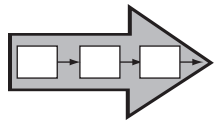
materials provided more guides and assessment questions about the progress and process of Change Teams than there was time to process during Institute meetings.

In their effort to bring the best that they know about implementing individual supports, the facilitators risked drowning participants in ideas because the Institute format didn't give participants a sufficient chance to learn more powerful swimming strokes. Moreover, the format made it difficult for participants to spend enough open time with those from other agencies for a community of practice to emerge. Most participants seemed to benefit from some new ways to look at their projects, their organizations, and their own work. Few if any have had the chance to absorb more than a fraction of all that the Institute materials offered.

There is plenty of room to try better ways to connect participants with the guiding ideas. The way to do this –and, more important, informing the implementation of the system's commitment to individualized supports– begins with exploration of what the Institute's experience can say about the kind of change that gives the best chance that the system will shift to individualized supports.

**The shape of change** 

Each organization joined the Institute with assumptions that fall along the continua on the facing page.



Most participating organizations, and most of the people who represented them in Institute sessions, began the Institute with expectations more like those outlined in the center or left hand

column than those in the right hand column.<sup>7</sup> Most expected access to funds and a curriculum that would make incremental change easier for their agencies, primarily by offering greater flexibility in the use of the new money that would support new program initiatives. These expectations mirror the system's frequent view of change as a technical problem, solved by a sort of procurement process in which purchasers specify a desired product, provide financial incen-

<sup>7</sup> The scales are an aid to exposition and are not intended to have measurement properties. They were constructed in this reflection on the Institute. So my judgements about where participants would fit are speculative, informed by listening to discussions and reading proposals and reports on exercises the participants completed.



Incremental change: A technical problem		OR	Transformation: A developmental challenge	
Our services are individualized & person-centered now & most consumers are satisfied.	-----	While we serve most people in an individualized way, there are some who are not served as well as possible & express dissatisfaction; more individualized supports will benefit them and expand what our organization offers.	----	To provide the level of individualized services that people deserve, we will need to fundamentally redesign the ways we offer & manage support. If we make deep enough change, significant improvement is possible for (almost) everyone we support.
We know what we need to know in order to improve our person-centered, individualized services.	-----	We will learn what we need to know from experts who will train us in evidence-based techniques & strategies, proven to deliver individualized services & maintain financial stability.	----	We can only generate relevant knowledge through action focused on the capacities of the people & families we support, our communities, & ourselves. We learn by doing new things with people & reflecting on them.
Our greatest need is for more funding & greater flexibility in the way we can use funds.	-----	We will benefit from learning more about strategies for improving outcomes & stabilizing costs (e.g. shared living; customized employment; community connecting)	----	We need to learn how to be an innovation generator, able to create a great variety of responses to changing circumstances at the individual, organizational, & community level.
We already make good person-centered plans. We could use some techniques for dealing with people who are difficult to plan for (e.g. resistant families or people who don't speak).	-----	We can improve our approaches to person-centered planning and our ability to implement plans, especially where involving people in the community or dealing with troubling behavior is concerned.	----	There is a critical opportunity for developmental growth in personal capacity to listen & sense opportunities for creativity. Developing this creativity is essential to inform innovations.
Our ability to make change depends on OMRDD changing. We can't change without more money to pay for it.	-----	Our involvement in the Institute puts us in a good position to negotiate with OMRDD for improvement money.	----	Offering individualized supports for all requires re-purposing the funds we already have. We should fund change with money we already have.
While it may take hard work, making change is a matter of making a good plan, marketing the change, & controlling implementation by monitoring & correcting. There is a straight line between setting a goal and achieving it.	-----	We will need to discover better ways. Delivering services to the first group of people we plan for will give us the funding & flexibility to try new approaches. We'll roll the change out to more people as additional funding allows.	----	Making the vision of individualized supports real means dealing with risk, uncertainty, and loss. Leadership requires the ability to observe, interpret, & intervene in emotionally charged situations & mobilize people with different interests. This calls for more than changes in the organization; it calls for changes in our selves.

tives, offer technical assistance, and monitor process and outcomes. This sort of change happens in manageable increments, adding to what is already there. The design of the Institute reflected a different understanding, a view of change as transformation.



