

Person-Centered Planning and the Quest for System Change¹

John O'Brien

Approaches and Contexts.....	3
Some Common Approaches to Person-Centered Planning.....	3
Contexts and Functions for Person-Centered Planning	6
What Person-Centered Planning Reveals About System Change.....	9
Change Strategy 1: Adopt New Rules and Procedures for Individual Planning.....	9
Change Strategy 2: Use Person-Centered Planning In Service Reform	13
Change Strategy 3: Person-Centered Planning Guides Purposeful Innovation.....	16
Conclusion	20
References.....	21

¹ A version of this paper is published in Martin Agran, Fredda Brown, Carolyn Hughes, Carol Quirk, & Diane Ryndak, Eds. (2014) *Equity & full participation for individuals with severe disabilities: A vision for the future*. Baltimore: Paul Brookes Publishers. Pp. 57-74.

TASH² advocates deep change in typical service practice in its position statements on Community Living (2011) and Integrated Employment (2009). These statements, which are the most recent expressions of positions that reach back to the organization's early history, converge with The UN Convention on the Rights of Persons with Disabilities at Article 19 (Living Independently and Being Included in the Community), and Article 27 (Work and Employment), which adds the moral force of a world wide consensus of advocates, experts and politicians to the weight of international law in those nations who are party to the convention. Article 19 provides the right to choose where and with whom one lives with the personal assistance necessary to support inclusion and prevent isolation or segregation from the community. Article 27 provides the right to an opportunity to gain a living by work freely chosen in a labor market that is open, inclusive and accessible. As of this writing the US has signed but not ratified the Convention; however, these two Articles are largely consistent with long-standing US policy. In this chapter, "TASH values" is shorthand for these two results: people live included in community life as occupants of their own homes and workers in integrated jobs.

Progress toward realizing these rights can be marked by steadily growing numbers of people with severe disabilities securely inhabiting their own homes and filling contributing roles in the life of our communities, especially by holding jobs in integrated settings. Available measures of the current performance of US services to adults with developmental disabilities show how far we have to go to make TASH values real. Fewer than 30% of people with developmental disabilities receiving residential support in the US in 2010 lived in a place they or another person with developmental disabilities owned or rented (states report a range from 2% to 85%) (Larson, et. al, 2012) and 20% of all adults funded by US developmental disability services were in integrated employment (states report a range from 5% to 88%) (StateData.info, 2012). As well, the Council on Quality and Leadership reports that only about a third of 7,800 interviewed as part of their accreditation process perform the social roles they desire in their communities (CQL, 2010). None of these accounts speak specifically to the experience of people with severe disabilities and none says anything about the quality of people's home or work life, but they indicate the distance that services must travel in order to approach TASH values. (See chapter 15, Romer and Walker, for a description of the quality of the person-centered work required to support people to exercise choice in their home life).

In this paper, the term *system* refers to the network of policies and practices concerned with assistance to people with severe disabilities. This network is reproduced and changed by the interaction of people with disabilities and their families and allies, advocacy groups, service providers, administrators charged with managing the availability and quality of services, and legislators and courts as they take an interest in policy and resources for people with disabilities. Person-centered planning is one of many practices that each of these actors has adopted to change the system. The US Centers for Medicaid and Medicare

² TASH is an international organization that advocates for people with severe disabilities (www.tash.org).

Services has promoted person-centered planning in initiatives to shift the system's balance of long term care from institutions to community services since at least 2001 (NHPF, 2008). It has been central to policies aimed at transforming the system in England since 2000 (Routledge, Sanderson, & Greig, 2002). This chapter reflects on the functions person-centered planning has been assigned in system change efforts, the impact it has had, and lessons some of its practitioners have learned. The paper first reviews approaches and contexts for person-centered planning and then discusses what the implementation of person-centered planning reveals about the work of deep change when it is deployed as a part of three different change strategies.

Approaches and Contexts

Person-centered-planning figures in many efforts to reform systems from New York to New South Wales. The effectiveness of person-centered planning depends on the competence of facilitators, the adequacy of the match of a planning approach to the situation and the context in which planning is done.

Approaches

The table below identifies nine of the most frequently used approaches to person-centered planning. Though each approach has continually refined its practices over time, none is new (Lyle O'Brien & O'Brien, 2002). TASH's 1991 account of critical issues included a chapter that drew on ten years experience of person-centered planning, understood as the shared construction of stories that led to action for inclusion through an organized search for capacity and connection engaging people with developmental disabilities, their families and allies, and their communities (O'Brien & Mount, 1991). Over time, and to varying degrees, services and systems have adapted some of these practices and incorporated them into their reform efforts, often labeling the result person-centered plans. Throughout this history some practitioners have facilitated person-centered plans outside formally organized services to assist people and families who want something different from what the system currently offers them. Sometimes these efforts at the edge of the system have opened better ways to realize TASH values.

Some Common Approaches to Person-Centered Planning

There are many reasonable approaches to person-centered planning; these are the most common and the most commonly adapted to fit other's styles and situations.

