

What More Is Possible?¹

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The purpose of person-centered practice is to assist people with intellectual disabilities and their allies to co-create the conditions for a life together that they have good reasons to value living. Such a life includes a personally suited version of the ordinary experiences that matter to anyone: the experience of being present in typical community places for the same purposes as other citizens; a sense of belonging as an equal among others; opportunities to develop gifts and capacities and experience the respect and sense of meaning that comes with the expression of those capacities in contributing social roles; and the power to make choices about their life circumstances.

Despite progress in articulating the rights of people with disabilities, the social devaluation and exclusion of people with intellectual disabilities, especially those people who require substantial and sustained assistance with communication, self-regulation, movement and learning, continue to limit many people's access to valued experiences. Person-centered practice –which includes many forms of person-centered planning as well as the active search for opportunities in community life and the design and delivery of whatever individualized supports may be required to make the best of these opportunities– mobilizes resistance to the common effects of devaluation: being excluded from ordinary life, subject to a professionally controlled regimen designed for not for any individual person but for groups of similarly labeled people, and limited by low expectations, even to the extent that these low expectations can be internalized by the person and his or her allies.

Person-centered practices are relational and intentional. They are a process of co-creation, not a means to issue instructions or make requests of a service provider. Their time comes when people want something more in life. They gather people who cannot achieve the future that they want alone and without intentionally upsetting equilibrium by asking more of themselves and others. As such, they should not be imposed on people as a bureaucratic requirement. There are people with intellectual disabilities who are, at least for the moment, content with the life that they have. There is no reason to expect that they participate in a process designed to challenge and change everyday life or to waste time in a bureaucratic ritual discussion of their dreams and goals. There are people with intellectual disabilities and families who know what they want to change in their

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lives and have or can get what they need to make that change. There is no reason to require that they participate in a system prescribed process as a condition of moving forward. Respecting people’s lack of interest in change does not exempt support workers and professionals from the responsibility to build relationships that respectfully encourage people to imagine better and actively seek it.

Theory U (Sharmer, 2009 and Scharmer & Kaufer, 2013) is a good guide to the process of co-creation that is the heart of person-centered practice. As Scharmer and Kaufer (2013) summarize it, “The gist of this framework is simple. The quality of results produced by any system depends on the quality of awareness from which the people in the system operate... The structure of awareness and attention determines the pathway along which a situation unfolds” (p.18). As this diagram shows, the framework is simple to describe but practice requires discipline.

It is easy to neglect the work involved in convening the group of resourceful



people who are necessary because the person can’t accomplish the change that he or she wants alone. Numbers need not be large at first. A core of one or two people who are willing and able to act through time with the person to discover and connect to opportunities for valued experiences can bring others into the process as need requires. But nothing predicts failure like a person sitting in what is called a person-centered planning meeting with no one besides a few professionals and support staff who are so overcommitted or constrained by their roles that they have no time to act outside their routine and beyond the meeting. Staff can be the resourceful people needed (and in some situations staff might be all a socially isolated person has) but only if they have freedom and time to commit themselves. Staff time becomes available when organizations make it possible to stop downloading more of the same service offerings and thoughtfully invest in social invention.

Observation from multiple perspectives is more demanding than it might seem at first. First of all, it can't be done inside a meeting room. It calls for a kind of discovery that involves walking out of familiar settings and taking to the streets with the person: looking more closely at a person's surrounding neighborhood, seeking other people with disabilities and families to learn from, connecting with and listening openly to strangers who come from different worlds across whose borders a person might find meaningful connection, finding out what is going on outside the boundaries of a person's routine, noticing the person's indications of ability and interest and imagining and investigating possibilities created at the intersection of the person's capacities and a variety of community settings. And observing means more than traveling in the outside world. It also means opening the internal space to listen in a way that creates a deeper and more complex sense of the situation. Observing calls for slowing down and making space for diverse views, noticing and letting go of the obstacles each of us can place in the way of empathically seeing what matters from another's point of view and so getting a richer picture of what is and what could be. In situations where the listener has power over a person, at least in the sense that he or she has a responsibility to supervise the person or make important decisions about the person's daily life (as professionals and direct support staff and their managers typically do and as parents often do), observation becomes the occasion for reflection on one's own assumptions and beliefs. It takes courage to notice low expectations or look at current limits on choice or participation in community life or the lack of diversity in a person's relationships and ask, "What is it about the way we were thinking that contributed to this result?" It is difficult to discover a previously unrecognized and underdeveloped capacity or interest and ask, "What is it about the way we were thinking that hid this capacity from us?"

Creating artifacts together is a powerful way to gather what has been learned from a period of observation and discovery. Templates can guide the organization of discoveries about how life is now and images of how things might change for the better (see, for example, O'Brien & Mount, 2005 for the templates that guide personal futures planning or O'Brien, Pearpoint, & Kahn, 2010 for the templates that guide PATH and MAPS sessions, or Callahan, Schumpert & Condon, 2009 for the templates that guide Discovery for customized employment). Maps and collages and vision posters and collections of meaningful and informative objects, music, stories and images show patterns and possibilities and provide a foundation for attention to the highest potential in the situation.