The right hand column summarizes the facilitators' beliefs about the depth of change necessary to offer supports that assist people to have a life of distinction. For them, the Institute is focused on supporting Change Teams to meet

a developmental challenge: individualizing supports is a disruptive move, calling on people and structures to reach a new level of functioning to generate the variety of solutions necessary to support distinct lives of distinction. On this view, the ten people at the focus of person-centered plans prime the organization's capacity to consciously and continually generate innovations in response to changing opportunities to individualize support for growing numbers of people. In the longer term, as the agency constructs the capacity to individualize support, it will purposefully de-construct most current services because, being designed to group people according to clinical categories in order to remediate their deficiencies, they inherently limit the possibilities for individualization and self-direction.

Exploring the tensions between the facilitator's understanding of the change task and the assumptions about change typical in the system has been the motor for much of the Institute's learning. Many of these tensions reflect what the system takes for granted about change. For example...

... applicants defined their change projects before becoming involved in the Institute, as if they were responding to a procurement request; this preempted the critical process of framing the necessary change by listening into people's aspirations for a life of distinction and set most applicants to approach the Institute from a position of knowing how to individualize services and work in a person-centered way rather than as an opportunity to discover what they don't know and create new ways to do new things.

- ...several change teams consisted mostly of people responsible for individual planning, suggesting an assumption that change would have limited impact on the organization's structure and strategy rather than a commitment to disrupt typical practices in order to catalyze long term transformational change.
- ...the Institute's invitation to participate implied that experts have the answers to how to provide individualized supports and assure financial stability and that a few days investment of a small team's time would be sufficient to learn what an agency needs.
- ...OMRDD's management identified the Institute as a small but important test bed for its move toward more individualized supports, and senior OMRDD staff have played an active and important role in the Institute's work; however the Institute's modest budget, and its continuing struggle for the money to support its gatherings, suggests the assumption that big change can be had with a very small investment in learning and reveals that, though the system's budget is very large indeed, it is hard to loosen up money to fund innovation and especially support for innovation. This implies that innovation in the design and delivery of support is easily and cheaply done.<sup>8</sup> OMRDD invests substantially in research aimed at the prevention, diagnosis, and clinical treatment of conditions associated with mental retardation and autism –expressing the medical model mindset that shapes the system– but has trouble finding money for action learning critical to realizing its strategy.
- ...OMRDD assumed that innovation sufficient to creatively disrupt provider organizations is possible without disrupting its own rules, requirements, and procedures in order to fund and free the space necessary for learning.

## **A challenge to the system**

From the facilitators's point of view, deep change is necessary because experience shows that supporting lives of distinction and self-direction calls for organizational cultures, structures, and practices that are significantly different from those that have made organizations successful in an environment that has been shaped since the 1970's shaped by compliance with OMRDD's increasingly

---

<sup>8</sup>Given the scale of agency budgets it might have been reasonable to ask for a very substantial financial investment from participating organizations rather than offering them a modest money incentive to participate. If this might have risked reducing the number of participating agencies, it indicates that learning in support of innovation has a very low value in the system, and, perhaps, that the system has very high confidence in its capacity to individualize supports without additional organized support for learning.

DRAFT 07-04-09

sophisticated ways of maximizing medicaid revenues and a 40 year pattern of incremental growth in group service models. Failure to do the developmental work necessary to make this transformation will result in a great deal of activity that renames usual practices and makes small improvements within the boundaries of current structures. This will dilute the possibility of lives of distinction and betray what organizations committed to transformation are working hard to learn. It will be more of mostly the same with different labels.

Not only is the process of change a developmental challenge to participating organizations and their management, the system itself is challenged to develop into new forms. This perspective, shared by the facilitators and summarized in the table on the next page, depicts the challenge as pervasive. It entails creativity transforming the relationship between people with developmental disabilities and professionals, the way organizations offer services, the approach to innovation, the ways efforts are coordinated, and the foundations for service provision. Meeting these challenges means finding ways to engage different levels of complexity. On the facilitators view, the right hand columns –Integrative Supports and Community Supports– have the potential to hold the system’s vision of assisting people in lives of distinction. The left hand column describes current reality, with most organizations delivering services under the provocatively named heading of Institutional Care –long after most people have left the buildings.