Approach	Some Defining Features
Personal Futures Planning	<p>A person and their allies generate powerful images of a rich life in community that will guide a search for opportunities for the person to take up valued social roles & guide the development of service arrangements to support the person in those roles.</p> <p>Collects & organizes information by looking through a set of windows for change, which describe, for example, the person’s relationships, important places, things that energize the person, the person’s gifts & capacities, & ideas & dreams of a desirable future. (Mount, 2000)</p>
Pathfinders: Group Person-Centered Planning	<p>A group-of-groups (5-8 focus people with their families and allies) support one another to make, implement & revise individual Personal Futures Plans. Emphasis on taking action toward a desirable future in a community setting before seeking services. Mutual support grows with shared discoveries, questions & resources. Large group meets once to plan and then quarterly for at least a year to share learning & revise plans. Groups do their own facilitation and recording with guidance from large group facilitator. Commonly used when people share a life transition, such as moving from school to adult life. (Lyle O’Brien & O’Brien, 2002; Mount & Lyle O’Brien, 2002).</p>
Make a Difference	<p>Applies Personal Futures Planning as a way to build organizational capacity by developing learning partnerships between a staff member and a person supported aimed at developing a contributing community role for the person. (O’Brien & Mount, 2005)</p>
PATH	<p>A group process for discovering a way to move toward a positive and possible goal, which is rooted in life purpose, by enrolling others, building strength, & finding a workable strategy. (O’Brien, Pearpoint, & Kahn, 2010)</p>
MAPS	<p>A group process for clarifying gifts, identifying meaningful contributions, specifying the necessary conditions for contribution, & making agreements that will develop opportunities for contribution. (O’Brien, Pearpoint, & Kahn, 2010)</p>
Support Plans	<p>A way to mobilize all available resources to support a person’s citizenship. Based on six keys to citizenship: self-determination, direction, money, home, support, & community life. (Duffy, 2004)</p>
Essential Lifestyle Planning (ELP)	<p>Asks what is important to and for a person in everyday life. Specifies the support the person requires and person-specific ways to address issues of health or safety that balance what is important to the person & what is important for the person. Clearly identifies opportunities for improved assistance. Guides continuing learning about the person’s supports in a way that is easily understood by those who assist the person. (Smull & Sanderson, 2005).</p>

Approach	Some Defining Features
Person Centered Thinking Tools	A set of tools deconstructed from ELP, adopted through whole organization training, that develops the skills and behaviors necessary to think and work in a way that delivers person-centered support at the direct support, agency management & system management levels. (Sanderson & Lewis, 2012)
Facilitated Discovery	A systematic process of answering the question “Who is this person?” that generates a rich background for negotiating a customized employment role. Focuses particularly on people failed by typical methods for supporting employment (Callahan, Schumpert, & Condon, 2011).

Contexts

Two distinctions are important for understanding the differing contributions that person-centered planning can make to people living in their own homes and working in real jobs: the difference between working *in* a system and working *on* a system (Deming, 2000), and the difference between technical problem solving and meeting adaptive challenges (Heifetz, 1998). In some contexts, person-centered planning is a way to work *in* a system, implementing and improving procedures to perform system defined and regulated functions according to its rules. In other contexts, person-centered planning is a way to work *on* the system, revealing, testing and reshaping taken for granted rules and typical patterns of practice to suit new purposes. Working *in* the system makes sense when the system reliably produces assistance to people in their own homes and jobs. Working *on* the system makes sense when the system needs to embrace new purposes and innovate in order to realize TASH values. When the change necessary to support new purposes is a matter of correctly applying expert knowledge to a clearly defined, if complicated and demanding, problem, the change can be called *technical*. Deciding on new criteria and procedures for allocating self-directed individual budgets is a technical change. When new ways must be found to navigate uncertain territory and when a common understanding of purpose and ways of proceeding must be negotiated among people and organizations with different interests who face real losses, necessary change can be called meeting an *adaptive challenge*. Successfully closing a sheltered workshop and finding integrated work for its participants is an adaptive challenge because it departs from the familiar and demands the creation of new patterns of relationship and practice.

In practice, person-centered planning is a means to identify important future possibilities for a person and coordinate action that moves toward that future. The horizon of possibilities people identify and the extent of social learning they mobilize to move toward those possibilities varies with the context for planning. The table below outlines six contexts for person-centered planning in terms of the function person-centered planning is expected to perform, the main actors who

are intended to meet productively when the process performs its function, the initiator and owner of the process, and its intended benefits.

Contexts and Functions for Person-Centered Planning³

Function	Actors	Initiator	Intended Benefit
<p>I Service Planning</p> <p>Define outcomes Choose service provider (or self-management)</p> <p><i>Working in system. Technical change</i></p>	<p>System management engages person</p>	<p>System service coordination</p>	<p>Best fit between person and available service options and providers Best available service option at points of life transition (e.g. leaving school; leaving family home; moving from institution or nursing home) Good mix of paid & unpaid (“natural”) assistance Agreed, individually referenced measure of outcomes</p>
<p>II Support Planning</p> <p>Identify goals and specify service offerings</p> <p><i>Working in system. Technical change</i></p>	<p>System Management and Person engage Service Provider</p>	<p>System service coordination, typically as (part of) Individual Service Plan (ISP)</p>	<p>Mutually agreed goals, roles, procedures & schedules that reflect individual choice as much as possible within existing service offerings Regular, required update of goals & service offerings Provider appreciation of personal history and preferences.</p>
<p>III Service Improvement</p> <p>Improve quality of existing service offerings by adjusting the service provided to changing conditions and opportunities</p> <p><i>Working in system. Technical change</i></p>	<p>Service provider engages Person</p>	<p>Service provider or system reform process</p>	<p>Best fit between person and day to day routines Effective framework for identifying and pursuing opportunities for improvement Assistants and their managers better informed about the person → greater potential for good relationships</p>

³ In many cases “Person” includes family members.

