

Closing the Gap between Vision and Reality:
Building Person-Centered Organizations

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Part 1 Defining the Core Challenge

The Values Change

Perhaps no field of human services has experienced as deep a sea change in its values base as has developmental disabilities. Wolfensberger, O'Brien, Mount, Taylor and others, as early as the 1970's, repudiated the predominant medical-institutional model and supplanted it with person-centered values and approaches. The ideological leaders of the field were clear that a facility-based continuum model, even though "community-based", was dysfunctional and static—in effect, perpetuating the institutional model for people with disabilities. Person-centered supports were defined as relevant to people regardless of how much assistance a person might need. The vision was unequivocal on this point: *The institutional landscape, including all facility-based models, was to be completely converted to person-centered supports to lives at least as good as those of respected citizens.*

The person-centered values base was perhaps best summarized in John O'Brien's *Five Accomplishments*, first published in *What's worth working for?* in 1988:

- Community Presence
- Community Participation
- Choice
- Contribution
- Valued Roles

The "Discovery" of the Direct Support Professional (DSP)

In addition to person-centered values, a new vision of direct support professionals (DSP's) and their roles emerged in the early 90's to challenge the medical institutional model. The traditional roles of the DSP as sitter, attendant and skills trainer had grown out of the view of people with disabilities as both deficient and incompetent. The person-centered values

base had at its core the experience of people with disabilities as fully human—as *us* not *them*.

The view of people with disabilities as people first engendered the role of the DSP as “maker of a difference” or “friend with a purpose” on the journey to lives at least as good as respected citizens.

What has become increasingly clear over the past decade is that the quality of the *relationship* between the DSP and the person-supported is the foundation for providing quality support and achieving person-centered outcomes, especially for people with substantial support needs. Person-centered approaches are rooted in as deep a knowledge of the person as is attainable. The DSP is the person within any agency context who knows the person best, and in relationship with the person supported, comprises the foundation for creating relevant and effective supports.

The Values Changed. Why didn't the lives?

In 2002, the Human Services Research Institute and the National Association of Directors of Developmental Disabilities Services conducted a national survey of 5000 family members and people with disabilities seeking to assess the achievement of these outcomes. The results were as surprising as they were disappointing: Most people with significant support needs had no relationships with people without disabilities. 80% of people with developmental disabilities were unemployed. People with significant disabilities seldom chose where they were living or with whom. Few people had achieved respected roles as workers, friends, spouses, lovers, members of associations or churches.

In contrast to the disappointing results of outcomes surveys, interviews with staff over the past decade consistently display a widely shared values base, rooted in the Five Accomplishments, often even using O'Brien's language. One thing is clear: Actors on all levels within the disabilities community have embraced person-centered values.

The pressing question then is: Why aren't those values being realized in the lives of people with disabilities?

The Values changed. The Organizational Model did not.

Despite the prevalence of person-centered values, the medical-institutional organizational model proved remarkably resilient and remained a potent obstacle to attaining person-centered outcomes: The defining patterns of the model include:

- A top-down and segmented hierarchy
- The marginalization of direct support staff in roles as sitters, attendants, aides, and skills trainers.
- The exclusion of DSP's and people supported from empowered roles in supports planning, design and implementation.
- Mid-level staff formulate and write plans of support, assign plan objectives to DSP's and monitor DSP's in carrying out the objectives.
- Plans of support focus on health, safety and skills training.
- Plans of support do not focus on the Five Accomplishments

The Key Disconnection: Knowledge from Authority

Typically, mid-level managers formulate and write support plans, with little or no input from DSP's. Mid-level managers, who do not know the people supported nearly as well as the DSP's involved, nonetheless have the authority to chart the person's life direction, in time frames for often as long as a year at a time. The DSP's, who possess the key knowledge base, the knowledge of the person gained in daily relationship, have little or no authority in shaping the life plan, the support design or plan implementation. DSP's are not viewed as doing intelligent work; the intelligence of the organization is ascribed to the mid- or executive-level. DSP's are then assigned the task of implementing plans they have had no role in developing and are monitored by mid-level managers regarding the accomplishment of plan "objectives." The separation of knowledge from authority leads to two major outcomes:

- 1) Plans are not personalized and have often become standardized litanies of health, safety and skills.
- 2) The DSP is cast in a passive role, being defined as little more than a pair of hands, carrying out tasks with slight opportunity to develop internal commitment or motivation. Indeed the most frequent criticism of the DSP is that he or she is unmotivated.

