

TASH's Contribution to Person-Centered Work¹

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TASH² and person-centered work grew up together, taking shape in the late 1970's, growing in the 1980's and 1990's, and adapting to the changes in the political-economic environment and shifts in system demands in the new century. Person-centered work emerges from a network of people and associations (Lyle O'Brien and O'Brien, 2002) and person-centered planning, its most common form, has grown to include many different approaches and serve multiple purposes (O'Brien, 2014). The network includes people like me who have contributed to some of the common practices identified with person-centered work and have made good use of their involvement in TASH through their shared history (I joined The American Association for the Education of the Severely and Profoundly Handicapped in 1976). In this chapter I want to describe person-centered work as I understand it, reflect on what TASH has given me as a practitioner and the organizational qualities that made those gifts possible and identify a vulnerability that I think person-centered work and TASH share in the current environment.

As I understand it, person-centered work is a way to co-create the means for a person to live a life that they and the people who love them have good reasons to value. Person-centered work takes three forms. Person-centered planning facilitates a person and their allies to discern the person's purposes, gifts and capacities and identify and coordinate access to the opportunities and supports necessary to show up in community life as a valued friend and a contributing citizen. Person-centered direct support develops and sustains respectful and productive relationships with personal assistants who align their capacities with the person's chosen path to contributing citizenship. Person-centered design orchestrates available resources and constraints at the personal, organizational and system levels to reliably offer the assistance and support a person requires to show up in community life as a contributing citizen. Multiple resources make it possible to show up as a contributing citizen and all may be encompassed in each level of person-centered work: friends and allies, a secure home, an adequate income, a real job, a rich leisure life, membership in associations, wellness, connections to sources of meaning, chances and supports to learn and grow, technology that amplifies personal capacities.

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² TASH is an international organization committed to the inclusion of people with significant disabilities and support needs. tash.org

Person-centered work supports adaptive change: the people involved notice and let go of practices, structures and stories that stand in the way of valued friendship and contributing citizenship and learn through action how to co-create alternatives. It demands that all those involved notice and revise the limiting narratives that trap people in devalued or marginal social roles under surveillance as “special” (i.e. excluded) students, clients of day programs, or inmates placed in a group living arrangement. Perceived impairments are a magnet for limiting narratives and people whose differences in movement, communication or self-regulation lead the service system to assign the status of “severely or profoundly disabled” are most vulnerable to their devastating consequences.

Stories framed as unquestioned realities cut off the search for capacities and opportunities that define person-centered work. “No one would ever hire him.” “She can’t communicate.” “He is so dangerous that staff have to be on their guard every moment they have to be near him.” “There is no way families can be trusted to control individual support budgets.” Person-centered work reframes these certainties as testable propositions that form design challenges. “How might we customize an employment situation in collaboration with him and an employer in his neighborhood?” “How might we better tune into and build on her efforts to communicate?” “How might we match him to staff who could form relationships that would support greater self-regulation?” “How might we assist families to effectively direct supports?” Meeting these design challenges moves attention and resources outside familiar service places and practices and onto new ground, common to other citizens of similar age and interests. Regular classrooms, workplaces, associations and housing become the sites for offering personalized support.

The general question that drives reframing in person-centered work is “What more is possible?” Over 40 years, this question has defined the most productive intersection between TASH and person-centered work as I know it. TASH has expanded my imagination of what is possible for people with multiple and challenging impairments, given me alternative narratives to understand the experience and consequences of those impairments, provided arguments and benchmarks that sharpen analysis of what service providers and systems offer, given me people with relevant insight and expertise to connect with others in my network, and encouraged and inspired me.

“What more is possible?” is a restless question. It wants to be asked again and again rather than settling down after there has been a bit of progress. From my earliest contact I felt a restlessness from TASH’s leaders that echoed and refined my own. The first volume to feature chapters by many of them, *Educational programming for the severely and profoundly handicapped* (Sontag, 1977), notes the growing capacity to influence molecular units of behavior and persistently from chapter to chapter asks what real world opportunities for participation and contribution those changed behaviors open up. This book also expressed impatience with diagnostic efforts that “spent too much time defining students and too little time defining effective services.” This line of questioning extended my own concern that the field of adult services, my particular interest, would freeze in the forms devised to remedy the neglect

endemic to institutions. In too many places, requirements for professional assessment, individual service plans and “active treatment” had already become ends in themselves, mindless activity traps in dead end group homes and day programs. TASH provided sharper questions and a variety of examples of provocative answers.