## Evolving System to Support Individuals with Developmental Disabilities<sup>9</sup>

Hanns Meissner, February 2009

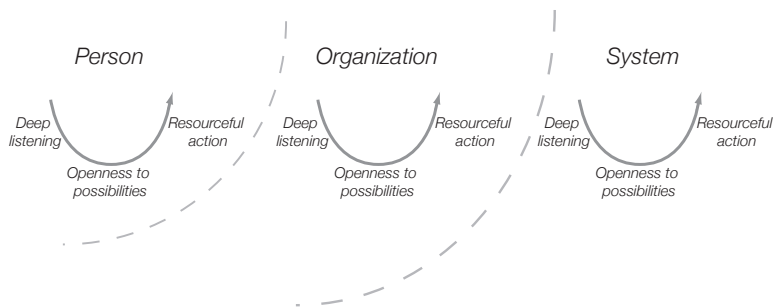
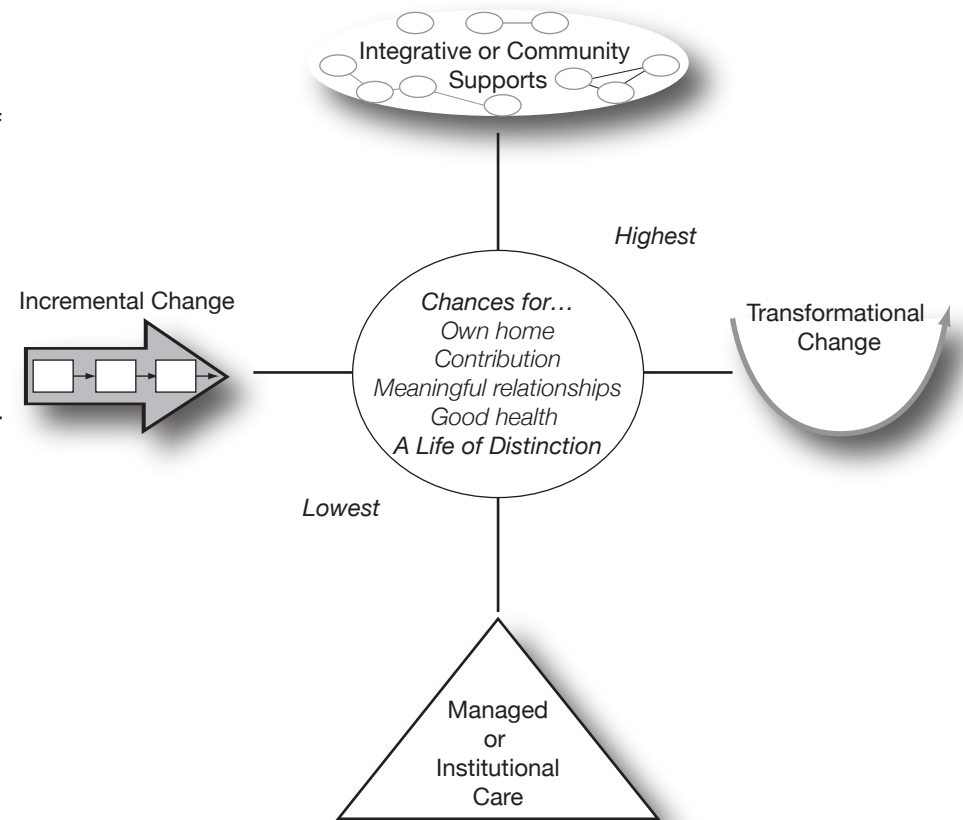
	Institutional Care	Managed Care	Integrative Supports	Community Supports
Organizing Principle	System-Centered	Outcome-Centered	Person-Centered	Citizen-Centered
Individual –Professional Relationship	Expert-Patient (professional direction)	Provider-Consumer (professional responding)	Facilitator/Broker-Self-Directed Individual (professional facilitating and partnering)	Resource-Autonomous Citizen (professional ancillary)
Service-Individual Interface	Functionally Specified Services and Models Model-Driven (pull)	Habilitation Pathways (core process) Service-Driven (push)	Wrap-Around Supports Person-Driven (negotiate)	In-Home & Community Located Supports and Resources Community Driven (allocation)
Innovation Mechanism	Administrative and Functional Effectiveness & Efficiencies (internal to the system) Make standardized products	Outcome Driven, cross functional and inter-organizational Deliver customized services	Person-Centered, inter-organizational Stage and co-create personalized experiences	Citizen-Centered, Community Based Support individual citizen autonomy
Dominant Type of Complexity	Many details to manage	Complex interaction between environmental factors	Complex interaction between key stakeholders	Unclear and emerging futures
Coordination Mechanism	Hierarchy and command	Market price	Network, dialogue and mutual adaptation	Seeing from the whole
Infrastructure	Social Legislation (laws, regulations, budget)	Rules, norms to make the market place work	Infrastructures for learning and innovation	Infrastructures for seeing in the context of the whole.