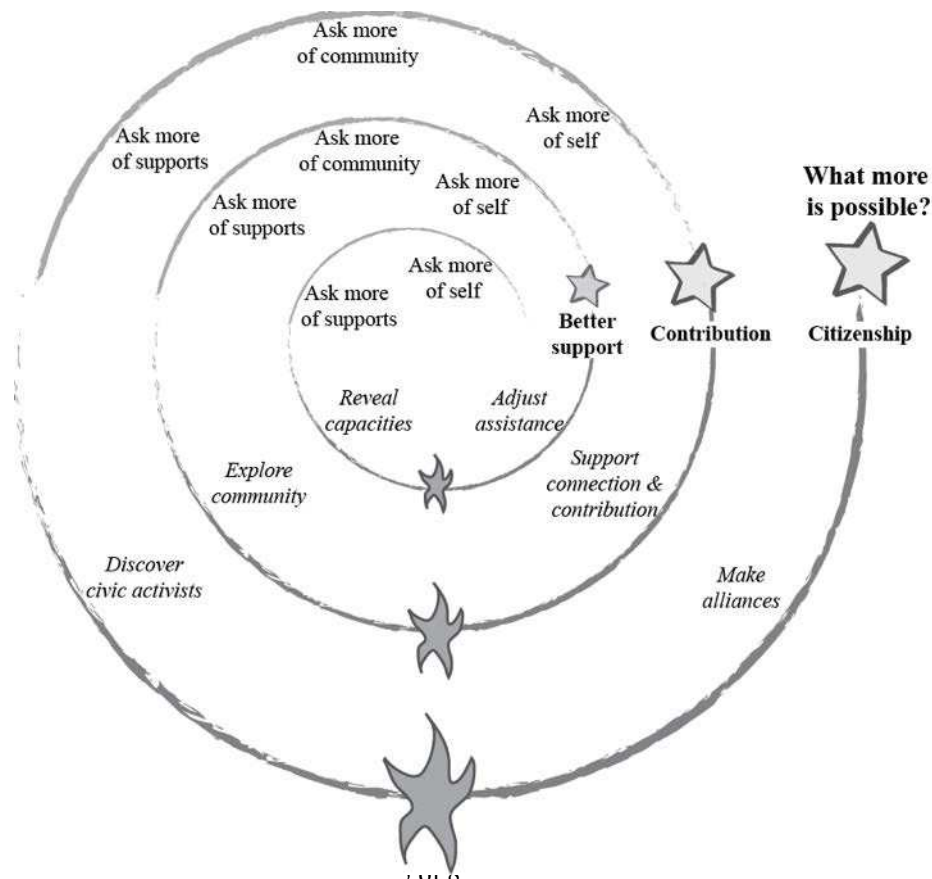
Observation prepares the way for becoming present to the highest potential in the situation. This is simply a matter of making a place of stillness that allows a sense to form of what can and must emerge to realize what matters most to the person and his or her allies. This sense is crystalized in a vision that guides a process of learning by rapid prototyping: designing and taking action that creates conditions for what matters most, reflecting, revising and trying again. Both the stillness that allows a sense of the new to arise and acts of rapid prototyping can challenge assumptions that service providers and professional advisers are efficient purveyors of proven answers that eliminate risk and reliably produce measurable outcomes who are far too busy to try new things. Even though it is the foundation of design thinking in many other organizational contexts (Brown, 2009), most human service systems are not prepared to hear, “We don’t know how to make this happen yet, but we take responsibility to figure it out together by trying things outside familiar boundaries and improving a step at a time.”

Two personal and organizational realizations and a key question open the way for person-centered practices. First, recognition that there are powerful incentives to keep things stable by downloading patterns of thought and activity reproduce more of the same. The service world is powerfully shaped by compliance routines designed to control cost, minimize risk and protect what has been achieved in the way of continuing public investment, accumulated capital and worker’s rights. These are good things that can become oppressive unless disrupted by people who organize to resist the limitations that they impose. Person-centered practices for designing individualized support to contributing community roles, along with self-advocacy and family advocacy, applied research, and disability scholarship enable the disruption necessary to defeat the reign of control and exclusion. Second, recognition that more of the same can not overcome social exclusion sufficiently to make the rights enshrined in the *Charter on the Rights of Persons with Disabilities* real for people who are significantly impaired by intellectual disabilities. (For an account of one organizations 30 year struggle to transcend downloading the structures and practices that limit people’s rights, see Meissner, 2013.) The choice to step responsibly into the tension created by acknowledging that what is good now, the result of generations of hard work, can not get people with intellectual disabilities the fullness of opportunity that they deserve begins the journey that person-centered practices serve.

The key question: “What more is possible?” Holding this question in a useful way makes room for the uncertainty that goes with a process of discovery, emergence and iterative design. Predictors shift from judgements about the

effects of a person's impairments on their potential achievements to the level of resourcefulness, courage and creativity a person and his or her allies can mobilize over time. Person-centered practices at their most useful offer ways to gather and guide people who want what is currently impossible.

