

NYSACRA Learning Institute on Innovation in Individualized Supports

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Parent Perspectives on Innovation

John O'Brien



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Highlighted [www](#) links are live in the pdf version of this document.

To learn more about the NYSACRA Learning Institute on Individualized supports, visit www.nysacra.org

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Purpose and process

The Learning Institute exists to challenge and support participating service providers to develop the capacity to provide individualized supports to people with developmental disabilities. This is a process that requires social innovation at different scales. Each person and his or her allies need to design the assistance that they require to live a good life. Service providing organizations need to develop sustainable ways to deliver a greater variety of individually tailored supports. Policy, especially the rules that specify how money flows and how services are regulated, needs to increase service provider flexibility to respond to different and changing individual circumstances.

Change efforts initiated by agency staff benefit greatly from partnership with active family members. We wanted to give change team members from participating agencies the opportunity to gain a deeper understanding of parent perspectives. Parent innovators have made important discoveries about what is possible and what it takes to act resourcefully in the system as it is now. We wanted to give parents who are finding new paths with their sons and daughters a chance to inform participating agencies and connect with one another.

This inquiry focused on 17 parents of people with developmental disabilities who are actively seeking good lives for their sons and daughters with developmental disabilities. Most are initiating or participating in the creation of new opportunities and new forms

of support. Some make use of options to self-direct supports; others act in partnership with service providers.

Our purpose is to gain a deeper understanding of family* perspectives on supporting good lives for people with developmental disabilities by creating conversations that allow reflection and thinking together and are open to the emergence of insight. This understanding will influence the ways we build alliances for positive change in the supports available to people and their families. (The guide that describes the process can be found in “Appendix A: Family perspectives on supporting good lives” on page 14).

The Institute is guided by an approach known as **Theory U**,** an understanding of social innovation

that calls people to move outside the familiar assumptions and patterns of behavior

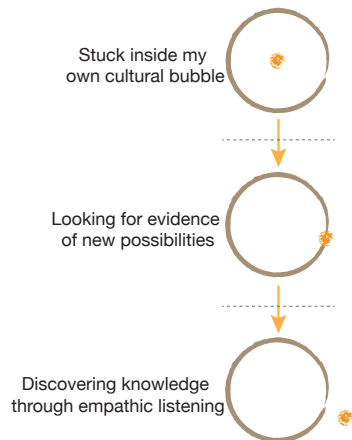
that re-produce current reality, search for new ways of understanding, sense an emergent future, and act to discover new ways to move into that future.

Theory U offers a series of practices that support social innovation.† The first set of these practices

*As it happened, all of the people interviewed are parents. There is room for further inquiry with brothers and sisters and extended family members.

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

† For a description of these practices, see the *Theory U Toolbook* at www.presencing.com/docs/tools/UToolbook_v1.1.pdf



build a better knowledge of the field for innovation. To extend understanding we aim to move outside the taken for granted assumptions that keep us in our own cultural bubbles. This involves mindfully shifting attention, first to the edge of current understanding in a search for evidence of different possibilities and then to dialog which allows a deeper understanding by shifting attention into an effort to take another person's perspective through empathic listening.

In this inquiry we aimed to move past a consumer interview which focuses on gathering the parent's ideas about what is working and not working about the services their son or daughter receives. This kind of listening is valuable as a way to gather evidence about the quality of services and ideas for improvement, but it puts the parent in the role of offering comments on present service arrangements. We wanted to encourage a search for knowledge of the conditions for a good life with the parent. Accordingly we invited listeners to explore the parent's perspective on these very broad questions:

What contributions do families make to making good lives possible for people with developmental disabilities and what makes it possible for families to make these contributions?

Each dialog interview took its own course. There was no attempt to standardize questions or collect and analyze information in a uniform way. Most of the parents have a history of activism and developing new

forms of support, a number through participation in the self-directed services waiver option. Those who listened and some of those who shared their perspective gathered for a day of making sense by looking for what their dialogs might offer those who want to strengthen alliances for individualized supports with and among parents. These notes summarize some of the key points from that discussion as well as ideas that came from the group making sense of practice interviews on the initial organizing day.