<sup>9</sup>This table describes a developmental process. Each step to the right changes the context for what is on the left incorporating, re-framing and changing it. For example, a Citizen-Centered system would need to effectively manage many details, work to budget and almost certainly include some superior-subordinate relationships. But these activities are transformed when the system is centered in seeing from a whole that includes people with developmental disabilities as active citizens and acting to realize the opportunities that emerge. CSS, the user-unfriendly approach to self-directed services offers a case example of an attempt at Integrative Supports trapped in a system centered on Institutional Care. I think the evolutionary metaphor is helpful as an aid to thinking, but I don't believe it holds strongly. In particular, I don't think that it describes a necessary progression or that anything much would be lost by leapfrogging steps (This note is my comment on Hann's table.).

## New ways to see and think

This diagram summarizes the facilitator's assumptions about the way to offer the most people with developmental disabilities the best chances of lives of distinction. On their understanding, a system that wants to offer individualized services will be struggling to organize itself in the pattern suggested by the description of Integrative or Community Supports. This will engage all of the system's actors in transformational change: people and families who use services, advocacy groups, providers, administrators, payers, and legislators. Individualizing supports represents a disruptive technology: a new way to do new things. The necessary change calls for sustained creativity, involves uncertainty, risk, and loss, and demands that people accept responsibility for offering leadership.

The source of support for lives of distinction lies in the relationship between the person or family that requires assistance and those who design and deliver assistance. When this relationship is enriched by deep listening, openness to the emergence of new possibilities, and resourceful action that allows learning, people will make good use of available resources in service of a good life and a stronger community. They will also press the organization and the system to offer more coherent and extensive opportunities to individualize supports. To the extent that those with authority in the organization and the system are practice the same disciplines in alignment with what emerges at the personal level, organizational and system capabilities will grow.





Launch platforms for change

Because the current system is not designed to support transformational change or Integrative Supports or Community Supports, it is important to create launch platforms that allow innovators to invent and explore new ways. The most important condition for such platforms is that they offer more degrees of freedom to experiment and learn than the current system does. The current system is very tightly coupled, with many details of structure and practice constrained by rule, pervasive distrust, and compulsive oversight leading most people to assess changes that create greater variety and more room for self-direction as carrying almost paralyzingly high risk. The trend in the system has been toward fewer, rather than more degrees of freedom even as OMRDD’s leadership has become increasingly visionary in its call for individualized supports to lives of distinction and greatly expanded opportunities for self-direction. Systemic fear of risk disposes some people to quietly discount the call for individualized supports as “unrealistic” and to wait out the call to generate disruptive approaches by making very low stakes moves at the far edges of their areas of responsibility while continuing to devote most of their resources to business as usual. This avoidance of learning is usually justified by claims that current practice is person-centered, individualized, and chosen by its clients (who are often re-labeled consumers) and that much better is only a matter of much more money.