From a New Way of Thinking to a New Way of Organizing

In 1987, the Minnesota Developmental Disabilities Council published the nationally influential booklet, *A New Way of Thinking*. With its emphasis on person-centered thinking and a penetrating critique of the facility-based continuum, the “new way of thinking” became the motto for deep change in the late 80’s and 90’s. The field of developmental disabilities has indeed been remarkable for its embrace and internalization of the person-centered mental model.

What has become vividly apparent in the past decade is the imperative to develop and internalize a person-centered *organizational model*. Without deep organizational change, the person-centered mental model is largely reduced to rhetoric, while the gap between values and reality grows wider.

In the absence of an understanding of the internal organizational barriers to person-centered outcomes, alternative and inaccurate analyses have emerged to explain this glaring phenomenon of non-accomplishment: People are too “disabled” to live typical lives. The community is too rejecting to support inclusion. Providers are too incompetent and greedy to become person-centered. Parents are too controlling. DSP’s are too unskilled and unmotivated to support life changes that matter.

Probably the analysis which has most currency is a simplistic interpretation of Self-Determination, which assumes: The provider system cannot be reformed; system change should, therefore, seek to phase out or greatly reduce the role of formal provider organizations; federal and state dollars should be reallocated from providers to people with disabilities, who will then hire and manage their staff with support.

Given that more than 90% of state and federal allocations go to provider organizations, this approach to system change seems on its face to be unrealistic. But the central flaw is the assumption that provider organizations cannot become person-centered. Indeed, unless person-centered provider change accompanies the empowerment of families and individuals, the “customer” will have resources but be unable buy supports which foster inclusion and personal freedom.

Part 2 The Partnership for Excellence: A New Way of Organizing

Since 1997, Associates for Community Entry (ACE) has worked with more than 30 provider agencies (residential, vocational and support coordination) throughout Louisiana with a focus on creating person-centered organizations. The Partnership for Excellence project has integrated best practices in developmental disabilities and organizational development to create a person-centered organizational model as a *network of direct support-led, person-centered teams*.

Person-Centered Teams: Organizing for Real Life

Person-centered teams are the structural foundation of the person-centered organization. The teams comprise two to six direct support professionals, a mid-level professional and the focus person whom they support. A mid-level professional, who supports several teams, facilitates both a person-centered plan and periodic reviews of the plan. The team is empowered both by authority and resources to develop and implement the plan.

Person-centered teams are effective for three reasons:

- 1) The team, coupled with the person-centered planning process, builds on and amplifies the inspiring force of *identification*. At the core and origin of the medical institutional model is the failure to identify with people with disabilities—to experience people as essentially different from “us” or as Martin Luther King said, to “thing-ify” people. The central role of the person-centered facilitator is to support team members in identifying with the focus person—to experience on a deep level that “they” are “us.” DSP’s, in the absence of opportunities to identify, will lack the conviction essential to supporting people in lives like “ours” and will continue to support lives for “them”—including control, congregation and personal isolation.

Identification is able to shatter stereotypes and inspire team members to take action that will make a difference. The team approach amplifies and intensifies the impact of identification on team members and the focus person.

- 2) Person-centered values are about supporting real life, with a focus on roles and relationships. People, who have been excluded from real life, need opportunities to learn how to be “us”—to learn how to get a job, be a lover, a spouse, a homemaker, a friend, a neighbor, a church member. The most important contribution DSP’s make to a person with a disability is to lend their *life experience*. DSP’s have Ph.D’s in life experience, which is virtually never tapped by the medical-institutional model’s focus on health, safety and skills. When the focus is on real life, DSP’s are able to exercise leadership and be remarkably creative.