Family experiences vary widely and there is no sense in which these notes speak for all parents. Every statement should be qualified by their source: my summary of the understanding that emerged as a small group of people came together to make sense of what came up as they listened to each other. They do however reflect the perspective of a number of parent innovators and carry useful messages for service providers seeking to increase their capacity to offer individualized supports.

Try it yourself

Perhaps the strongest message from those who participated in these dialog interviews is the advice to make conversations like these a part of change efforts. Making time and adopting a mental and emotional attitude of curiosity and openness to a parent's experience and perspective produces both insight and shared energy. This was true even with someone the listener knew very well.

Most parent-service provider interactions are properly about conducting some sort of business. Meeting the deadline for a plan. Selling (or resisting) an idea for program change. Negotiating a schedule. Making or dealing with a complaint. Collecting information. Gathering data to demonstrate quality. Surveying sat-

isfaction. Dealing with these typical and necessary transactions keep things moving along, usually on typical and predictable paths.

Making time to just listen to understand the other's sense of what matters for a good life can open the way to new possibilities if it leads to the reflection that allows new knowledge to come and lead on to learning through action.

A lesson of this inquiry is that staying open to another's distinct experience without getting pulled back into one's own preexisting ideas takes a discipline that can be hard to maintain. The principles for practicing this form of listening are below.

Principles for dialog interviews

- **Create transparency and trust** about the purpose and the process of the interview.
- **Suspend your voice of judgment (VOJ)** to see the situation through the eyes of the person you are with. What matters at this point is not whether you agree or approve but that you learn to see the situation through the other person's eyes.
- **Access your ignorance** (access your open mind): As the conversation unfolds, pay attention to and trust the questions that occur to you; don't be afraid to ask simple questions or questions you think may reveal a lack of some basic knowledge. Always feel free to deviate from your prepared list if important questions occur to you.
- **Access your appreciative listening** (access your open heart): Connect to the other person with your mind and heart wide open; thoroughly appreciate the story that you hear unfolding; put yourself in the other person's shoes.
- **Access your generative listening**: Try to focus on the best future possibility for your interviewee and the situation at hand. Be open to insight: new ways to understand what the situation calls for.
- **Respect the power of presence and silence**: One of the most effective ways to learn is to be fully present with the other person — and not to interrupt moments of silence

Parents as innovators

Parents who have raised a child with a developmental disability are experienced social innovators. From the moment they recognize differences in their son or daughter's development, they live into their own particular answers to fundamental and enduring questions like these.

- What is possible for our child and who can help him or her to have the best chances for a good life?
- How will this child affect our family life as he or she grows up?
- How can we get our child what he or she needs?
- What can we trust to assure that our son or daughter has what he or she needs when we are no longer able to look out for him or her?

Parents differ considerably in the paths they take in answer to these questions. Many follow professional advice, seek the services most commonly available when places open up, and monitor their son or daughter's well being. Some turn inward and organize family life around looking after their son or daughter, expecting very little from services. Some, including most of the parents involved in this inquiry, work to create new opportunities and new forms of support that suit their understanding of their son or daughter's possibilities better than existing service provider offerings do.

Living with these questions motivates innovations large and small. Parents learn to create what they understand that their children with developmental disabilities need. They blend ideas acquired from

professionals into daily routines. They advocate with schools and hospitals and services. They exercise political influence and shape state and federal law and policy. They found and fund and grow organizations dedicated to offering entirely new forms of service and support.*

The notes that follow focus mostly on communicating the perspective of parents who work to generate new kinds of supports. Some use individualized funding to manage supports, others have created partnerships with service providing organizations. Some are part of a group of parents, others work on their own. Some have created a support system and are refining it, others are in a process of development.