An adequate launch platform for innovation would elicit actions that fall in the upper right squares of the diagram in the next column and amplify the messages from their experience throughout the system. One sobering discovery of the Institute’s first 18 months is that the system lacks a launch platform for innovation that its participant organizations and their potential partners can trust. Current reality makes it hard to move outside the first row on the left, even for as few as 10 people. It is even difficult to reach the top left hand square, though acting from this level gives people the best chance at a life of distinction.

Change emerges from action that builds on the capacities revealed from deeply listening to individuals, linking with community opportunities, & then shaping assistance. Efforts are informed by what others have shown to work, but adapted to each person.

Change originates with an idea for organizational innovation (e.g. implementing shared living or a community participation project). Planning with people is framed by their willingness to receive the new form of assistance.

Change originates from the organization’s desire to solve an organizational problem. Planning with people is likely to be focused on discovering more individualized ways to meet needs defined by the organization.

Source			
Challenge			

Change focused on improving a process or adding a known service to those the agency provides. It requires new resources (usually money, sometimes training or technical assistance) but demands little change from the OMRDD system

Change requires substantial learning by the organization & its people. It may require new resources. It adds capacity for individualization to the organization but does not demand much change from the OMRDD system.

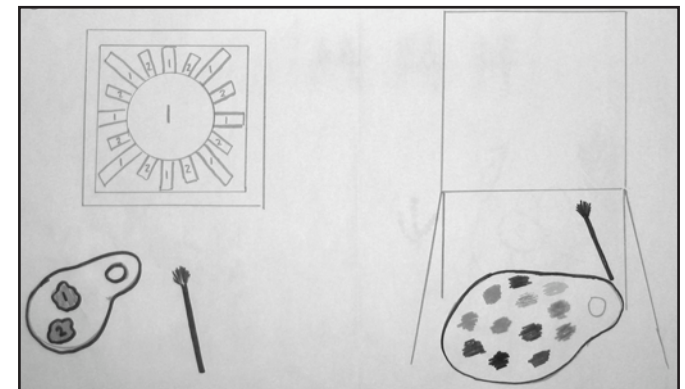
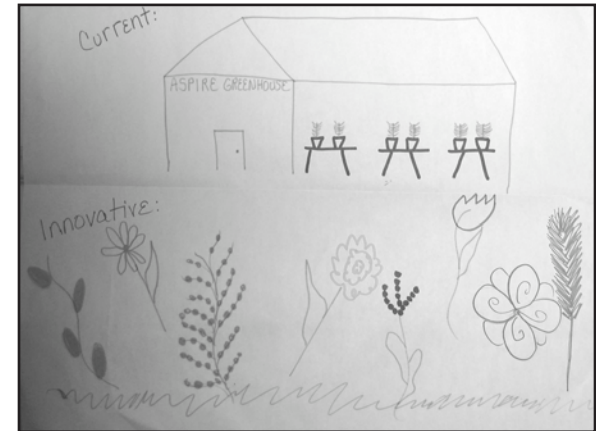
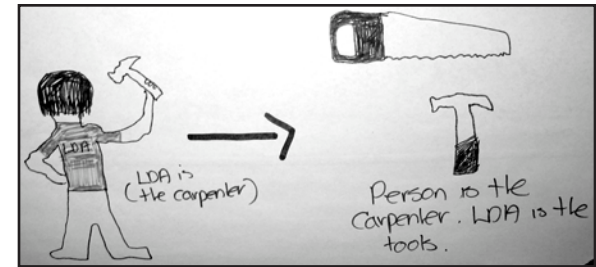
Requires deep change in order to develop levels of individualization that could raise expectations throughout the system. This change will demand that OMRDD experiment with new administrative capacities.

This positions Institute participants in an unfortunate way. Most are committed, creative people who have signed up to an appealing vision of a desirable future, grasped next steps that they need to take if they are to learn to move toward it, and are stuck for the freedom to act to take those steps. A constraint free environment is a fantasy, but many participants have trouble finding enough freedom among the restrictions to even begin to deal creatively with limits in action.

