

15 December 2015

To: Network Participants

From: John O'Brien¹

Reflections as the Network Seeks a New Form

In November 2015 the New Paths to Inclusion network reached a turning point, marked by the completion of a cycle of the Network's support from the Lifelong Learning Programme of the European Union. Partners gathered in Vienna to exchange stories of change, reflect on their learning and harvest seeds of possibility. Later in the month, a smaller group joined parliamentarians and officials, self-advocates and family advocates in Brussels to report on the policy implications of the past three years' work. It is clear that many participants in Network activities have formed personal relationships, collaborations and organizational connections that they value, both within and across national boundaries. These people are alert to possibilities for the Network to find a new form that will support their continuing effort to make social change by opening new paths to inclusion for growing numbers of people.

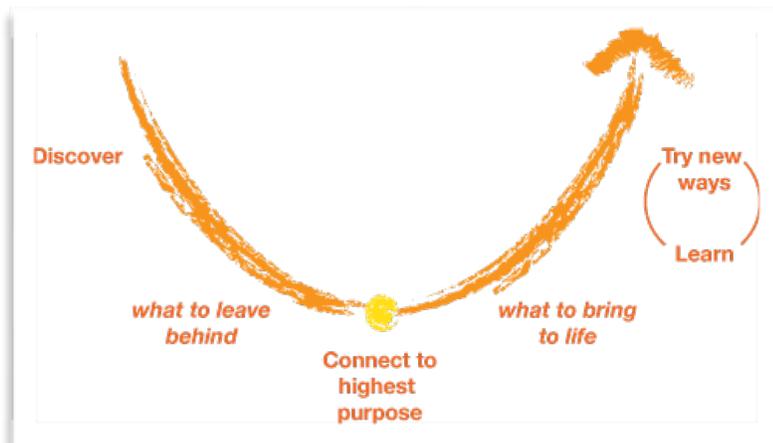
The work of inclusion

New paths to inclusion develop best when people organize an ideal seeking system, an effort that creates diverse patterns of collaboration to serve a purpose that can be approached but never fully realized. The work of inclusion can never be finished because people's lived experience keeps moving the goalposts when they have allies and partners willing to join them in learning how to inhabit their communities in new ways. The meaning of inclusion deepens because its possibilities grow as more and more people figure out how to live it together. The past no longer determines the future when people attune themselves to what wants to be born in their lives and in their communities and set about learning by acting together outside their usual boundaries. Professional diagnosis and prognosis used to decide who could work in community jobs; good supported employment practices break the correlation and open a zone of creative uncertainty. The same is true of the chance for people to live free of institutions in their own homes. Inevitability gives way to possibility as people invent new ways to organize available resources.

The work of inclusion redirects attention from familiar patterns of activity and taken-for-granted structures and stories that set life with disability and life in community at a distance from each other. It purposefully invests attention in places of greater potential and in actions that open

¹ These notes conclude a series of personal reflections on the Network meetings I have had the privilege of attending over the life of the project. They are simply what I think about what I heard, it is not a record of November's events. Each participant will have their own experience and their own reflections so this account does not speak for the Network. Documents from those meetings are available through the Online Learning Platform at www.personcentredplanning.eu/.

new possibilities. Places of potential show up at boundaries: between the person and those who design and provide assistance as people find voice and power through relationships based on equality and collaboration; between people with disabilities and the relationships, roles and resources of civic and economic life; between those who organize and manage service provision and the communities whose inclusiveness they influence by the ways they work. New possibilities emerge from a disciplined process, well described by Theory U.² This way of working begins with a decision to step out of familiar routine and intentionally go deeper



to discover new possibilities. Creating a point of stillness invites a connection to the highest purpose in the work, which clarifies what must be left behind and what wants to come to life through the shared action and learning of people with disabilities and their allies, community members and those who provide assistance.

Engaging resistance shapes the real work of inclusion. Social exclusion and the subordination of disabled people's autonomy are not accidents. They are produced by the interaction of cultural, social, political and economic forces as they affect people's life chances and the assistance that organizations can offer. As commonplace an activity as moving into one's own flat becomes challenging when the move is an exodus from an institution.³ Legal capacity may have been erased and a person's future assigned to officials charged to act in the person's "best interest" as they judge it. Public funds for necessary assistance and housing may be bonded to organizationally controlled buildings in a way that forces a stark choice: stay in the institution and live on its terms or give up assistance you need and live in your own place. Assistance available in one's own home and community may be inflexible and insufficient (as one person who braved the move to his own flat described the time before battles for personal

² See presencing.com for Theory U resources.

³As Senada Halilčević of the European Platform of Self-Advocates (EPSA) reminded participants in the Vienna meeting in her closing address, The European Coalition on Community Living defines "institution" in a way that challenges much current practice in organizations located in ordinary communities: "An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/ or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size."

assistance were won, “Living with home care wasn’t so nice and not what I wanted. They did not go out with me neither did they cook proper meals, just warmed up some microwave stuff.”⁴). Gatekeepers of necessary resources may define the person as ineligible on the basis of perceived deficits in the person without consideration of their rights or the difference that personalized assistance will make. Professionals and institution staff have unquestionable confidence in their judgements of people’s incompetence and doubt that people can be assisted in ways that can keep them healthy and safe outside their direct supervision. Family members may oppose change as a threat to wellbeing.

The path to inclusion leads through these and many other difficulties that demand persistence, endurance and social inventiveness. It is a path that turns through many U’s to create social inventions at different scales. People need resourceful companions who believe in in them and are willing to join in figuring out how the path must twist and turn in order to continue forward.

