

Seeking Transformation

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Organizations serving people with developmental disabilities are immersed in a challenging environment. Appreciation of people with developmental disabilities as citizens with rights and duties, underwritten by the accomplishments of socially inventive partnerships that open paths to employment and individualized support for community life, brings changes in law and conditions for public funding.* Changing expectations decrease demand for group living arrangements and day programs. Insufficient responses to demographic realities generate a chronic crisis of attracting adequate public investment and a sufficient workforce. The idea of transformation identifies the work of adaptation to these changes and shapes requests for consultation.

We are among those who respond to these requests. In company with friends** who share our commitments we have convened multi-agency learning groups, designed planning processes, facilitated strategic planning, conducted developmental evaluations, and aided organizational change efforts. These reflections capture some of the lessons from these engagements.

Consultation makes a positive difference when outside consultants and organizational insiders co-create a social field that allows them to work out the tensions that arise from making meaningful change. Transformational change involves reconciliation of differing interests and perspectives, loss of the familiar, uncertain risks, negotiation of power shifts, and social invention through boundary altering and disruptive co-creations. One way to identify these tensions is to picture them as differences in understanding the practical meaning of key words –the action and conditions for action that a term like “person centered” implies rather than just the idea it names.

Transformation is one of these key words. Some organizations seek consultation from the view that transformation results from implementing a new procedure, redesigning a process, accessing a new funding source, or following a model to implement a new program. Some expect training and technical assistance to provide a blueprint and minimize uncertainty by answering any “how-to” questions that arise. Our efforts can't meet these expectations. Some organizations adopt the concept of transformation solely as a way to comply with external requirements, especially if money is available to support their effort. If those requirements relaxed, so would their investment in change.

Our understanding of transformation generates tension in the social field that joins us to the organizations that decide to engage us. We experience transformation as a deep and encompassing effort to co-generate organizational capacities that serve a vital social purpose. That purpose is to establish and build on valued community roles for people with developmental disabilities, thus increasing their experiences of the good things of life and building a more inclusive community. The work of transformation involves sensing what more is possible, identifying and letting go of what detracts from discovering better ways to serve this purpose, and supporting people to experience new opportunities. Through a

Social Field: *The structure of relationships that shapes awareness and attention and so the pathway along which new capacities emerge.*

If we were really committed to the pursuit of what matters, we might be well served to hold a moratorium on the question, 'How'?

It would force us to engage in conversations about why we do what we do. It would create the space for longer discussions about purpose, about what is worth doing. It would refocus our attention on deciding what is the right question, rather than what is the right answer.

–Peter Block

* John O'Brien & Beth Mount (2015). *Pathfinders: People with Developmental Disabilities & Their Allies Building Communities that Work Better for Everybody*. inclusion.com

** Beth Mount and Hanns Meissner have been frequent partners.

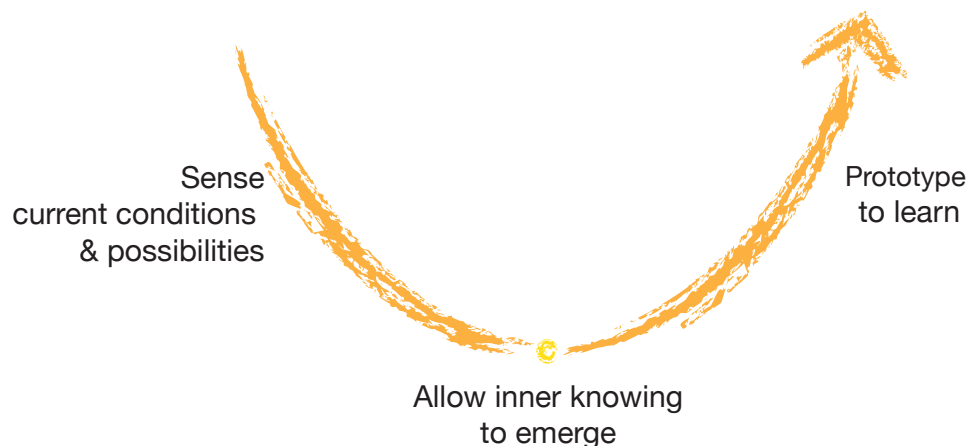
continuing dialogue between insiders and outsiders, transformation develops both organizational capacities and the inner capacities of the people involved.