Function	Actors	Initiator	Intended Benefit
<p>IV Customized Employment Discover the basis for negotiating employment <i>Working in system.</i> <i>Technical change</i></p>	<p>Employment Facilitator engages Person + Network</p>	<p>Employment Facilitator</p>	<p>Identification of interests and capacities that are of economic value to an employer as an integral part of negotiating customized employment.</p>
<p>V Innovation Through Partnership Generate innovation in service offerings: new roles supported in new ways <i>Working on system.</i> <i>Adaptive change</i></p>	<p>Service innovator engages Person</p>	<p>Service innovators seeking partners in learning through action or person negotiating a new service arrangement</p>	<p>Learning that produces more individualized supports fit to what could be for person + community Pathways to new and valued social roles Co-production of new service capacities through strong & sustainable relationships</p>
<p>VI Person & Family Generated Action-Learning Pursue a good life in contributing community roles <i>Working on system.</i> <i>Adaptive change</i></p>	<p>Person + allies engage community settings and, when necessary, support providers often with assistance of independent facilitation</p>	<p>Person + allies</p>	<p>Action arising from deeper understanding of person’s emergent future Pathways to contributing community roles Establishment of desired partnership with service system and providers (Best use of individual budget)</p>

Given the gap between what TASH values and what most people who receive services currently experience, person-centered planning will make its greatest contribution when those involved are working on the system to generate adaptive change. The difficulty of working this way means that the contribution of person-centered planning is profoundly contingent on the values, purposes, commitments, relationships and creativity of those who practice it.

Most person-centered plans happen as a matter of routine when people join the developmental disabilities service system, make a transition that calls for a change of services or meet requirements for an annual individual service plan. Context I, **Service Planning**, and Context II, **Support Planning**, modify or replace procedures for producing individual service plans. Both of these contexts are owned by the service system, at least to the extent that the terms of people's participation are governed by system rules and routines. Plans that result in the entry of new or modified goals in a plan maintained by a service coordinator are typical of these two contexts.

Context III, **Service Improvement**, includes intentional efforts to improve the quality of existing services by discovering more about how each person would want to live and adjusting services and policies to offer a better fit. Adjustments to group home schedules and the addition of new activities that better reflect resident's interests are common results of planning in this context. In these first three contexts, participants in person-centered planning are working *in* the system, aiming to negotiate the best possible fit between people's ideas about the way they want to live and whatever flexibility is available in existing service offerings and policies as they are.

Context IV, **Customized Employment**, aims to negotiate a personalized job role that matches what a person can contribute to a need with cash value to an employer. The discovery process described in Box 1 is the essential first stage in customized employment. Where this service is developed and funded its practitioners are also working in the system. Given the importance of customized employment to assuring people with severe disabilities access to employment, this is an especially important support offering for systems to develop (Callahan & Condon, 2007).

In Context V, **Innovation Through Partnership**, people in the system consciously choose to work on the system, forming co-productive partnerships with people, family members and community members and their associations, surfacing conflicting values and devising challenges to the assumptions that limit possibilities, and inventing new ways to support people in their own homes and valued community roles, especially inclusive education and employment. Listening to the educational aspirations of some of the people they support led Onondaga Community Living into partnership with Syracuse University to create ACCESS, an opportunity for inclusive university study (OCL, 2012).

Context VI, **Person and Family Generated Action-Learning**, is created by people and family members with their allies. It is often supported by skilled facilitators who act independently of any service (Lord, Leavitt & Dingwall, 2012). It can exist at the edge of the system, outside publicly funded disability services, or it can mobilize a partnership with service providers and system managers committed to innovation. Self-directed individual budgets multiply the resources available. Person-centered planning in this context can open new pathways to valued community roles. Skilled facilitation can create a deeper understanding of a person's identity and capacities, extend resourcefulness and initiate the creation of new forms of assistance.

Resources matter in all six contexts. To expect good results, there must be adequate investment in those who facilitate plans. Facilitators need well designed opportunities to learn whatever processes they use and improve their practice by systematically reflecting on their experience. They need adequate time and space to develop and maintain the sort of relationship with people and families that matches the task they are assigned. The richness and reach of plans depends on the resources those engaged in planning can steer. Levels of energy, good ideas about what is possible, connections and networks, skills, good character and good will in those who offer assistance make a difference, as does the accessibility of mainstream resources, the adequacy of public funds and the flexibility with which they can be configured, and the capacity of available services to offer personalized assistance. When resources are sufficient, person-centered planning can assist people to build strength of common purpose and guide and motivate learning by connecting with new people, trying new things and building on what works.

What Person-Centered Planning Reveals About System Change

Person-centered planning offers a perspective on change that reveals some of the ways our system responds to different change strategies and clarifies what it takes to make TASH values real.