The use of a team approach connects the focus person to a range of life experiences, a situation which amplifies and intensifies the learning context for the person with a disability.

- 3) The person-centered team supports the focus person in being able to identify with team members. Just as people without disabilities have stereotypes of people with disabilities, people with disabilities have powerful stereotypes of people without disabilities. In the film, *I am Sam*, Sean Penn’s character Sam, a young parent with an intellectual disability, at one point cries out to his lawyer in utter despair and terror that the court will take away his daughter:

You were born perfect and I was born like this. People like you don’t know what it’s like to try and try and never get what you want!

His stereotype of people without disabilities is immobilizing him, because only “perfect” people can act effectively. Sam’s lawyer Rita, played by Michelle Pfeiffer, exclaims:

People like me feel lost and little and ugly and dispensable. People like me have husbands who are screwing someone far more perfect than me. People like me have sons who hate them. Every morning I wake up and feel I’ve failed. I’ll never be enough!

Sam holds her and says, *You’re much more than enough. Rita, you’re much more than enough.*

A person-centered team is about such deep and mutual relationships among “friends with a purpose.” As a network of interdependent relationships, the team supports staff and the focus person to shatter immobilizing and harmful stereotypes. The team and the focus person are engaged in a real life journey in which everyone’s gifts and limitations are recognized.

The team approach supports the focus person in experiencing identification with several team members, which amplifies and intensifies the experience that we are all “us” and therefore all able to live lives of meaning, contribution and imperfection.

This combination of mutual identification, shared life experience, collaboration and person-centered values creates an almost unstoppable force for changes that matter in the lives of people with disabilities.

The Person-Centered Organization: Shared Authority and New Roles

In the person-centered organization, authority and accountability are dispersed throughout the network of person-centered teams, in contrast to the traditional hierarchy, where position or level defines, roles, authority and accountability. *What identifies the person in a person-centered organization is his or her role in relationship to the person supported.* The issue is not position or title but what authority, information, resources and accountability does this team or team member require in order to support life changes that matter.

One of the deepest role changes, as described above, is that of the DSP—who becomes an empowered planner, actor, maker of a difference and leader within a person-centered team.

The dispersal of authority and accountability for life planning and plan implementation also necessitates deep role change for staff described as mid-level managers. The mid-level manager within the traditional bureaucratic organization writes plans of care, assigns plan-generated tasks to DSP’s and monitors DSP’s in task completion. The role is bureaucratic, top-down supervision.

In the person-centered organization, the role of staff, who are currently defined by being in the middle of the hierarchy, is identified as both a capacity-building resource to the team and an active partner in the team's work. That role is perhaps best summarized by his or her function as the person-centered facilitator, a role which supports the learning and leadership of DSP's and the person supported. He or she both supports the team and plays an active role in implementing the plan, especially by accessing needed resources or information, including training and technical assistance, and recommending agency policy changes.

Because he or she works with several person-centered teams, the new role might well be described as facilitator-coordinator, defined by his or her relationship to the focus person, the person-centered plan and the teams, not by level or position in a hierarchy.

A major challenge, in what amounts to a substantial redistribution of authority, is the role of the facilitator-coordinator in supporting the authority and accountability of the team. The team is the decision-making structure. If team members experience difficulty in making decisions or taking responsibility, the facilitator-coordinator seeks to affirm the authority and accountability of the team, at the same time refusing to retreat into the role of supervisor.

The executive director or executive team is key to initiating and sustaining the dispersal of authority and accountability, which is at the core of creating the organization as a network of person-centered, direct support-led teams. Executives develop policies and procedures to support the team structure including reward and opportunity structures, which incentivize teamwork over individual effort. Recognition focuses on team performance: It's no longer "employee of the quarter" but "team of the quarter", displayed in the reception area.

Executive leadership attends some team meetings, both to demonstrate support but also to learn. *Person-centered teams are where the vision and mission of the organization is unfolding.* Vision development is a global process: executives learn from teams and teams learn from executives through a circular dialogue which enriches and deepens the organizational vision.