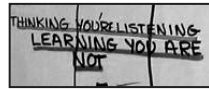
### *Listening Practice*

Beginning the change process with deep listening for emergent possibilities is essential, but difficult. Perceptions of who people are and what is possible for them are powerfully shaped by the current reality that contains both people with disabilities and the Change Team. Without disciplined practice, the Change Team will download usual assumptions without questioning the context that shapes those assumptions and makes them seem like “the way it is”. The person we encounter week after week in Day Hab shows little interest in work; anyway, supported employment would be “unrealistic” even if he wanted a job. So, perhaps out of a desire to respect choice and avoid raising unrealistic expectations, and almost always without consciously considering an alternative place from which to listen, we explore with him on premises that don’t even imagine the possibility of a good job for him. This limits uncertainty, risk, and anxiety for everyone. It also limits the person to a life that is only as distinguished as is possible in Day Hab with minor changes. The change that results from listening within what’s typical may be worthwhile, but they will not disrupt the organization or system in a way that motivates transformational change.

Practicing new ways to listen and see begin when Change Team members notice the contexts that shape what they see and how they imagine possibilities. An exercise that asked Change Teams to draw metaphors expressing current reality and their desired future focused some participants on the mindset that good person-centered planning will disrupt, as the images of transformed power relationships, greater variety of life in natural settings, and artistic openness to possibility in the next column suggest.



Noticing that you are not listening as deeply or imagining as powerfully as possible takes a measure of humility and courage. One change team recorded a key realization that set them on a path to deeper change this way:



Claiming the freedom that comes from not knowing exactly what will come from a project before moving down the left curve of the U is difficult in an environment that demands extremely high levels of guarantee for any change: prescribed health regimens will not be compromised; no unscreened person will be alone with the person; no possibility of abuse or neglect will be tolerated; there will be no financial risk; compliance with all policies will be correctly documented. As this Change Team has moved forward, the winds of fear keep rising up and blowing them back towards the same old thing.



What this Change Team called the winds of fear influence every participant in the Institute. Like the wind becomes visible in the movement of a tree's leaves, the ripples of anxiety becomes visible in the work of Change Teams when insights or possibilities are dismissed. "We are doing our best given the shortage of good

staff. People are satisfied now.” “Families would never allow it.” “The rules don’t allow it.” “It would never work for our people, they are too disabled.” “It won’t work where we are, we are too rural/urban.” “Our DDSO won’t let us.”

The Institute has the possibility of supporting Change Teams to develop the strength to contain these fears. A strong team gives its members a safe space to notice anxiety and its effects; to sort through what they value, what they will need to leave behind and what they want to conserve as they go on; to identify what is working and what is not; and to figure out how to keep developing the capacity to offer individualized supports. In such a space, fears provide important information for interpreting situations and figuring out how to positively affect them, but they do not control thinking and dictate action. Without regular practices that allow the Change Team to build this safe space, plans will be shallow and change will be incremental at best.

### **Next steps 1: A searching discussion about overcoming immunity to change**

The table on the next page indicates a method for a conversation that could inform the Institute’s next steps.<sup>10</sup> It is intended to illustrate what a more searching discussion might reveal. It is not in any way complete or uncontestable.

The human system that genuinely wants to change, resists change. It is as if the system had a powerfully effective immune system, allowing only a mild case of difference before snapping back to the previous equilibrium. As many diets result weight loss that is followed by a gradual return to overweight, many attempts at transformation result in better for a few for a while and more of the same over time for most. A cynical view of this common phenomenon is that the system’s leaders are hypocrites, covering some self-serving agenda with fine words, or fools cavorting at a great distance from the real world. A pessimistic view is that people and organizations are just too set in their ways to change much, at least not without unreachably enormous levels of investment and external control.

---

<sup>10</sup> Oh no, another framework to assimilate. I admit that I am at least as much a multiplier of perspectives as the Institute’s facilitators are. But this is the most compact way I can think of to summarize some important things the Institute has learned about the system in a frame that could allow a useful discussion of more adequate strategies. This perspective is borrowed from Robert Kegan and Linda Lahey (2009) *Immunity to change*. Boston: Harvard Business Press. I only want to point at the possibility of this next step and I have greatly oversimplified their ideas, possibly to the point of distortion.

