

DISSENT FROM CONSENSUS

A Response to the NQF Person-Centered Planning & Practice Interim Report

The National Quality Form (NQF) has been funded by the Federal Administration on Community Living (ACL) and the Centers for Medicare and Medicaid Services (CMS) to provide a consensus based definition of person-centered planning, outline a core set of competencies for facilitators, and identify the ways systems can support person-centered planning which includes a framework for quality measurement within person-centered planning.

NQF has drafted an Interim Report and is seeking public comment. You can download the report and submit comments at http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx

As the title of this paper suggests, for reasons we describe, we have to stand aside from the consensus proposed in this report.

Our sense is that trends in the health care industry will result in system adoption of definitions and practices like these, if in revised form. We can't imagine how to stop the train carrying medical-administrative mindsets and measurements even deeper into the lives of people with disabilities (though we are eager to hear other's ideas about how we might). Our confidence remains where it has been for the past generation, in those people and organizations who find ways to make as much space as possible to co-create the way to more of a good life with people, families and fellow citizens.

We did decide against letting this report pass unremarked. Our emotional responses to the denaturing of person-centered planning that we see expressed in this report energized thoughts and discussion that are summarized in the pages that follow.

We intend this as a simple statement of differences in understanding rather than what would amount to a request to rethink the project as a whole.

We share this with the idea that our reflections might interest you. Please feel free to make use of it as you choose.

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Carol Blessing, Marcie Brost, Beth Gallagher, Kirk Hinkleman, Peter Leidy, Beth Mount & John O'Brien

Carol Blessing has facilitated person-centered processes and system change for over 30 years. She is the author and curator of the landmark online international community of practice *Citizen-Centered Leadership*, (ccllds.org). She co-developed *A Framework for Planning*.

Marcie Brost is the Executive Director of the Wisconsin Developmental Disabilities Network (ddnetworkinc.org) and the Coordinator for Citizen Network USA (citizennetwork.org). Marcie's family includes her 40 year old son, André, who experiences intellectual and physical impairments. She has spent over 45 years in the field and co-created the *Getting To Know You* method of person centered planning.

Beth Gallagher is the CEO of Life Works Supported Living Services in San Diego, CA (lifeworks-sls.com). She has worked for over 33 years to create customized supports for persons labeled with I/DD. She is the co-creator of the *Liberty Plan*, a framework to guide person centered planning.

Kirk Hinkleman (lifeworks-sls.com) has worked in human services for 21 years. Co-author of *Intentional Teaming: Shifting Organizational Culture*, and co-creator of the *Liberty Plan*, he is committed to realizing the highest potential in people while dismantling archaic structures, systems and thinking and finding valued social roles in neighborhoods and communities with people who experience disabilities.

Peter Leidy provides workshops and consultation for organizations and families in such areas as inclusion, relationship-and team-building, stress reduction, and finding (and keeping) paid supporters (peterleidy.com). For 19 years he worked for Options in Community Living, a supported living agency in Dane County, WI, where his work included direct

Person Centered Planning encompasses many different perspectives and practices. We don't claim to define one right way. We do claim a voice that rises from our experience. Among us, we have worked from 21 to 51 years in support of people with developmental disabilities. Our appreciation of the possibilities and practicalities of building more just and inclusive communities continues to grow. Our work includes designing methods –Personal Futures Planning, MAPS, PATH, A Framework for Planning, Getting to Know You, The Liberty Plan, and many ad hoc methods to meet the demands of particular projects; supporting others to learn and practice these methods; facilitating planning with hundreds of people and families; and assisting dozens of organizations to develop good responses to the many demands for innovation that result from good person-centered planning.

We dissent because we do not recognize our own lived experiences in the Interim Report. We think this is a matter of difference in mission and mindset. When we think of person centered planning, we think of specific faces, names and stories. As we read it, the Interim Report aims to meet health system demands that position person centered planning as an instrument of that system, bounding a universally defined process in meetings, specifying competencies to facilitate plans, and outlining system management processes to assure compliance in implementation. It addresses Long Term Services and Supports (LTSS), a new level of administrative abstraction that fuses constituent groups and muddles fundamentally different forms of service from self-directed individual supports to nursing homes. Authoritatively defining person-centered planning in terms of this administrative category homogenizes distinctive histories and approaches. Those who speak from other traditions may share our sense of loss.

Our experience gives us a different understanding. We align with disabled people, families and allies who adopt a citizenship focus and resist framing support as if disability were a medical condition (though we recognize, and struggle persistently with, the fact that the United States still organizes long term support financing within a medical model). Rather than on time compliance with a procedure required of every person receiving LTSS funding, we experience good person-centered planning as a voluntary expression of passion for social justice, focused on supporting growth in valued community roles, one interested person at a time, in their own time. Controlling one's meeting is less significant than increasing control of one's whole life by animating new possibilities.

The Interim Report offers too neat a picture for us. In the Report's view, a person moves smoothly from assessment to person-centered plan to experience of services effectively organized by the plan to reflect what is important to them and support their work on chosen goals. Implementation and improvement are a matter of attention to rule and metrics. The Report largely ignores constraints that we frequently encounter:

support, planning, community building, staff recruitment, and support coordination.