There is great variation from place to place in what is impossible without intentional, creative action by people who want a change and their allies. In some places there are good supports to people who want their own home, decide with whom they will live and have effective control of the assistance they require (see the appendix for an example). In other places the alternative to living with families is some form of group living. In a few places, a majority of people with intellectual disabilities can expect access to at least part-time paid work in inclusive settings. In other places, access depends on a professional judgement of "readiness" that classifies many people as too impaired to ever work and consigns them to sheltered settings. In some places assistance in connecting to civic life is well developed. In other places membership opportunities are exclusively under the control of disability service providers. In the places where opportunity is more open, person-centered practices can help to customize the connections among person, community setting and assistance. In places where opportunity is very scarce, person-centered practices can make a critical difference in developing new opportunities.



Thirty years of practice traces the exploration of three contexts in which people with intellectual disabilities and their allies ask “What is possible?” and search for new opportunity. The first, at the center of the spiral, is a search for a better fit between a person and the form that his or her assistance takes. The process reveals a person’s capacities and interests and adjusts assistance to better support the development and expression of those capacities. A person who wants to move from group living into his own place with individualized support will pursue this search. This is the spiral in which person-centered practices originated. A concern for social inclusion soon expanded learning into the second spiral. This search moves across the boundary of social exclusion and seeks a contributing community role. The process explores interactions of a particular person’s capacities and interests with community settings and develops ways to make a good connection and support the person to make a difference there. A person who wants a paying job that matches her interests in an ordinary workplace will pursue this search. Recognition of the importance of collective civic action to developing more just and inclusive communities opened the third spiral. This search shifts perspective and asks “What is possible?” by constructing a view of the whole community, its assets and issues. It seeks a person’s best answer to this question, “How might I make a positive difference to civic life?” The person-centered practices assist people to identify and learn from community activists and others who work hopefully to build a more just community and forges alliance with them and the formal and informal civic groups they create. A person who cares about making sure that people in her neighborhood have access to fresh food and gives his time to supporting a weekly farmer’s market is on this search.

To trace the history of person-centered practices in this way does not suggest that any particular person must follow these searches in sequence. A person might develop a civic connection without requiring any change in the service she receives. A person might find his way into a job and then negotiate a change in service provision. The spiral image communicates the impulse to cross social boundaries and increase the diversity of ways that people with intellectual disabilities make a positive difference that person-centered practices embody.

Each search for possibilities begins with the same question, “What more do I want to ask of myself and my allies?” Seeking a home of one’s own or a good job or more active citizenship will disrupt what has become familiar, stretch beyond comfort zones, and risk disappointment and failure. Is the desire for change strong enough to set out on the journey? Each search asks more of the supports a person counts on to be successful. “How might we organize the assistance that

will support my move into new life stages and new roles?” The two searches that move beyond the borders of service settings ask more of the person’s community. “How might we develop the relationships and accommodations that productively link the person’s interests and capacities with a real economic or civic need?”

Ironically, despite the publicly stated embrace of community inclusion by many service systems it is often harder for services to answer the call to adapt the way they provide supports than it is to find the hospitality and support among citizens that makes contributing roles possible. In too many places, service policies and practices create an undertow that drags people out of community life. It is a continuing struggle to win the service system investments necessary to try new ways of discovering what is possible and to sustain people in contributing community roles. A struggle that will be lost without mindful and courageous leadership.

As the numbers of citizens grow –intellectually disabled and not– who experience the mutual benefits of contributing roles and the numbers of service workers grow who are comfortable applying their skills in equal relationships with people with intellectual disabilities and their allies, so do the chances increase for a more just, more vibrant and more inclusive community life. This social development will not happen as quickly as would be desirable and there will inevitably be conflicts, setbacks and defeats, but those who choose to strengthen person-centered practices by applying them respectfully and creatively will make a meaningful contribution to it.

References

- Brown, Tim (2009). *Change by design; How design thinking transforms organizations and inspires innovation*. New York: HarperBusiness.
- Callahan, Michael, Schumpert, Norceva and Condon, Elizabeth. (2009) *Discovery: Charting the course to employment*. Gautier, MS: Marc Gold & Associates.
- Meissner, Hanns (2013) *Creating blue space: Fostering innovative support practices for people with developmental disabilities*. Toronto: Inclusion Press.
- O’Brien, John & Mount, Beth (2005). *Make a difference: A guidebook for person-centered direct support*. Toronto: Inclusion Press.
- O’Brien, John, Pearpoint, Jack & Kahn, Lynda (2010). *The PATH & MAPS handbook: Person-centered ways to build community*. Toronto: Inclusion Press.
- Scharmer, Otto (2009). *Theory U: Leading from the future as it emerges*. San Francisco: Berrett-Koehler

Scharmer, Otto and Kaufer, Katrin. (2013). *Leading from the emerging future: From ego-system to eco-system economies*. San Francisco: Berrett-Koehler

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