Commitment	Do/ Not Do Instead	Competing Commitment	Big Assumptions
<p>Provide services that are...</p> <ul style="list-style-type: none"> <li>... individualized</li> <li>... person-centered</li> <li>... offer the option of as much self direction as a person chooses</li> </ul> <p>Deliver basic outcomes consistent with a life of distinction...</p> <ul style="list-style-type: none"> <li>... living in a home of the person's choice</li> <li>... working or engaging in activities that contribute to their community &amp; personal growth</li> <li>... having meaningful relationships</li> <li>... having good health</li> </ul> <p>Implement a transformational change agenda</p>	<p>Continue large investments in congregate services defined by programmatic models (e.g. res hab, day hab, clinics, &amp; transportation). Program designs significantly constrain efforts to respond in an individualized way according to many Institute participants. Person-centered plans take current service models (with minor variations) as their context.</p> <p>Few people experience naturally supported relationships outside their families. Assisting &amp; supporting such relationships is very problematic for most Institute participants.</p> <p>11% of all people receiving day services from OMRDD are supported in employment. Integrated employment for typical income is not included in person centered plans prepared for the Institute.</p> <p>Total of 273 people (out of 125,000 funded by OMRDD) approved to self-direct services through CSS in 6 years.</p> <p>Procedures related to regulatory compliance &amp; risk management are experienced by Institute participants as constraining individualized supports &amp; community participation in ways that they can't find ways to modify.</p> <p>Most Institute proposals for change are incremental, within existing patterns, rather than transformational &amp; set breaking.</p> <p>Etc.</p>	<p>Do what is best for people. This commitment makes it difficult to notice that current service models impose limitations that other possible models surpass.</p> <p>Avoid risk of harm to vulnerable people.</p> <p>Assure client conformity with prescribed activities, especially health regimens.</p> <p>Avoid the organizational and personal consequences of being publicly perceived to have allowed harm to occur.</p> <p>Comply with the very detailed regulations &amp; policies associated with the flow of medicaid money to the system and to the organization. Avoid the risk of non-compliance &amp; the costs of correcting non-compliance.</p> <p>Keep the programs, buildings, &amp; working arrangements that represent organizational assets.</p> <p>Don't create conflict by disrupting situations in which workers or family members have an investment that they will defend, especially when clients either express satisfaction or are not seen to express dissatisfaction.</p> <p>Don't keep people waiting for services when it can be avoided. (This leads to the practice of "backfilling" rather than closing group settings.)</p> <p>Etc.</p>	<p>The claimed advantages of different models of providing assistance are either unproven and exaggerated, inapplicable to the population we currently serve in other ways, infeasible under local conditions, or insufficient to outweigh their risks. Our approaches are the best that is realistically possible.</p> <p>The system cannot fulfill its mission without maximizing federal financial participation through the Medicaid program as we currently use it.</p> <p>Compliance with detail complexity driven by regulations is the most efficient use of public money because without detailed and redundant oversight the system would be swamped by abuse, neglect, &amp; fraud.</p> <p>The constraints on choice and association built in to current policy, procedure, &amp; practice are necessary &amp; unavoidable protections.</p> <p>Wellness &amp; security are maximized by compliance with health &amp; safety protocols.</p> <p>Opportunities for good relationships with people outside the boundaries of regulated services are extremely limited for most clients &amp; risky anyway.</p> <p>The possibilities for creative negotiation of conflicts are minimal.</p> <p>The system owes people and families a choice of different kinds of service settings. Many families prefer more contained &amp; supervised environments.</p> <p>Etc.</p>



Since both perspectives lead to withdrawal and inaction, neither cynicism nor pessimism hold much promise to improve people's chances for lives of distinction. What the Institute can do is encourage a way to account for immunity that leads to strategies that have a better chance of leading toward significant and sustainable change.

The first column accepts the system's commitment to individualized supports as both desirable and sincere. The second column begins to answer the question "What does our system do or not do instead of fulfilling this commitment?" The third column recognizes that the apparently inconsistent system behavior described in the second column is far more likely to result from honoring competing commitments that protect the system from fear rather than from laziness, stupidity or perversity. The fourth column asks "What big assumptions make it hard for us to develop new responses to the commitments in Column 3 and so hold the contradictions we identified in column two steady in place?" The understanding from this discussion informs purposeful action to test big assumptions and find new ways to deal with competing commitments.