Change Strategy 1: Adopt New Rules and Procedures for Individual Planning

This is the strategy for system change that currently affects the largest number of people. The logic is straightforward: a new approach to planning specifies goals and objectives and mobilize resources that drive change by specifying the outcomes that people want from the service system and instructing service providers to deliver it. There are at least four reasons that this strategy makes sense to managers and advocates who want change. First, practices associated with person-centered planning do improve people's experience of service when done capably. A chart that identifies a person's important relationships, a helpful format for discussion of what is important to a person and what is important for a person, a one page profile that serves as a summary introduction of the person to support workers, all carry face validity as components of a good individual plan and each draws attention to potential improvements in assistance. Second, person-centered planning enacts important values. The participation, voice and choice of people with disabilities and their families are central to most contemporary accounts of good practice. When an established approach to person-centered planning is ably performed, many people and families find the experience an accessible and engaging way to have their say about what they

want from services. Understanding and responding to the whole person is valued. Capable person-centered planning allows the construction of accounts of the person that include expressions of the person's strengths, capacities, desires and preferences, relationships and cultural identity. An evidence base for practice is valued. There is modest evidence (Claes, et al., 2010, Holburn, et. al., 2004, Robertson, et al. 2006) that associates person-centered planning with increased number and variety of community activities, greater choice of activities, expanded social networks, increased contact with family and friends with disabilities, decreases in challenging behavior, and satisfaction with life and services –meaningful results even though they may not include the results TASH values. Quality is valued. The prefix, “person-centered,” is sticky, signaling aspiration to quality in everything from nursing home regimens to self-managed individualized supports for a rich community life. Third, most people who experience well designed opportunities to learn about person-centered planning report enthusiasm for applying what they have learned and many identify specific positive changes in people's lives that have resulted from their training (Amado & McBride, 2002; Dinora, 2011; Lunt & Hinz, 2011). Fourth, since the human service reforms of the 1960's there has been a powerful but seldom questioned assumption that service behavior is controlled by individual plans. On this mechanistic assumption, changing a plan issues new instructions that service providers convert into outcomes that embody quality as defined by the system's mission.

These are good reasons to implement changes in the way individual plans are constructed and whose voice is heard in the planning process. But from the perspective of the field as a whole it seems that changing the individual planning process isn't sufficient to increase the number of people with disabilities who are supported in their own homes to live an engaged and contributing community life and gain at least part of their living from integrated employment. As it has worked out so far, the usual results of a system modifying its planning process by adopting person-centered planning discloses three challenges to realizing TASH's values: many systems simply lack the capacity to support people in their own homes and jobs and existing offerings tend to overpower new possibilities; competing values limit the practice of person-centered planning; and person-centered planning tends to slide from a relational process to a transactional procedure.

Most instances of person-centered planning are powerfully influenced by the state of available local services, and most local service systems have not reached a tipping point that routinely offers personalized supports to valued social roles rather than assistance based on pessimism about people's employability and grouping people on the basis of disability for daytime and residential services. A system with wide competence in customized employment will radiate a far different sense of possibility than one that is only familiar with less individualized and less powerful approaches to employment support. A system that organizes its residential support to people with severe disabilities around group homes will typically develop person-centered plans that select and refine what's offered in group settings. There is nothing nefarious here, though there is a danger. Most people plan within the horizon they can see and most planning conversations are powerfully shaped by what their owners take for granted. Most people interpret visions of possibility in terms of their current reality: group homes will be celebrated as people's own homes; group based community experience programs and sheltered workshops will be unchallenged as the outer limit of meaningful occupation for all but the exceptionally capable or connected person. The danger is that person-centered planning will mask the work necessary to overcome system defined and controlled housing and unemployment behind the belief that people have chosen these conditions through person-centered plans.

Even reforms that employ person-centered planning to guide expenditure of individual budgets struggle to overcome the inertia of "stick with what's most commonly available". Substantial numbers of people and families choose to invest their individual budgets in whatever available local services they can afford; others pool individual budgets and set up group living arrangements or day programs that differ little from typical services that underperform on TASH values; others individualize assistance but don't seek contributing community roles. This may happen because self-managing supports to a person's own home or integrated job is too difficult, or because the allocation of funds is too small or rules governing expenditure discourage people, or because those involved don't know what is possible. Whatever the reasons, the highly desirable policy of granting people discretion to direct their service funding is not a sufficient link between person-centered planning and the results that TASH values.

Person-centered planning can play a part in developing new opportunities for people to be at home and at work but its practice is constrained by competing system values. Accountability for establishing and maintaining the flow of funds for services often means that those charged with facilitating person-centered plans are also responsible for compliance with rules that, for example, set the timing of person-centered planning meetings and reviews and meeting requirements for documentation that can take considerable time and attention to system determined and audited detail. Those who facilitate may also be expected to enforce system or organizational policies that limit what can be offered or purchased (“The system can’t pay for that.”) or implement an organizational risk management plan (“We can’t allow that.”). Assuring that everyone in a system has equal access to a person-centered plan means that a proportion of planning meetings will happen with people who are not interested in change at the time their plan is due. Responsibility to make the most of scarce public funds often means that those responsible for facilitation have large and growing numbers of people to plan with and are charged to represent the system’s strategies for rationing in the planning process (“We only fund needs, not wants, and the cost effective way to meet your need is a group home and a group based community experience program.”). Growing numbers multiplied by compliance with increasing detail complexity means less time to build relationships and less time to join people in learning from action that springs from planning. This can undermine job satisfaction for those who facilitate and lead to increased turn-over, which leads to a lack or loss of personal knowledge and makes building trust with people and their families more difficult. While the ways that systems serve the values of accountability, equity, and economy badly need redesign, these competing values are legitimate and, maybe more important, sanctions for failure to comply shape not just the behavior but the consciousness of many staff assigned to do person-centered planning.