*For an account of past generations of service structures created by parent energized political and organizational innovation, see David Goode (1998). *"And now let's build a better world" The story of the Association for the Help of Retarded Children, New York City 1948-1998*. New York AHRG
To read about parents and people with disabilities as co-creators of innovative supports, see Beth Mount & Sandy VanEck (2011). *Keys to life: Creating customized homes for people with disabilities using individualized supports*. Toronto: Inclusion Press.

Moving mountains

This work is not easy nor is a problem free existence within reach. There was widespread agreement among the parent innovators when one offered the image of needing to move mountains.

Some difficulties recur close to the person who requires support. Matching supports to changing needs, new opportunities, and rising expectations can be difficult. Finding and sustaining good support workers and dealing with the problems created by workers unsuited for the task are regular challenges. Anxiety about budget cuts clouds the horizon. Uncertainty about who will keep things going when parents no longer can persists as a concern.

But the heaviest, slipperiest boulders to shift are forged and rooted in the current reality of the developmental disability service system itself. As parent innovators have experienced it, the system...

- ...remains biased toward serving people in groups and common program patterns; so some people who have developed a good life in their own neighborhood are expected to leave that life and take a special bus to a distant and unfamiliar place to receive “day hab” services.
- ...adapts so slowly to development opportunities that some people have been forced by circumstances to accept a bed in a typical group living arrangement rather than the individualized supports designed for them.

... appears to arbitrarily ration access to self-determination options despite provisions in the state’s medicaid waiver that should make self-determination an option for anyone who chooses; so parents have to spend time on decoding the system and advocating for system change.

...imposes a considerable burden on those who choose self-determination: accurate and useful information is hard to come by and those who should know (MSCs and DDSO staff) are often ill informed or mis-informed; the application process is difficult and the detailed requirements for using the funds can be arduous and anxiety provoking to fulfill; back-up and timely adaptation of budgets to crisis is chancy at best.

...lacks transparency, perhaps in part because of the detail complexity the the system has accumulated.

...seems to be based on distrust of families and disrespect for them.

...tempts cynicism because of the large, long enduring, and mostly unacknowledged gap between the system’s espoused values and their actual experience.

What, then, makes parents into mountain movers? There are still many cultural messages that leave some parents isolated and struggling with a sense of embarrassment, shame, and fear that close off their sense of possibility and discourage them from actively supporting their daughters and sons to follow

- Belief in the person's potential
- Recognition of the importance & challenges of community participation
- Conviction that individualized support is right
- The organized support of other parents
- Service provider partners

their interests into community life with individualized support. Our inquiry identified some of the resources and beliefs that support parents to move beyond what is ordinarily available.

A deep belief that their son or daughter has the potential to confound limiting expectations if they have individually tailored supports. People with developmental disabilities continue to surprise with the capacities and interests that come alive when they have opportunities and reasonable support. Life is seldom if ever problem free, but people whom professionals said would “need” group living and day hab are growing into their own apartments and integrated jobs. Sometimes parents themselves are surprised by their inability to accurately predict what will be satisfying. Curiosity about the possibilities that lie outside the box of familiar service provision is important. So is a mind open to exploring new ideas.

Recognition that their sons and daughters grow into great people in community with others. This means much more than just being there in community places. It means being a part of community life and playing active roles by following their interests into relationships and places where they can be involved and develop. Friendships grow when people are engaged together in things that matter to them. Families that have invested in neighborhood connections while their child is growing up want to strengthen and build on these connections when their son or daughter reaches adulthood, not sacrifice them in order to receive services far away.

Imagination, hope, and courage are important because far too many community places are not welcoming. There is a cultural pattern that reacts to difference with labels and hurries through the now without time to notice and appreciate the way differences show up in particular people who can make a real contribution when people slow down, look, listen, and learn to make (usually simple) adjustments. Even religious congregations that deeply understand and value the gifts that people with developmental disabilities bring are rare. Congregations, where people have reason to expect acceptance, too often fail to adjust and make whole families welcome, sometimes excluding the whole family, sometimes leaving one parent at home with the person with a disability while the rest of the family worships without them. This can leave parents feeling let down and either resigned to their son or daughter's exclusion or angry about the unresponsiveness from those who should know and do better.