As the arrows suggest, action toward commitments gets stuck in a constraining loop with action to maintain competing commitments and big assumptions tighten the hold of competing commitments with their unexamined claim to mark the boundaries of what can be known and done. The task is to figure out how to loosen these loops enough to allow some freedom to follow the path indicated by the Institute's guiding ideas. This process begins with designing doable experiments that test the big assumptions. These experiments will have greater leverage if the teams that design them function with adequate mental complexity to look through, over, and past the big assumptions and find alternative ways to deal with competing commitments.

The point is to support discussions in Change Teams that allow them to reach a deeper understanding of their situation and stretch their mental complexity to design and try strategies with greater leverage on transformation. This stretch is the product of what Kegan and Lahey name "optimal conflict". To paraphrase them, optimal conflict has these necessary conditions...



...The persistent experience of some dilemma that  
...causes us to feel the limits of our current way of knowing  
...in a sphere of our living that we care about, with  
...sufficient supports so that we are neither overwhelmed by the conflict nor able  
to avoid it.

It might be worth beginning a conversation about the system immunity with the Think Tank or another established group committed to transformation. Such a discussion might lead to further refinement of the Institute's design and curriculum. It could also be the starting place for organizationally focused discussions among Change Teams.

## **Next steps 2: Strengthening communities of practice**

The Institute can offer even better support to its participants expanding their mental complexity and courage by revisiting the original intention to support the emergence of communities of practice.

The best understanding of a community of practice is captured this way: a self-organized group of people who share a passion for something they do and learn to do it better as they regularly interact.<sup>11</sup> This means that communities of practice can be an effect of the Institute, as people with a passion for transforming their organization's capacity to offer individualized supports find each other, make connections, build trust through contact over time, share what they know, and figure out how to be of help to one another. They cannot be a direct product of the Institutes curriculum and they cannot be created by the facilitators' declaration that the participants are a community of practice.

There are at least six implications of this understanding of communities of practice for the Institute.

- Organizations need a clear account of what change will cost: time and other resources, not just for Change Team work but for some contact with other Institute participants.
- Change team will be most effective if they combine an important perspective

---

<sup>11</sup> Etienne Wenger (January 2000). Communities of practice: The organizational frontier. *Harvard Business Review*, 139-145

(person who uses services, board member, direct service worker, manager, etc>) with organizational credibility and passion for finding better ways.

- The Institute needs to design ways for people to collaborate across change teams and allow some open space for participants to get together and discover what they have to share. This means thinking about both the amount of time allocated to meetings, their agenda, and the settings in which they happen.
- Institute sessions should be designed as a practice field where people can try on new ways of framing their work and reviewing what they are doing against the guiding ideas. Each session should give participants a well developed chance to engage the guiding ideas and process homework with participants from other organizations.
- Site visits strengthen participant's sense of possibility by providing brief but immediate personal experiences of good efforts toward individualized supports within the system's current constraints and a great opportunity to strengthen connections. The connection among participants from different organizations should be part of the plans for a visit.

The diagram on the facility page sketches a possible shape for the next round of the Institute.

## Local

Learning  
Team



weekly

The aim of local learning teams is the development of organizational capacity to generate innovations necessary to offer personalized supports.

## Regional

Learning  
Network

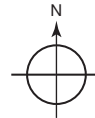
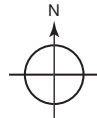


monthly

Contact may be virtual or face to face. Networks have some access to resource people & facilitation.

## Statewide

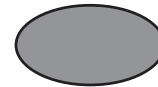
Learning  
Journeys



quarterly

Learning journeys are selected from a menu or self organized & may be visits to organizations or participation in training events.

Institute  
Sessions



biannually

Sessions are 2.5 days in retreat setting.

Informing  
Policy



Half-day sessions focused on providing perspective to development efforts of interest to those concerned with the development of the whole system (OMRDD, NYSACRA, SANY). Representative participants from learning networks vs whole sessions. As requested, similar informing sessions may occur at DDSO or Regional level.