Capacity expanding person-centered planning arises from people’s free choice to work for change they care about. It is personal and relational. It generates knowledge that leads to positive action when people with developmental disabilities and their families trust those facilitating their plans with at least a glimpse of what really matters to them. This trust unlocks an energy that animates any effective person-centered planning process, a sense of identification with the person’s human desires for an ordinary life: greater control of daily routine, friends, an intimate

relationship, a real home of their own, a job and other roles that fit their interests and desires to develop and contribute. This trust personalizes and animates the planning process in ways that more detached discussions cannot. It calls participants in planning to step into the gap between deep desire and current reality and act together to move toward what matters most. Absorption of person-centered planning into the routine, required, professionally distanced bureaucratic functions of selecting, specifying and monitoring services substitutes transaction and compliance for relationship and shared purpose.

Change Strategy 2: Use Person-Centered Planning In Service Reform

Person-centered planning has been assigned an important part in deinstitutionalization and in whole system reform. The most careful studies of its effects, described below, report on its impact in these environments.

Deinstitutionalization. The Willowbrook Futures Project involved 40 people who remained in state institutions because the extent of their challenging behavior exceeded the willingness of service providers to provide the supports they required despite their membership in a class entitled by court order to community placement. The study (Holburn, et. al., 2004) divided the group in half to contrast the effects of person-centered planning with traditional interdisciplinary team planning and assessed participants' quality of life at eight month intervals for almost three years. Compared to those receiving traditional Individual Service Plans (ISPs), person-centered planning participants were significantly more likely to move into a community living arrangement designed specifically for them; their teams were more strongly mobilized to identify opportunities and solve problems than the ISP Planning teams were; and measures of autonomy, choice making, daily activities, and satisfaction showed greater improvement.

A second narrative account of the Willowbrook Futures Project documents the perspective of those planning with Hal, one of its participants. Those involved in person-centered planning with Hal had to go far beyond making a good plan to deliver on the desired results of a home chosen by Hal's parents and taking steps toward community employment (Holburn & Vietze, 2002). Power shifted as Hal's parents were actively engaged in problem solving and decision making about where and with whom he would live and from whom he would receive assistance. Risks grew and subsided as safe ways for Hal to be individually present in family and community life

were tested in action. An understanding of Hal's identity, interests and relationships provided a frame for applying technical expertise in behavior analysis to supporting activities and relationships that mattered to Hal. Innovations emerged: a community bridge builder, selected by Hal's parents, assisted him to try out a number of community roles in his new neighborhood before he moved from the institution; personalized funding for day services allowed him to escape long term placement in a disability-group space and routine that did not suit him when he tried it in favor of community activities that reflected his interests and engaged his competencies. This took persistence and sustained commitment to values-guided problem solving and skillful advocacy. Despite legal advocacy for the move, a high level of flexibility and cooperation from system authorities, additional funding to support innovation, and an unusually high level of competence in team members and consultants there were delays. It took two years from the time Hal's father located a suitable house until the house satisfied administrative requirements and Hal could move in. There were strong pulls away from the more individualized, person-directed supports identified through person-centered planning into the typical facility-based services. Hal gained access to a community life because his allies chose to use their power and competencies to move from working in the deinstitutionalization process to working on the process to personalize supports for him. They joined to assert and defend family responsibility for the selection of house and staff. The professionals involved persisted in creating the conditions that allowed them to deploy their expertise in behavior analysis in service of the arrangements identified as desirable for Hal through person-centered planning.

Whole system reform. In 2001, after wide consultation with people with intellectual and developmental disabilities, family members, service providers and professional experts, the English government adopted *Valuing People*, a policy that called for national transformational change in service delivery (Routledge, Sanderson, & Greig, 2002). The policy goal is to assure that people exercise their rights, experience independence, have the power of choice in the services and supports they receive, and are included as active participants in their communities. Overall, the change effort included new governance structures that provided people with disabilities and their families a key role in planning and decision making, carefully developed and authoritative guidance, a cadre of change agents and trainers, funds dedicated to the change,

and research and evaluation. Person-centered planning plays a central role in the transformation process.

The initiative to implement person-centered planning to guide and energize the implementation of *Valuing People* included a longitudinal study that followed 93 people from four diverse areas that demonstrated a common approach to person-centered planning in a way that allowed an assessment of the impact of person-centered planning on their lives (Robertson, et al. 2006). Large-scale training exposed a broad cross-section of people in each locality to the values and purposes of person-centered planning. Over two years, expert external consultants supported local organizations to develop policies, procedures and practices necessary to implement person-centered planning and provided intensive training (85-100 hours) and support to local person-centered planning facilitators and local managers. Despite top down requirements, local commitment, and extensive investment in training, impact was meaningful but modest. Person-centered planning demonstrated positive impact on measures of contact with friends and family, choice, and an increase in the number, variety and extent of community activities. Negative outcomes included greater staff perceived risk, more identified health needs, and more identified emotional and behavioral needs. These negative outcomes are likely the result of greater attention to health and mental health needs and greater presence in community being seen as potentially risky. Evidence of a significant impact on inclusive social relationships or paid employment was lacking. As the years have passed since the study's conclusion, the policy has been re-vitalized, person-centered planning remains an important element of the reform and people's use of personal budgets has grown significantly, but delivery on TASH values remains modest. In 2010 about 15% of people in funded residential services lived in their own home and about 7% of adults with any degree of intellectual and developmental disability worked regularly in either paid or unpaid jobs (the range across 152 local authorities is from 1% to 30% employment among people served) (Emerson, et al. 2012).