It makes a difference to seek out places and people with openness to welcome people with developmental disabilities. These may be places with a different tempo from the hurry that is common or people who observe and listen rather than labeling and jumping to conclusions. Welcoming places and people may be more common than we think if we look for them on purpose and have the courage to risk asking.

A conviction that individualized support is the right thing strengthens voice. Voice is central to overcoming the many barriers to real life in commu-

nity. A sign of successful parenting is that the son's or daughter's voice grows strong enough to join their parent's in whatever way their capacities permit, sometimes in agreement and sometimes in disagreement. Voice grows powerful among people who listen and speak respectfully to one another and when people's energy uplifts their words as good music uplifts a good lyric when people join in song. Words that don't express people's desires for a good life and lead to action lack the power necessary to speak and act for the best chances at a good life.

The organized support of other parents makes it possible to deal positively with the difficult feelings that can keep expectations for a good life in community low. Otherwise, too many families will feel like they are drowning unless they grasp and hold tight to whatever services are available at the moment.

Careful reflection with other parents is important to clarifying what it takes to provide a good life. Sometimes reflection leads to new understanding, as among the families who have formed The Big Tent, a fellowship that recognizes that it is the purposeful interdependence of a neighborhood-rooted intentional community that offers their families the best life chances. This recognition of the centrality of interdependence to the development of voice and capacity for self-direction confronts the more commonly stated service system objective of independence. If it develops in a good way, self-direction will unfold into a growing variety of ways for people to throw in

together on more and more different arrangements for support.

Making a good life with people with developmental disabilities is a creative process. Creativity is necessary even at the level of language. We don't yet have a common language that effectively holds what we want. We keep getting drawn back into the vocabulary and grammar of a system that cannot develop until it breaks out of its current forms. Our lack of language pulls us into habits of labeling and cataloging deficiencies as the path to designing good supports. We need language that aids us to notice and build on capacities and learn to offer precise supports, matched to the uniqueness of each developing person's body, mind and spirit.

The path of self-determination holds much promise but it is very difficult to travel alone. Parents can't leave informing, organizing and supporting those who could benefit to service system staff, who are too often overloaded and ill informed. At present this means finding some parents who will pursue the arcana of medicaid waivers, rules and financing to the point of practical understanding and then share their knowledge in ways that lead more families to take up the option.

Service providers who are willing to partner in inventing the sorts of assistance that will make a person's supports more flexible and more sustainable will underwrite trying things that seem too risky without back-up and add new perspectives and resources.

The shift

Parents who expect the service system to deliver individualized supports easily and as a matter of course will be frustrated and disappointed. The parent innovators in our inquiry have each concluded in her or his own way that they have an active, even a primary role to play. Beliefs differ among them about whether this is the way it should be, but there is agreement that this is how it is for them. (This is not to deny that there are a number of self-advocates who can self direct with the support necessary from their own organizations or committed service providers. It does recognize that a significant number of people with developmental disabilities will benefit from individualized supports and self-determination when they have the active support of their families.)

The sense-making group made collages as one way to access what they learned from their dialog interviews. Diana McCourt, a parent innovator of long standing, depicted a shift in focus with profound implications for generating individualized supports which is pictured on the facing page.

The images are on opposite sides of the page because the shift is complete, from one way to a fundamentally different way of understanding and acting. The first and more common way is organized around getting the service system to deliver what's necessary for a good life. Parents attempt a variety of maneuvers that mostly fail because the system's hands are tied by its own efforts to gain and administer the

money necessary to operate itself as it is. The mental model that shapes it is mechanistic; better suited to servicing cars than serving people. The scale is too big and power too centralized for the system to free the ribbons it holds for new purposes, no matter how attractive the idea may be to those who manage it.