The adventures in deep and sustained system change that Lou Brown, his students at the University of Wisconsin and collaborators at the Madison Public Schools can be traced from this Sontag’s collection through fourteen years of development to the first account of the state of the art issued under TASH’s name, *Critical issues in the lives of people with severe disabilities* (Meyer, Peck & Brown, 1991). Their work, which continues to bear fruit (e.g. Brown, Shiraga & Kessler, 2006), embodies decades of relentlessly asking “What more is possible to improve student’s inclusion and their life chances after graduation?” and figuring out how to answer in action. It represents the longest sustained effort to improve a systems’ capacity to include students with severe disabilities from earliest education on, integrate the specialist services that improve their life chances, and give them access to individualized employment as adults that I know of. It is an exemplar of the personal, organizational and systemic learning necessary to realize the promise of TASH values. Of course it was not necessary to wait 14 years. Journal papers and lively and crowded conference presentations kept the unfolding story of learning and change alive from year to year.

I am not much of a joiner. My engagement with TASH has been sustained first of all by the fact that over the years a number of my friends have taken responsibility for leadership and occasionally ask me for some assistance. Nearly as important is my resonance with the nature of the organization and its clearly stated values. TASH has never been a trade association, and from the beginning it took the value of inclusion as its point of departure, a welcome rest for someone engaged in endless, heated arguments with advocates for institutions in most other places. From the beginning TASH has done its best to put first the interests of people who are most likely to be placed last because of the way their impairments are perceived. It has been unequivocal on moral issues that many other organizations fudge: making a behavior management technology of pain is always wrong and ineffective; segregation is unnecessary and anyone can be supported in ways that overcome barriers to friendship and community participation; it is fruitless to make predictions about employability in the absence of competent support to customize jobs. From the first sentence of the first chapter in the first collection of its leaders’ thinking they acknowledged the civic contribution of people with severe disabilities, describing severely and profoundly disabled students as “catalysts for major changes in public education” –a role that TASH members expanded to *agents* of major change as experience grew. TASH has recognized the key role of parents and family members and welcomed them in positions of leadership and influence.

In addition to its diversity of perspectives within common values, what has impressed me among TASH members is a widespread sense of genuine enjoyment in personal engagement with people with

substantial impairments and their families. For many members, as for many practitioners of person-centered work, passion for social justice and commitment to high standards of research and practice are animated by good and sustained relationships with real people.

People draw different resources from TASH. I am in many ways an outsider. I did not choose a career with people with ID/DD nor was I academically trained for it. I was literally conscripted into a direct service job to satisfy my service obligation as a conscientious objector to the Viet Nam war and learned with people as I worked my way through a variety of service system roles. My academic background is in philosophy, with complementary study of social systems interventions (especially the tradition represented in Trist & Murray, 1990). Once I experienced the injustice visited on institution inmates, I became preoccupied with developing settings and supports that expand people's opportunities to assume valued social roles, an interest that I imagine I will pursue for the rest of my life. My involvement with Wolf Wolfensberger, especially around repeated use of the PASS approach to analysis of service settings (Wolfensberger & Glenn, 1975), and the Center on Human Policy predated TASH, powerfully shaped my contributions to person-centered work and set me at some distance from the research and intervention narratives common among the professional TASH leaders who I admire and have learned from. My own way of understanding is shaped more by philosophy, design, and sociology than by behavioral psychology and law. This makes me like most TASH members in my commitment to making segregation and external control on the basis of disability a thing of the past and different from others in my assumptions about epistemology and the ways individual, organizational and system change happens. I have found this difference very fruitful.

There are different pictures of what TASH should be. Many, reflecting the most commonly shared engagements of the founders, see the association and its journal primarily as a source of information about practices established by behavioral research as socially valid and reliable. On this understanding TASH teaches people how to do what it is right to do. Others, especially those who joined TASH from the world of community services, see TASH primarily as a place to flock, gathering with likeminded others to learn by conversing, commiserating, celebrating and scheming. It is an opportunity to feel that one is not mad, not alone and justified in feeling some hope for real change. As well, many members count on TASH as a channel to influence policy.

I appreciate each of these facets of TASH. My approach to person centered work begins with the recognition that alternative narratives of impairment are possible and consequential. TASH has been a rich source of such alternatives. Three examples among many. Marc Gold and Tom Bellamy, contrasts in temperament and preferred theories of learning, demonstrated assisted job performance that opened the possibility of meaningful work for many people who would otherwise be trapped in a story of incompetence. Karen Berkman and Luanna Meyer's account of *Going "all out" non-aversively* offers an inoculation against the story that some people "need" the professional application of pain and that

meaningful community participation is beyond some people's reach. Anne Donnellan and Martha Leary's (2012) reframing autism in terms of sensory-movement differences shows the way to discover accommodations that increase self-regulation and reduce distance between people. TASH has also provided a good place for people who do person-centered work to gather and share the learning from their struggles.