Valuing People has created many positive changes, but the tipping point to people's widespread access to their own homes and jobs is yet to come. The reform aimed at a significant shift in power toward people with disabilities and their families. Such a shift poses a substantial adaptive challenge. Those in management face growing uncertainty about how to be accountable

for prudent use of increasingly scarce funds, compliance with multiple agendas and standards set by central government, labor agreements and contractual relationships, and conflicting demands from those who see the move away from congregate, staff controlled services as a serious threat and those who see it as a moral imperative. Those people and families who are expected to take up power and make and manage support plans that meld system assistance with mainstream services and natural supports face new roles and responsibilities, often while practical supports to these responsibilities are either lacking or in their early stages of development and mainstream services remain inaccessible. A centralized change effort, pushed from toward the top of government, has the advantage of some authority to drive the change, but its medium is technical change through rule, monitoring, guidance, expert technical assistance and training.

Transformation can only happen to the extent that local people are willing and able to do the work of moving together through adaptive challenges. Overemphasis on technical change and transactional strategies severely limits the impact of person-centered planning on TASH values.

Change Strategy 3: Person-Centered Planning Guides Purposeful Innovation

The first two change strategies assume that the capacity to support people in their own homes and jobs exists, either in the system as it is (Strategy 1) or as a best practice technology that can be assimilated as part of a reform through detailed requirements, training and technical assistance (Strategy 2). In each case, it is as if person-centered planning is assumed to work by assisting a consumer to place an order that directs available resources to deliver what is agreed in the plan. Like a good waiter who advises on the menu, accurately transcribes what a diner wants and negotiates special requests with the kitchen, the person-centered planning facilitator mediates between consumer and provider.

The third change strategy suspends the assumption that existing resources can do what is necessary and re-frames the task as generating innovations that emerge in particular individual circumstances. Innovation guided by TASH values detects new possibilities, crosses boundaries and mobilizes diverse resources in order to open and sustain new opportunities for people to be at home and at work. This process of person-by-person innovation differs in both process and content from routinely placing people in disability provider managed supported apartments or placing a person on a pre-developed job. In this frame, people, families and service providers

join their resources and organize themselves as innovation generators (Meissner, 2013). Innovations grow through a process of social learning in partnership with people and their families and allies and those community members who offer housing, jobs and other opportunities for membership, engagement and contribution. Partnerships design, negotiate, acquire, update and improve the means to create and sustain people in contributing roles at work and at home as their life circumstances change.

The whole system's task is to generate an ecology of social innovation which makes it easier to form partnerships and act resourcefully. In this environment, person-centered planning provides a forum to negotiate and renew the partnership and the highest purposes of the partners, hold the knowledge created as partners try new things, and support the design of next steps. Things almost never work out as anticipated and experience often modifies people's interests, so planning is a record of intentions and designs and a source of prototypes –good tries to be improved through further learning in community settings– not a blueprint that guarantees attainment of preset individual goals. Tying people to measurable goals a year away is unnecessary because the process of innovation involves multiple adjustments (Kay, 2010) In an ecology of social innovation, accountability is oriented toward higher purpose and outcomes can be tracked on a population base: what proportion of people receiving public support are secure in their own homes with individualized supports; what proportion of people are earning in integrated jobs and what is the trend and distribution of their earnings.

People and their families and allies and partners are capable of generating and self-managing the innovations necessary to pursue a good community life when they have sufficient capabilities: good connections to a diverse network of relationships, working links to local resources and associations, opportunities to develop knowledge and skills (including knowledge of what is possible for people with severe disabilities), assets (greatly aided by control of a flexible individual budget of public money to pay for assistance and accommodation), and a sense of self-efficacy. Independent facilitation that supports planning, opening opportunities, and organizing assistance multiplies the number of people and families that can self-manage their assistance (Lord, Leavitt, & Dingwall, 2012) and so do family groups who support one another to plan, develop individual opportunities and learn together from their efforts (Mount & Lyle

O'Brien, 2002). Educational opportunities for people and families to deepen their understanding of and desire to experience what TASH values and learn about how others realize these values positively influences demand and advocacy. Reflection on organizational journeys to partnership with people and their families identify some of the adaptive challenges that are likely to arise (Inclusion Press, 2008; Meissner, 2013; Mount and VanEck, 2011).