There are many external obstacles to negotiate along the path to inclusion, but outside troubles are not all there are. Many people who commit to inclusion face internal conflict as well. Some of this conflict arises as people’s desires for a home or a job of their own make reasonable demands that an organization’s current structure can’t meet. Even high quality service settings often are structured and funded to house or occupy groups of people with disabilities at the margins of community life rather than offering individualized assistance for extensive and satisfying community participation. Practices and structures that limit people’s autonomy and disregard their voices can be taken for granted as “the way it has to be”. Organizational culture may be shaped by images of hierarchy and bureaucracy that make it difficult for members to act as social inventors. Some of the conflict is personal. People discover that they have internalized stories about powerlessness, social unacceptability and incompetence that undermine confidence in inclusion and confine attention inside the comfort zone of existing service boundaries. Such trapped attention makes community life distant, exotic and maybe even ominous. It can be as if community life comprised places only safe to visit as a consumer or spectator under staff protection rather than a wealth of opportunities for engagement and contribution. Staff and managers find that they have imagined inclusion narrowly, focusing on those obviously most able and consigning people with substantial need for assistance with mobility, communication, emotional regulation and learning to a life of exclusion and supervision. As they realize the limiting effects of their current practice, managers and staff can experience a wound to their identity. People with disabilities themselves can swallow exclusionary stories and beliefs and so can their families and allies. As these and other limits in practice, structure and story come into awareness opportunities grow to develop new organizational and personal capabilities. Competent person-centered planning and the work it energizes generates counter-stories and disruptive experiences that

⁴ from Jurgen Vanek. *Jürgen Moves Out* personcentredplanning.eu/trainingpack/index.php/en/juergen

raise consciousness and focus attention on agency –the power that people and their allies can exercise, the gifts people have to offer other citizens, as well as everyone’s assets and developmental potential.

Organizational capabilities

A reading of *The UN Convention on the Rights of Persons with Disabilities (CRPD)* identifies the capabilities that organizations dedicated to assisting people with disabilities develop in order to uphold people’s rights, including capabilities sufficient to...

- ... offer people the opportunity to choose where and with whom they live without requiring them to occupy particular living arrangements. (Article 19)
- ... support community inclusion and prevent segregation and isolation (Article 19)
- ... offer real opportunities to work and shape a labor market and work environments that are open, inclusive and accessible. (Article 27)
- ... enable people to fully develop their potential to participate effectively in a free society. This includes participation in age-appropriate, inclusive educational opportunities throughout life. (Article 24).
- ... actively support the establishment of legal capacity for people who have been stripped of it, the development of a range of decision supports and the transition from the “best interests” standard to “will and preference” for people whose communication others find difficult to understand. (Article 12).

How much new capability organizations aim to develop depends on their interpretation of inclusion and choice. Those who see life in a person’s own home as possible for anyone who has access to skilled adjustments, useful technology and competent personal assistance will have more to do than those who believe that one can experience the same sense of being at home as any other citizen when living with a group of people with disabilities composed, placed and supervised by disability organizations. Those who see groups of people with disabilities working in buildings identified with disability services as included in their community will have much less to do than those who define inclusion by considering the number of people working individually in typical community jobs that reflect their interests.

An ideal seeking organization committed to inclusion and support to autonomy encourages a challenging interpretation of *CRPD*. In most organizations necessary change reaches deeper than simply adopting new practices, like person-centered planning or the techniques of supported employment. The leadership of organizations that want to stretch into new capabilities takes responsibility for structures and activities inconsistent with people’s rights to live, work and learn in community. They struggle to move a growing proportion of their resources into personalized supports to people in community settings. These supports can not be developed by command or by mindlessly following a blueprint, people must commit

themselves to acting and learning together as equals. The uncertainty that accompanies any effort to discover a new path and the continuing possibility of rejection by fellow citizens who still live inside devaluing stories of disability⁵ that haunts the path into community life produce risk and anxiety. Organizations that tend to relationships and strive for openness and mutual support among people with disabilities, family member and allies, staff and managers, and governors and funders in pursuit of challenging goals have a better chance of regulating this anxiety and redirecting it to creative ends than organizations ruled by impersonal hierarchy.

Developing the capabilities to do the work of inclusion takes sustained, committed leadership. For a number of those involved the New Paths to Inclusion project has become a support to their leadership.

Network as resource

The end of this formal project saw more than the usual sentiment that accompanies the finish of a project. For a number of people, including me, there was a desire that reaches deeper than promises to stay in touch on Facebook. For us the relationships that have formed through the project have become an important resource for our work. We would welcome a new form for the network that would continue these benefits.

- A sense of belonging to and being personally accountable to others who share many commitments and beliefs.
- The regular use of practices drawn and adapted from Theory U has not only given some participants useful ways to engage people in their own organizations it has let them build trusting relationships with one another that offer support, encouragement and allow effective challenges to their current understanding and perspectives.
- Mutual involvement in one another's projects have allowed the development and try-out of new practices and ways of supporting inclusive learning and organizational change.
- International differences in policy and practice increase knowledge of possibilities and highlight limits that have been taken for granted. Cross-border learning journeys and have been especially important for some.
- The time to think and encouragement to reflect that the Network offered is scarce in many people's work lives.

- Listening & speaking from an open mind, open heart & open will
- Learning journeys
- Telling stories of meaningful change & learning through reflection on them
- Journaling
- Stillness
- Making social reality present through embodiment
- Modeling potential actions

⁵ “ They are happy with their ‘own kind’.” “Taking care of them is a special calling; I’m glad I don’t have to do it.” “They have nothing of value to contribute.” “They have the minds of little children in big bodies.” “I’d rather be dead than like them.” Etc.