Making sense of struggle is an increasingly important function for TASH. Both person-centered planning and TASH are vulnerable to the stubborn persistence of practices and structures that those committed to its values know to be not just ineffective and unnecessary but socially unjust. Despite a growing body of evidence to underwrite the possibilities for employment demonstrated by TASH leaders of 35 years ago, less than 20% of people funded by US ID/DD systems are employed in integrated jobs (Windsor, 2014). Despite a mass of research on practice to support the effective inclusion of students with severe and profound disabilities, 25% of students assigned a multiple disability status are in separate schools and 46% of those in regular school buildings spend less than 40% of class time in regular class; about 8% of students assigned an intellectual disability status are in separate schools and 48% of those in regular school buildings spend less than 40% of their time in regular class (NCES, 2014). 9% of students assigned an autism status are in separate schools and 34% of those in regular school buildings spend less than 40% of their class time in regular class. For those convinced that inclusion is right, this is a dispiriting return on 40 years of hard work.

I am not a political strategist. I have no program to recommend to the TASH members and staff who dedicate themselves to influencing policy and shifting those troubling numbers through organizing campaigns, testifying in legislatures and courts, offering well informed advice to system managers, or collaborating with those who make rules and regulations. Many of my friends who do person-centered work feel like obstacles are growing faster than we can navigate around them and I am out of clever tactics to suggest. In part the situation has become more difficult because the success of advocacy for people with severe and profound impairments and their allies is contingent on trends in the social and political environment that we do not control. We are simply too small and have too little political power to shift the climate compared to the health care and elder care industries and our federal political process has not lately thrown up legislative champions with the power to deliver even such a symbolic thing as ratification of The UN Convention on the Rights of Persons with Disabilities (which ratification would surely include sufficient reservations to pull its teeth). The broader movements for social justice and reform which uplifted the TASH agenda and its allies in government in the first decade are now in a period of searching for ways to translate the desire for a beloved community of equal citizens into practical influence on massive social exclusion, alienation and economic inequality.

I do however see a temptation worth resisting: losing touch with the power generated when we hold our focus on people with severe disabilities. As with many ordinary tragedies of human existence the classical

Greeks had an apposite story. Heracles was on his way to complete the 11th of his labors by stealing the golden apples kept in the garden of the Hesperides when he met Antaeus who challenged those who tried to pass him to wrestle and used his incredible strength to kill them. The secret of his great strength was its source: contact with the earth, his mother. Whenever Antaeus was thrown to the ground he rose up stronger. Heracles figured this out, lifted Antaeus off the ground, crushed him in a bearhug and passed on his way.

If you hear this story from Heracles' point of view it demonstrates how clever and efficient it is to lift obstacles up and crush them. This is an appealing way to hear it. The hero, undaunted, outwits and disposes of obstacles by elevating them off the ground and then moves on to check off his next goal. It tempts us to think that all we need is clever ways to take issues higher up and deploy power over to demand compliance with what is right. In this story we give more and more attention to negotiating abstractions like the bureaucratizing definitions of "community setting" and "person-centered planning" in a recent CMS Rule and embedding commanding words that require people to do the right thing in regulations, court decrees and laws. This is certainly important and necessary work, but the conflicting interests at stake are powerful and there is a big and persistent gap between what we intend and the actions our commands produce. Think of all those rules and technical assistance manuals dedicated to inclusion and transition producing real jobs for less than 1 in 5 adults with ID/DD. A complex system is harder to outwit than a giant.

There is always another angle on a story. The great Irish poet, Seamus Heaney (2001), invites us to consider Antaeus' point of view. His power depends on staying in touch with the earth.

*When I lie on the ground
I rise flushed as a rose in the morning.
In fights I arrange a fall on the ring
To rub myself with sand.*

This is worth thinking about. At their best, TASH members and good practitioners of person-centered work stay grounded in co-creative relationships with the people most likely to be excluded and controlled. They use what they have to make life as good as their shared creativity can make it for real people. At its best, TASH demonstrates that a passion for justice focused on practical action that improves the lives of people with severe disabilities animates good research, good person-centered work and strong association.

We need not choose between Antaeus and Heracles; they embody different capacities we can nurture and deploy. Of course we can outwit, pick up and destroy some obstacles. What we must never do is lose touch with the practical commitment to the people and families whose experiences and possibilities called TASH into existence a generation ago.

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