In most places, systems currently invest most of their resources in operating and attempting to control the quality of group living arrangements and congregate alternatives to real employment. There are significant costs sunk in buildings. There is attachment to approaches to services and enabling administrative policies and procedures that are irreconcilably at odds with TASH values. The loyalty and advocacy of many people and families and service providers when these insufficient forms of service are threatened complicates the adaptive challenge. As more service providers choose to make the journey from serving groups of people with developmental disabilities camped out at the margin of community life to supporting people in their own homes and jobs as engaged and contributing citizens, more people and families will be able to form productive partnerships with them and redesign their offerings.

The results that TASH values cannot be delivered to consumers. Real homes and real jobs must be co-created by active citizens working in partnership to make good use of system and community resources. Currently there is a powerful assumption, embedded in the administration of system funds and the expectations of many families, that responsibility for a good life can be fully delegated to service providers. This expectation needs to be re-negotiated in recognition of the need for partnership.

In most places, a very large number of people with severe disabilities live with the daily practical support of their families and family investments have been critical in generating many innovative living arrangements. An understanding of person-centered planning that ignores the person-in-family, perhaps from a desire to respect the person's autonomy, risks distorting the realities of interdependency in every person's life. Missing the opportunity to provide a space in which all of those who are interdependent with a person can search for what they want to co-create robs the person of powerful emotional and practical resources. Holding the inevitable

conflicts among people as they search for their next steps forward is an essential contribution of person-centered planning facilitators.

There is a continuing tension between demands for stability and demands for innovation. Stability requires maintaining financial viability; compliance with system requirements; improving quality within the limits of existing, group based services; and satisfying those who choose not to enter partnerships to seek real homes and real jobs. Innovation requires investing time in building partnerships by operating from a place of generative awareness; deepening understanding of values; designing, learning from and redesigning multiple individualized forms of support; growing new methods of appreciating and safeguarding quality; creating new roles organizational structures and alliances to support innovation; dealing fairly with staff's conditions of employment; redirecting funds and negotiating money and regulatory room for innovations from funders and monitors; and developing access to additional community and mainstream resources. The organization must find a form that allows it to be ambidextrous, dealing creatively with competing commitments and attending to both the necessities of stability and the desire for innovation (Meissner, 2013).

There are real losses; not everything can be win-win. Familiar routines, procedures expectations and assumptions must change. Buildings become redundant. Uncertainties grow and predictability declines, at least for the time of transition. Ways of exercising power that may have been taken for granted need to shift. To deal effectively with this, managers and growing numbers of staff, family members and people with disabilities need to develop their leadership capacities and act as instruments of change. This means developing the ability to engaging self and others in sensing possibilities, mobilizing action, learning from action, and sustaining what works. The commitment to operate from a generative level of awareness animates both person-centered planning and the organization's strategic and tactical plans.

It isn't enough to focus exclusively on individual strategies to assist a person to take up the roles characteristic of secure and valued citizen by addressing the question "How can this person's interests and capacities make a positive difference in this community?" It is also necessary to play a constructive role in building inclusive communities by addressing the

complementary question, “How can we design our social arrangements so that everyone is welcomed as a contributor?”

As more organizations choose to move into the gap between their current structures and the ecology of innovation necessary to move toward TASH values, stronger contexts for person-centered planning emerge. But good efforts can be threatened, even crushed, because governments under economic or political pressure retain the power to cut or constrain necessary resources in ways that may overwhelm a social innovator’s adaptive capacity. Even as the rights of people with severe disabilities gain greater recognition, to the degree that they rely on public resources, force of these rights remain contingent on administrative structures that continue to (unconsciously) reproduce devaluing assumptions about their capacities and even the worth of public investment in their lives. This is why a diverse network of strong and personally committed allies guided by a person-centered planning process and holding the search for the valued roles of worker and neighbor remain a person’s best safeguards.

Conclusion

In any context and under any change strategy described here, competent person-centered planning can make a positive contribution to what people with severe disabilities experience. The depth of systemic and societal change necessary to create wide and reliable pathways to homes of people’s choice and integrated jobs means that person-centered planning will only serve those valued outcomes when people are willing to partner to create new strategies and structures to act together. The work of articulating broad values, enshrining them in law and policy, and demonstrating their feasibility at a small scale is mostly done, though these victories remain vulnerable to regression. The adaptive work of creating new roles and relationships for significantly more people with severe disabilities remains a critical field for innovation.

References

- Amado, A. & McBride M. (2002) Realizing individual, organizational and systems change: Lessons learned in 15 years of training about person-centered planning and principles. In S. Holburn & P. Vietze, Eds. *Person-centered planning: Research, practice and future directions*. Baltimore: Paul Brookes. Pp. 361-378.
- Callahan, M. & Condon, E. (2007) Discovery, the foundation of job development in Griffin, C., Hammis, D. & Geary, T. (Eds.) *The job developer's handbook: Practical tactics for customized employment*. Baltimore: Paul Brookes Publishing.
- Callahan, M. Shumpert, N. & Condon, E. (2011). *Discovery: Charting the course for employment*. Gautier, MS: Marc Gold & Associates.
- Claes, C., Van Hove, G., Vandevelde, S., van Loon, J. and Schalock, R. (2010). Person-centered planning: Analysis of research and effectiveness. *Intellectual and developmental disabilities* 48, 6: 422-453.
- CQL (2010). *Measuring what really matters. Data Quarterly #11*.
- Deming, W.E. (2000). *Out of the crisis*. Cambridge, MA: The MIT Press.
- Dinora, P. (2011) *Becoming a person-centered organization: Evaluation results 2009-2010*. Richmond, VA: Partnership for People with Disabilities, Virginia Commonwealth University.
- DoH (2007). *Valuing people now: From progress to transformation*. London: Department of Health.
- Duffy, S. (2004). *Keys to citizenship: A guide to getting good support services for people with learning difficulties*. Birkenhead, England: Paradigm.
- Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S. Evison, F. and Glover, G. (2012). *People with learning disabilities in England 2011: Services and supports*. Lancaster: Improving Health and Lives: Learning Disability Observatory.
- Heifetz, R. (1998). *Leadership without easy answers*. Cambridge, MA: Harvard University Press.
- Holburn, S., Jacobson, J., Schwartz, A., Flory, M., & Vietze, P. (2004). The Willowbrook futures project: A longitudinal analysis of person-centered planning. *American Journal on Mental Retardation*, 109, 63-76.