Beth Mount has practiced the art of person-centered work with thousands of people with disabilities and their allies since she co-created *Personal Futures Planning* in the early 1980s. She is the founder of Graphic Futures, providing consultation, facilitation, organizational development and support to people and initiatives seeking to demonstrate the values, practices and innovations related to person centered planning and development. (BethMount.org and inclusion.com)

John O'Brien has learned from people with developmental disabilities, their families and their allies among service providers and system leaders since 1968. He has helped in the design of several approaches to person-centered planning and studied, written, facilitated learning, and advised social inventors co-creating individualized supports (inclusion.com and centreforwelfarereform.org).

- The culture of power-over people with developmental disabilities is stubborn. Admonitions to respect the right to choice and dignity of risk are seldom sufficient to relax its grip. The dominant presumption that something about a person demands fixing or treatment hijacks thoughtful consideration of a whole person's purposes, will and preference and empowers professional judgments about health and safety. The struggle to create the conditions to intentionally exercise power-with people continually challenges our practice.
- Organizations structured to support people as individual citizens in community settings have multiplied paths of possibility. However, the bulk of current public investment pays to congregate people with developmental disabilities at the margins of community life. Moving into people's vision of a good life very often requires individualized supports when available services manage people in groups. A desire for a real job in a community business exceeds local capacity to customize employment. A desire to share one's own home with a friend demands a real alternative to the group home. These capacities are often missing or underdeveloped. When available services are funded to care for and treat groups there are considerable limits on people's freedom.
- Many people, families and guardians have learned to scale their dreams and desires to what they assume current services can offer. Unfortunately this distortion of the desire for full citizenship can be locked in by internalized low expectations.
- "Natural support" from people other than family members usually requires careful cultivation and support. Such assistance is seldom simply available as an option to deploy at will.
- Shameful underinvestment in the workforce leads to turnover and recruitment difficulties that disrupt relationships, undermine trust, and limit follow through and learning.
- Aligning differing perspectives on a person's capabilities, possibilities and vulnerabilities can take a good deal of listening and creative effort.
- Risk management policies, rules, service definitions and billing codes pose barriers to flexible individualized supports.

In light of these constraints, it isn't surprising that the **person-centered planning that we experience can be messy, confusing, and slow**. Progress can't be mapped and managed on a timeline. Goals change as people encounter unexpected opportunities and obstacles, not biannually. After setting direction, meetings bring key people together to make sense of what is happening in the search for good jobs, negotiations with landlords, exploration of neighborhood opportunities, and bargaining with the service system for more flexibility. They find better questions and agree next steps into possibility that all can live with. Neatly formed answers and confident predictions of progress are signs that people are settling for less than can be. In this form, person-centered planning is not primarily about choosing services. It's about exploring life in community and discovering the individually distinctive ways that services can play a necessary supporting part.

Remarkably, these somewhat chaotic, self-organizing processes can work. We have participated in remarkable expansions of what is possible when people

with developmental disabilities and their allies commit themselves to building more just and inclusive communities and find willing partners in social innovation among service providers and fellow citizens. So we position **person-centered planning as one disruptive element in a purposeful process of organizational and social change**. Absent organizational commitment to welcome and work with the new demands surfaced by good person-centered plans, people who rely on intensive supports must expect more of the same.

We read the Interim Report section on System Characteristics as placing **too much faith in top-down delegation through rules, abstract measurement, administrative admonishment, and training**. We have found that simply opening conversations to exploration of a good life as a citizen often builds commitment to imagine and reach into community for better. Ordinary human connection can energize a search for a good life. Feedback is direct and immediate as one cycle of trying, reflecting, and building on what is working follows the next. Organizational rigidity derails organizational and community change.

A deeper search for the conditions associated with person-centered plans that actually do open better possibilities would shape a system agenda that effectively encourages support for good community lives. Such a search would certainly ask how to abate the relentlessly rising tide of demands for compliance to rules and reporting protocols and reduce its disempowering and demoralizing effects on person-centered planning. If review of system level data informs real system level innovation instead of more demands on subordinates, the space for good person-centered planning will grow.

The Interim Report puzzles us by enumerating an exhaustive list of facilitator competencies. None are objectionable but the collection as a whole is daunting. Although we have practiced for years, often with good results, none of us could claim all these proficiencies. In a complicated world, **the qualities of a good facilitator seem to us a simple matter**. Someone who approaches people with deep respect, presumes competency and seeks possibility, listens with curiosity and compassion, finds a way to host conversations that suits them and learns to do a bit better with each experience, encourages deliberate action, and only makes promises they can keep will be a good enough facilitator. These are qualities of character and commitment to learning that are passed on through membership in communities of practice rather than transmitted through curricula.

Our nightmare: implementing an administrative demand to make person-centered planning a universal tool will cut its roots in the lives and strivings of people committed to work for communities that are more welcoming and more just. Reduced to a tool, deprived of sources of life, it will become one more rote required procedure that reproduces more of the same and drains attention and energy from the human experience of living together well with disability.

We don't request any revisions for the Final Report. The Project's mission and context are clearly different from ours. We want to say where we stand and share the different way to understand person-centered planning that we see from here. This understanding leaves us outside the consensus the Project aims to build.