Things change when parents stop believing that the system holds full responsibility and all necessary resources. They adopt a new pattern to guide their action. The work to gather a circle with the person that is animated by recognition of the person's inherent dignity and gifts and a commitment to supporting the person in a life of distinction. The whole circle holds responsibility for discovering, attracting, and organizing the relationships, opportunities, knowledge, and money necessary for a good life together. The system is not off the hook: it is a source of some of what is needed. Allies among service providers have the chance to play a valuable and satisfying role consistent with their values. Supports are more individualized because they develop with the person and more sustainable because the resource base is more diverse.



I

Parents try a variety of gymnastic moves to entice or coerce the system's hands to deliver the colorful ribbons of resources for a good life. However the hands, bound in red tape and chained to current constraints, can't let go and give parents what they want.



II

Parents shift their energy into a circle with those who know and care about one another's wellbeing. Together, they find ways to discover, attract, and organize the resources that they need for a good life. The service system is only one source of what's needed.

Messages for other innovators

Making good on the system's commitment to offer individualized services and provide the option of self-determination across the system involves a variety of technical shifts which the coming design and implementation of the proposed "People First Waiver"* should offer the opportunity to make.

Our inquiry shows that technical changes will be welcome if they...

- ...greatly increase the flexibility that service providers can offer in response to a greater variety of requirements for individualized assistance.
- ...make it much more likely that people will have real jobs and live in their own homes by substantially investing in support to re-direct existing service funds
- ...significantly decrease the costs and time required to negotiate innovations with OPWDD.
- ...make the whole system's finances more transparent to improve the system's credibility and accountability.
- ...bring the runaway costs of compliance monitoring under control.
- ...increase the attractiveness of self-determination by simplifying the application process; creating a straightforward on-line source of reliable information and linkage to willing people who currently use self-determination funds; reducing the complexity and controls on individual budgets

*This is a comprehensive demonstration waiver (1115) that will reshape the way OPWDD administers medicaid. See this waiver's developing web page at www.opwdd.ny.gov/2011_waiver/index.jsp.

...collaborate with innovators to design and implement a variety of assistance, back-up and partnership options so that there are stronger safety nets for crises and a menu of ways to purchase desired assistance with the work of managing people's assistance.

Technical changes matter, but they are only one aspect of a culture that can support the level of social innovation necessary to move the system toward offering the kind of individualized supports that will match the potential for growth that the sons and daughters of the families in our inquiry have demonstrated. Matters of commitment and relationship are of critical importance with people at every level of the service system.

- For every person you support or make decisions about, think about them and treat them as if they were your child, your sister, your grandchild, because they are (developmental disability can occur in any family).
- Make hope palpable. People need to see and touch the consequences of thoughtful individualized supports if they are to make good decisions and wise investments of their energy.
- Assume and risk trust and offer genuine respect not just formal correctness. The opportunity costs of distrust and distancing are enormous though unmeasured.

- Act with integrity. Be on time. Be prepared, don't pretend or misinform. Make clear agreements and follow through. Own up to difficulties and breakdowns.
- Encourage purposeful action. Proceeding from a place of fear and self-centeredness is too common and deeply limiting.
- Invest the time and attention to make real relationships.
- Listen with care and with the voice of judgement under control. Build with what people say when they encounter real listening and continue to build with what works from one good thing to the next.
- Respect existing community connections. Intensify local community development for connections. Discover what we can offer the neighborhood/community. Analyze how the individual can best participate.

- Tell joyful stories (which of course include our real frailties and fallibilities)

These human practices are not a parent prescription for service people. They are reciprocal and important for everyone who wants to live a good life that includes people with developmental disabilities.

One listener summed up her learning this way:

At any point we have a choice of moving toward hope and possibility or freezing and shrinking in the face of fear. As family members we live with these choices every day and try as hard as we can to reach for hope. What would the world look like if we could be mindful of the collective capacity to choose possibility. We can create a new world for our family members when we do this together.