- Holburn, S., & Vietze, P. (2002). A better life for Hal: Five years of person-centered planning and applied behavior analysis. In S. Holburn & P. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 291–314). Baltimore: Brookes.
- Inclusion Press (Producer). (2008). My life, my choice: stories, struggles and successes with person-directed living. [DVD]. Available from www.inclusion.com/dvdmylife.html.
- Kay, J. (2010). *Obliquity: Why our goals are best achieved indirectly*. London: Profile Books.
- Larson, S., Ryan, A., Salmi, P. Smith, P.D. & Wuorio, A. (2012) *Residential services for persons with developmental disabilities: Status and trends through 2010*. Minneapolis: University of Minnesota Institute on Community Integration.
- Lord, J., Leavitt, B. & Dingwall, C. (2012) *Facilitating an everyday life: Independent facilitation and what really matters in a new story*. Toronto: Inclusion Press,
- Lunt, J. and Hinz, A. Eds. (2011) *Training and practice in person centred planning: A European perspective*. Download from <http://tinyurl.com/7tbvet8> accessed 2 June 2012
- Lyle O'Brien, C. and O'Brien, J. (2002). The origins of person-centered planning. In J. O'Brien and C Lyle O'Brien, Eds. *Implementing person-centered planning: Voices of experience*. Toronto: Inclusion Press. Pp, 25-57.
- Lyle O'Brien, C. and O'Brien, J. (2002). Large group process for person-centered planning. In J. O'Brien and C Lyle O'Brien, Eds. *Implementing person-centered planning: Voices of experience*. Toronto: Inclusion Press. Pp, 275-284.
- Meissner, H. (2013). *Creating blue space: Fostering innovative support practices for people with developmental disabilities*. Toronto: Inclusion Press.
- Mount, B. (2000) *Person-centered planning: Finding directions for change using personal futures planning*. Amenia, NY: Capacity Works.
- Mount B. & Lyle O'Brien, C. (2002). *Building new worlds: A sourcebook for students with disabilities in transition from high school to adult life*. Amenia, NY: Capacity Works.
- Mount, B. and VanEck, S. (2010). *Keys to life: Creating customized homes for people with disabilities using individualized supports*. Troy, NY: The ARC of Rensselaer County (Contact SVanEck@renarc.org)
- NHPF (2008). CMS Programs for self-directed services: Independence Plus and the DRA: Historical reference. Washington, D.C. National Health Policy Forum /www.nhpf.org/library/handouts/CMS_factsheet10-09-08.pdf accessed 31 May 2012.

- O'Brien, J. & Mount, B. (2005). *Make a difference: A guidebook for person-centered direct support*. Toronto: Inclusion Press.
- O'Brien, J. and Mount, B. (1991). Telling new stories: The search for capacity among people with severe handicaps. In L. Meyer, C. Peck, and L. Brown, Eds. *Critical issues in the lives of people with severe disabilities*. Baltimore: Paul Brookes Publishing. Pp. 89-92.
- O'Brien, J., Pearpoint, J. & Kahn, L. (2010.) *The PATH and MAPS Handbook: Person-centered ways to build community*. Toronto: Inclusion Press.
- OCL (2012) Access http://www.oclinc.org/college/college_index.htm accessed 14 December 2012
- Robertson, J., Emerson, E., Hatton, C., Elliott, J., Macintosh, B., Romeo, R. and Knapp, M. (2006). Longitudinal analysis of the impact and cost of person-centered planning for people with intellectual disabilities in England. *American Journal on Mental Retardation* 111, 6: 400-416.
- Romer, L. and Walker, P. (this volume). Evolving narratives in community living.
- Routledge, M., Sanderson, H. and Greig, R. (2002). Planning with people; the development of guidance on person-centered planning from the English Department of Health. In J. O'Brien and C Lyle O'Brien, Eds. *Implementing person-centered planning: Voices of experience*. Toronto: Inclusion Press. Pp, 373-396.
- Smull, M. & Sanderson, H. (2005), *Essential lifestyle planning for everyone*. Stockport: HSA Press.
- StateInfo.data www.statedata.info accessed 5 June 2012
- TASH (2011). *TASH Resolution on choice and community living*. <http://tash.org/advocacy-issues/community-living/> accessed 8 June 2012.
- TASH (2009). *TASH Resolution on integrated employment*. <http://tash.org/advocacy-issues/community-living/> accessed 8 June 2012.

