Up-Rooting Institutions

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> *The problems of life are insoluble on the surface. Getting hold of the difficulty deep down is what is hard. Because if it is grasped near the surface it simply remains the difficulty it was. It has to be pulled out by the roots; and that involves our beginning to think about things in a new way.*
>
> *–Ludwig Wittgenstein*

Getting to the roots of the problem of institutions means starting in the right place, choosing the right questions, and engaging people on a journey to creative answers to those questions.

The right place to start

There is no better statement of the right place to start than *The Community Imperative*, in the version prepared with and for self-advocates when in 2000 the Center on Human Policy reissued it's 1979 *Statement Against Institutionalizing Any Person Because of a Disabilit*y:

> ***In terms of Human Rights:***
>
> - *All people have basic human and legal rights*
> - *These rights must not be taken away just because a person has a mental or physical disability*
> - *Included in these basic rights is the right to live in the community*

> *In terms of education and support services:*
>
> - *All people are valuable*
>
> - *All people have strength and abilities*
>
> - *All people have the right to services in their lives that support these strengths and abilities*
>
> - *These supports are best provided in the community*
>
> *So: To meet basic human rights and get the best services, all people, no matter what their abilities, have the right to live in the community.*

The claims are clear: institutions are illegitimate because they deprive people of the right to live in the community and institutions are wastefully impractical because the supports that help people develop their abilities are best provided in the community. The evidence is clear: as a group, people are better off when they leave institutions for community services and institution costs are, in aggregate, greater than the costs of community services (Kim, 20001; Shoultz, 2005). Experience is clear: only 2% of Americans with developmental disabilities live in institutions or nursing homes and ten states and the District of Columbia function without any public institution.

But this much clarity is not enough. State institutions hold on: 173 survived through 2006 and only one will close in 2007. The states that continue to operate public institutions vary in the numbers of people they enclose: six states hold fewer than 100 people in state facilities and three hold more than 3,000. Even in a time of fiscal restraint, daily costs average $458 per day (low $300; high $1,111) (Prouty, 2007).

Three right questions

The first question: **How can we mobilize sufficient political will in 41 legislatures to close the remaining state institutions**, release the nearly 38,000 people held by them, and redirect the nearly $6.5 Billion expended on them to support people in community life? The preamble to Ohio's 2006 Strategic Plan, *Developmental Centers' Role in Ohio's Continuum of Services*, neatly summarizes the claims of the institution's defenders:

> *It is the intent of ODMR/DD and its stakeholders to support the role of DCs in their service to Ohio's most difficult citizens with special needs as we ensure the health and safety of all residing within the DCs, the employees of the DCs, and the community.*

On this view, there exists a class of "most difficult citizens" who require institutions as part of a continuum of services in order to ensure their health and safety as well as the health and safety of the community and the institution staff. The institutions also serve a "regional resource role", offering services unavailable anywhere else. Later, the Strategic Plan incorporates the notion that some people now resident exercise a choice to do so that the state must respect. To TASH members, these are weak and weary claims. The idea of organizing supports in terms of a continuum of service buildings was practically and conceptually discredited by 1988 (Taylor, 2001), and the misuse of the value of choice to justify continuing, massive public investment in segregation for a few has been refuted (Taylor, 2000). But having the right answers is not enough when the question those in power are asking is how to satisfy competing interests. The strength of the institution's defense does not lie in evidence of effectiveness or eloquence of argument but in the political strength of its allies, the inability of community service advocates to convince legislators that parity or wages and benefits between institution and community service workers is simple justice, and the continuing ineffectiveness of most local service systems.

This ineffectiveness shapes the second question, **How do we make any sort of institution unnecessary?** As long as local service systems fail at two primary tasks, some citizens will be exported to one or another form of congregate institution which is willing to manage people locally judged "too difficult".

The first of these tasks is to follow the difficult principle of zero rejection. Local service systems must learn how to provide effective, affordable individualized supports for those people whose behavior, psychiatric symptoms, or complex health care needs currently scare and inconvenience them into handing them over to specialist congregate facilities, nursing homes, and state institutions. This learning is not by any

means easy, but until local services step up to measuring themselves against the goal of zero rejection, state institutions will be able to cling to life and other forms of segregation will balloon as state facility census deflates.

The second essential local system task is to reach out to families and to institutionalized people themselves and, with them, discover how to enroll them in a quest for a better life as members of a community struggling for inclusiveness. Some people who have moved from institutions have become effective allies for those who remain behind. Family-to-family efforts have been able to redirect some family energy from defending institutions to allowing and then supporting the move to local services.

Uprooting institutions calls for the deeper grip that can taken when people begin to think seriously about the third question, **How can we avoid re-producing the institution in small, local settings?** This question takes us well past what we can score with data from pie charts that show growing investment in residential settings with six or fewer occupants. It asks us to find a way to identify and overcome the practices and beliefs that generate the devaluation, segregation, deprivation, and control of people with disabilities which are the primary harms inflicted by the structure of the institution.

At root, these practices are based on the 19th century conviction that a professionally designed, standardized, impersonally administered regime that controls every detail of everyday life can develop or reform people who do not meet society's expectations. From time to time, this conviction has failed, replaced with a pessimism that substitutes focus on simple control at the lowest possible cost for concern with growth. But reform efforts, including the ICF-MR program and it's descendants and efforts by various courts to redress institutional wrongs, still embody the spirit of the institution. When an agency forbids its staff to introduce the people they supervise to fellow church goers for fear of violating confidentiality or requires staff to slice hot dogs into bureaucratically prescribed slivers for people with no impairments in chewing and swallowing or puzzle over whether they can invite a neighbor in for coffee without running a police check on her, the reforming institution lives on in staff who channel

rule from above. When staff become bystanders as people withdraw into game shows and junk food or when staff act as amused referees when people assault or flee one another or when nurses unquestioningly serve poly-pharmaceutical cocktails to control behavior, the custodial institution lives on.

The alternative to inviting the institution to grow in people's community lives is not absence of assistance and chaos but a different kind of support and a different kind of order. This order that grows when people take responsibility for respectful relationships.

Fortunately, many people with disabilities and their allies already live in ways that to show us how to replace the institutional regime. Their support is person-centered because it is founded on the conviction that…

…they are fully human and worthy of respect just as they are

…they have capacities to contribute to the well-being of others and the potential and responsibility to develop those capacities

…their development, opportunities, and happiness depend in important ways on their engagement with the family they belong to, the friendships they form, the memberships they hold, and the networks they are known to

…they are entitled to freedom of access to the same places, activities, and valued social roles as any other citizen

…their choices and preferences are worthy of support and their supports must be defined a steered by them with the active support of a circle of people who know and love them

Experience shows that these seeds of healthy growth can thrive in the soil newly loosened by uprooting the institution.

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