The image of an iceberg, borrowed from Theory U, illustrates. We believe that the struggle for right relationship between person and community and person and supporters is the **source** that shapes and activates real change. This is a struggle because relationships with people with developmental disabilities are commonly skewed by social devaluation: instantaneous distancing by instinctive assignment to the status of *OTHER*, mindless attribution of less worth, automatic imposition of difference making conditions, and reflexive assumption of power over the person. Voice and the sense of possibility shrink in the face of shallow listening and low expectations. Impaired relationships expresses themselves in **thought**. Devaluing fictions justify other's claims of authority to define people's identity, determine their

best interests, assess their needs, pronounce on what is possible and desirable for them, and prescribe what they will do and where and with whom they will do it. These exclusionary practices become routine, taken for granted as common sense, and so unseen. Right relationships expresses themselves in thought as well. A posture of listening opens the way to deeper understanding of what is desirable and possible and activates effort to reduce gaps between what is valued and what is done. New knowledge grows from critical thinking that notices and challenges limiting assumptions and harvests and builds on learning from action. **Process and structure** enable and constrain action. Organizations that gather and place people in professionally labeled groups at the margin of community life and structure their time according to staff defined roles and routines will have a steeper path to climb than organizations that design and deliver individualized supports to people as they discover and inhabit contributing community roles that match their interests.

Theory U has been helpful to our efforts to put this understanding of transformation to work.* We draw on The Presencing Institute, an international group of practitioners and theorists, to inform our approach to organizational transformation. In its simplest form Theory U offers theory and practices to guide three moments in transformation. The aim is to develop and practice awareness-based, compassionate action.



Practitioners apply Theory U to assist a broad range of organizations across many fields. We focus on organizations that support people with developmental disabilities and their

* Otto Scharmer (2018). *The Essentials of Theory U*. Barrett-Koehler and <https://www.presencing.org>.

families. We are committed to discovering paths inspired by a vision, namely a vision of an organization capable of co-creating individually tailored supports that protect, establish, and build on valued social roles.* Such an organization serves the purpose of building the Beloved Community. This commitment reflects our sense of our own highest purpose, which is informed by our learning with many people who have benefited from individualized supports to valued roles in community life. Because of our direct experience, we stand up for possibilities that sometimes seem to organizational insiders as unrealistic, unacceptably uncertain, indefensibly risky or just plain unintelligible .

Though we have a strong sense of the capacities necessary to co-create individualized supports, the path any particular organization takes to develop these capacities is unknown and only discoverable by doing the work of transformation over time. The practical meaning of transformation in an organization emerges from working out tensions around these key ideas.

- Working and planning in a person-centered way.
- Right relationship (power-with rather than power-over) with support workers and those with managerial and professional authority.
- Self advocacy, supported decision making and self-directed supports.
- Support for community integrated employment
- Support to live in your own home.
- Support for age-appropriate learning experiences.
- Support for community participation.
- Community building.

Each term in this list is in good currency. In fact, it's almost impossible to find an organization that would say it is not already providing and practicing these good things to a high standard of excellence. So, many organizations experience very little tension around them. Person centered planning is little more than a new name for the excellent care plans professional staff have produced for years. Consumers meet community experience goals through outings to the mall and visiting local events. The day program occupies those incapable of work. Group home residents now have a key to their room. No tension, no transformation.

Our task is to support the development of transformational change makers inside organizations that engage our help. Change makers' task is to sense and act on tensions between current reality and a vision of possibility. We advise change makers to work as teams of people with influence, some of whom have formal authority while others may be people with developmental disabilities, family members, direct support workers, and community allies. They share the sense that more is possible. They have the courage to question the ways their organization currently realizes the key ideas that define transformation. They have the spirit of explorers, curious to learn more, ready to cross boundaries, able to let go of what holds them back, and willing to co-create new ways. Change makers step into and amplify a tension between current reality and possibility and engage others in action shaped by that tension. If conditions are favorable, the differences that emerge can seed an expanding space of transformation.

* See, for example, Chris Liuzzo (2015), *Design principles for individualized supports*. New York Alliance for Inclusion & Innovation. bit.ly/36BsYhw

A transforming organization creates contexts and safe spaces for the voice of each person to emerge and align resources to support valued social roles that increase their experience of the good things of community life.

Cultivating the social field is central to the development of change makers. Building relationships that focus awareness and attention on what more is possible shapes the way an organization works out the tensions that arise from sensing deeper into key ideas and acting on the inner knowing that emerges. A social field grows fertile as some people in the organization come to see themselves, and act, as change makers. They feel a call, crystallize intentions, and commit themselves to work for transformation. This inner work shapes alliances and energizes the co-creation of new organizational capacities.

We have several options for facilitating the emergence and activity of change makers who engage the whole of the transformation iceberg, including these:

- Inviting the development of multiple sources of intelligence –open mind, open heart, open will– by increasing awareness of the level at which we listen. Deeper listening incorporates multiple perspectives and connects to the **source** of transformation: awareness of what wants to be born with our help.*
- Raising awareness of what more is possible informs the development of **thought**. SRV (social role valorization) Theory** can sharpen awareness of the ways that organizations (often unconsciously) reproduce social exclusion and oppression in the lives of those they serve. Learning journeys to places that deliver exemplary individualized supports to valued community roles encourages imagining better. Learning more about the day-to-day experience and visions of people with developmental disabilities and their support workers grounds accounts of current reality. Learning new ways to understand impairments –for example considering the implications of trauma, loneliness, and sensory and movement differences for offering good supports– provides critical distance from taken for granted stories about developmental disabilities and makes room for learning by trying another way. This rethinking is important when access to valued community roles is rationed by a logic of professionally assessed readiness that excludes people who require substantial assistance from opportunities for employment or support to live in their own home.
- Offering opportunities to learn new approaches and design structures that enable individualized community supports co-design of **new practices and structures**. Learning forms of person-centered planning grounded in support for self-direction and community inclusion, discovering customized employment as the path to work for people usually overlooked as unable to work, and exploring the processes that generate the great variety of supports people need to inhabit their own homes all make a difference in direct work with people with developmental disabilities. Study of different organizational structures, policies, and management practices that enable fitting supports to individual circumstances shape the redirection of organizational resources. Stories of organizational transformation identify potential costs and sticking points, suggest important strategy and policy questions, and offer leadership lessons.
- Advising on investments that develop change makers and facilitate transformation.

This quotation, from an insurance executive who played a role in the foundation of Theory U, reminds us that we too have inner work to do as outsider participants in transforma-

* For one form of this developmental process, derived from Theory U, see John O'Brien (2019).

[Cultivating Capacity](#).

** Wolf Wolfensberger (2013). SRV: *A brief introduction to social role valorization*. [Valor Press](#). Also see [socialrolevalorization.com](#).

The success of an intervention depends on the interior condition of the intervenor.

–Bill O'Brien

tion. To do our part in cultivating a strong social field we must balance advocacy for our perspective with inquiry into the multiple perspectives that make up the situation we share with insiders. This kind of inquiry is not a matter of gathering facts. It involves listening with open minds, open hearts, and open wills. This deep listening allows new patterns of possibility to form from appreciation of differences. It trusts that shared effort to sense what is possible will generate meaningful change when we can be still and know what wants to be born and what must die, and if that knowing animates social innovation.

Some organizations share our perspectives. In other situations differences between our experience and the experience of those we seek to assist are so wide that we see different things and assign different value when we look at the same thing. An insider sees a day program in which dedicated and caring staff deliver developmentally appropriate activities. We see limiting beliefs trapping people in age-inappropriate activities. An insider sees a group of people with disabilities as a self-contained and sufficient community who enjoy being with their own kind. We see system constructed marginalization. An insider feels pride in a no-deficiency inspection. We see goal substitution, swapping delivery of conforming services for improving people's life chances. An insider sees good person centered planning. We see missed opportunities to organize boundary breaking action. An insider sees a bold, risky, and transformational step forward. We see a minor, incremental adjustment. We are in danger of talking past each other, producing frustration and amplifying the voice of judgment.

These differences will be productive if we, and our insider partners, suspend judgment and each take another look, asking, "What else do I see?" We may also notice good relationships and loyalties. We may also notice gifts and assets. We may also notice people with the spirit of the explorer. Widening our sights need not dim or diminish our vision. We may come to better understand how history weighs on insiders' hopes for transformation. Moving from a condition of openness our task becomes creating dialogue with and among insiders that allow us all to see our taken-for-granted world and its stories in a new light. Letting more perspectives into the dialogue allows awareness of new possibilities to emerge. This enriched account guides change makers in prototyping new ways to source action in power-with relationships and find direction by discovering new thinking.

Establishing dialogue and launching change makers is often difficult. The more successful an organization has been in the era of professionally directed placement in staff controlled group settings the greater the pressure to understand transformation as renaming and revising the surface levels of current reality. Funders and regulators are inclined to expect transformation in the short term with small investments and little if any relief from external demand for compliance with backward looking rules. Loyalty to established ways is strong, even among people with developmental disabilities and their families. Technical problems of redirecting resources slow the pace of change: think of an organization with substantial real estate holdings, financed by group occupancy.

The gap between our personal commitment to transformation and the change we actually enable in the months of our involvement is often substantial. We experience occasional visits from frustration and discouragement. But the anger we feel at the social injustice visited on people with developmental disabilities continues to motivate us. So does the light around the growing number who have escaped the worst of social exclusion, inhabit valued community roles, and experience more of the good things of life.



Our teacher, Wolf Wolfensberger, stood for a principle he named “act validity”. To him this meant discerning the right thing to do in a situation and doing it regardless of the chances for success. He exemplified this principle in his decades long fights against institutions and structural deathmaking and advocacy for radically personalistic services. He was willing to be seen as pursuing foolish and futile quests, like Don Quixote.* His quests were influential well beyond expectations, in part because of their quixotic energy. On days when the odds on transformation feel especially long, his example encourages us to saddle up one more time.

* For an inspiring and informative discussion of Quixote as leader see this film by James March, a leading organizational theorist. *Passion and Discipline: Don Quixote's Lessons for Leadership* https://www.youtube.com/watch?v=NYmbiv_cbn8 March says, “Quixote reminds us that if we trust only when trust is warranted, love only when love is returned, and learn only when learning is valuable, we abandon an essential element of our humanness.”