A Note on the Voices and Roles of People with Disabilities in Person-Centered Organizations

Just as people do speak for themselves, leaders are needed to encourage others to listen. In a curious way, good listening is proactive self-advocacy. If people are heard and understood as a matter of course, they do not need to speak up in a deliberate sense. Being heard protects, for example, equal educational opportunity, universal access, freedom from stereotyping and the lives of people unwanted because they have disabilities.

(Michael Kendrick, "Leadership Challenges", P. 368 in *Individualized Supports*, Brookes: 1994)

What does it mean for the person with a disability to be at the *center* of the organization? As Kendrick emphasizes, effective self-advocacy hinges on effective listening. One key role of the person-centered organization is to create diverse formats where the voices of people with disabilities may be amplified and heard:

- Person-centered planning is the primary listening and learning forum: The agency from bottom to top is accountable for achieving the outcomes generated by listening to people with disabilities within these life planning sessions.
- People with disabilities participate on agency boards of directors and are supported in having a contributing role.
- People with disabilities are featured trainers within the agency's staff training program.
- People with disabilities participate in hiring staff and have the decisive voice in hiring and firing person-centered team members.
- The organization builds the leadership of people with disabilities in the broader community through support to participation in the self-advocacy movement or acting as statewide leaders by becoming, for example, trainers in the Partnership for Excellence.

A Note on the Role of Service Coordination

The role of the service/support coordinator or case manager in relationship to person-centered organizations represents a much debated choice point nationally. The typical activities of service coordinators in the current Title XIX environment are the production of fundable *plans of care* and the

demonstration of compliance with Title XIX regulations. Such plans of care and compliance activities serve the function of generating claims on Title XIX funding and of assuring the ongoing flow of federal dollars.

The choice point for any service system which seeks to be person-centered is:

Should the claims processing and compliance functions of service coordinators be driven and defined by person-centered teams and planning as a valid and indispensable means to access resources for person-centered plans?

Or should service coordination continue to be defined as a monitoring function which tracks compliance with the medical-institutional standards and regulations of funding and regulatory agencies and which accesses resources with no relationship to person-centered planning.

In the former scenario the person-centered team within the provider agency develops the person-centered plan; the role of the service coordinator is then to write a plan of care *based on the person-centered plan*, which demonstrates compliance and is, therefore, fundable. The monitoring function is one of assuring plan fundability, a process in which the service coordinator acts in partnership with the person-centered team. In this option, service coordinators are not defined as planners but as resources to the planning team in writing a fundable plan based on the planning activities of the person-centered team—the focus person and his direct support staff.

In the absence of an essential relationship to the person-centered team and plan, service coordination functions as top-down surveillance in relationship to the standards and regulations of funding and regulatory agencies. Kendrick once described the latter scenario as “quality avoidance”, so far are service coordination activities removed from knowledge of the person or an effective support design.

The shift from surveillance *over* to partnership *with* person-centered teams is a deep and challenging change and choice point for any support system.

A New Way of Organizing: The Alignment of Person-Centered Roles

The Organizational Framework

- The quality of the relationship between people with disabilities and direct support professionals is the foundation for quality support.
- The primary actors in planning are people with disabilities and direct support professionals functioning as empowered person-centered teams.
- People with disabilities are supported in leadership within person-centered teams, within the agency and throughout the state.
- Mid-level managers are resources, coaches and facilitators to the person-centered teams, who focus on shifting authority, resources, information and accountability to the teams.
- The role of the executive director or executive team is to create the context for developing a compelling vision of the organizational future—as a network of direct support-led, person-centered teams—rooted in feeling and thinking in terms of changes that matter in the lives of all the people supported.
- Service coordinators are in partnership with person-centered teams and act to access funding and other resources for team-developed, person-centered plans.

When staff roles are defined in relationship to the person and by person-centered values and organization, when, in short, there is person-centered alignment, powerful forces for deep change are set in motion. Such organizational changes and the commitment and creativity of innumerable actors are what it will take to close the gap between our values and the realities of life lived by people with disabilities.