Appendix A: Family perspectives on supporting good lives

Growing numbers of families are actively seeking good lives for their members with developmental disabilities by initiating or participating in the creation of new opportunities and new forms of support. Some families make use of options to self-direct supports, others act in partnership with service providers, still others act with very limited assistance from services. Change efforts initiated by agency staff benefit greatly from partnership with active family members. Listening carefully is a key to the process at the heart of the Learning Institute. The willingness and ability to find respectful ways into understanding the differing perspectives of people with complementary resources is essential to discovering the future that wants to emerge through our co-creative efforts.

Our purpose is to gain a deeper understanding of family perspectives on supporting good lives for people with developmental disabilities by creating conversations that allow reflection and thinking together and are open to the emergence of insight. This understanding will influence the ways we build alliances for positive change in the supports available to people and their families.

The inquiry will take place in 3 parts:

The whole group gathers on February 28 to organize ourselves for dialog interviews.

Members will work singly or in pairs to conduct at least one interview with a family member who wants to create the conditions for a good life in community.

The group gathers on April 1 to make sense of what we have learned through our interviews.

John O'Brien (johnwobrien@mac.com) and Beth Mount (graphicfutures@earthlink.net) will facilitate the inquiry. We are grateful to The Presencing Institute, whose ideas and materials we have adapted under their Creative Commons License (www.presencing.com).

Principles

Create transparency and trust about the purpose and the process of the interview.

Suspend your voice of judgment (VOJ) to see the situation through the eyes of the person you are with. What matters at this point is not whether you agree or approve but that you learn to see the situation through the other person's eyes.

Access your ignorance (access your open mind): As the conversation unfolds, pay attention to and trust the questions that occur to you; don't be afraid to ask simple questions or questions you think may reveal a lack of some basic knowledge. Always feel free to deviate from your prepared list if important questions occur to you.

Access your appreciative listening (access your open heart): Connect to the other person with your mind and heart wide open; thoroughly appreciate the story that you hear unfolding; put yourself in the other person's shoes.

Access your generative listening: Try to focus on the best future possibility for your interviewee and the situation at hand. Be open to insight: new ways to understand what the situation calls for.

Respect the power of presence and silence: One of the most effective ways to learn is to be fully present with the other person —and not to interrupt moments of silence.

Process

- Share a clear statement of your purpose with the person you have invited to help with your inquiry. The aim is for you to get a better understanding of the person's perspective on what it takes to support a good life for their family and their family member with a disability.
 - Agree on a place to meet that will support good listening. Allow about an hour.
 - Bring note-taking materials.
 - Arrive in time to relax, review the questions you want to ask and the principles above. Imagine the best possible result of the time you have with this person, for the other person and for you.
 - During the interview, listen deeply, take notes, follow the principles. Notice distractions –your voice of judgement, a desire to offer advice or disagree, a feeling of defensiveness– and bring your attention back to listening for the other's experience. Take some time immediately after the interview to reflect and write down your immediate impressions:
 - What struck me most?
 - What surprised me?
 - What touched me?
 - Is there anything I need to follow-up on?
1. Send the person you learned with a thank you.

Possible questions

- When has your family faced significant challenges and what has helped the most in facing them? (Avoid communicating the assumption that the challenges are necessarily about developmental disabilities or that the supports have come from the developmental disabilities system; this may or may not be the case.)
- What have been the strongest influences on your sense of what is possible for your (family member: son, daughter, brother, sister, etc) with a developmental disability? Recall a moment when what you want for your (family member) shifted in an important way; what helped that shift to happen?
- What is your image of a good life for your (family member)? (Take time to develop as good a shared sense of this as you can.)
- What do you see as the most important things in creating the conditions for that good life?
- How could services for people with developmental disabilities contribute to creating that good life?
- What do you see as your family's role in creating and sustaining the conditions for that good life?
- What are the next big steps into this good life?
- What do you and your family need now in order to keep moving in a positive direction?
- Think of a time when a service worker (a direct support worker, a professional, a manager) offered something that was especially valuable to you and your family. What did they offer and what made it particularly valuable? It doesn't have to be a big thing, just something –small or big– that you really appreciate.