

A Genealogy of Person-Centered Planning With People With Developmental Disabilities

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By a variety of names, person-centered planning is an element in social care reform, as in these examples. The US Department of Health and Human Services set person-centered planning at the center of disbursement for the nation's main source of social care funding (DHHS, 2014; NQE, 2020). The Act that establishes publicly funded services for people with developmental disabilities in the Canadian Province of Ontario established person-directed planning as the forum for selecting and coordinating services (S.O., 2008). *Valuing People*, an initiative to transform supports to people with learning disabilities¹ in England, identified person-centered planning as a necessary tool for changing systems of support (Routledge, Sanderson, and Greig, 2002)

These mainstream instances of person-centered planning happen as elements in centrally managed public service reforms. In contrast, this genealogy traces the origin of a person-centered planning lineage that emerged at the edge of social care systems, among a network of activists aligned with people with developmental disabilities and their families in Canada, the US, and the UK from about 1970 through about 1986. Approaches to person-centered planning which emerged then influenced the design of other methods. Some are still practiced in evolved forms. These approaches, along with many others, have had some influence on the mainstream practices adopted by systems (for a description of these early approaches, their commonalities, differences, and offspring see O'Brien *et al.* 2014). Retrieving the origins of this tradition highlights sources of social innovation that can contribute to social care system reform, if those engineering the reforms choose to learn from them and make room for such conditions to flourish.

This genealogy is constructed from my current reflections on memories of active participation in this network, aided by review of materials from that time and more systematic inquiries compiled from interviews with a number of person-centered planning innovators (Lyle O'Brien and O'Brien, 2002; O'Brien and Blessing, 2011).

Mainstream Person-Centered Planning Practice

From the early 1970s requirements for individual service plans played a part in social care reforms as attention to individual skill development overcame professional pessimism about the educability of people with developmental disabilities. Over about thirty years, approaches to individual planning developed, sometimes into the mainstream forms of person-centered planning in use today.

*Terms are contested and changing. Since 1950 the diagnostic label mental deficiency has been succeeded in turn by mental handicap, mental retardation, learning difficulty and learning disability (in the UK), and intellectual disability. I chose developmental disability to aggregate the human service labels assigned to the people who collaborated in producing the forms of person-centered planning discussed here. A North American administrative coinage, it identifies people with different diagnoses who share a life long need for coordinated services that originates before age 22. Intellectual disability, autism, cerebral palsy, epilepsy, and other conditions that produce needs for similar services are commonly grouped under this label. Social Care² is a common term for what the US knows as "Long-Term Care."



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In the context of mainstream service delivery, person-centered planning usually has characteristics like these. The stated purpose is to improve measurable service outcomes that advance system policy. The process addresses the person as a service user: consumer, client, recipient, patient. A system authorized service coordinator facilitates or oversees the process. It seeks the benefits of active service user involvement in care by clarifying goals and specifying available services that will cost-effectively assist goal attainment. The process promotes informed choice among available, cost-effective services and treatments a person is eligible to receive. It refers service users to services funded from other sources. It sees family members as carers who may also be eligible for services. The process aims for a good balance between what matters to a person and what matters for a person, where what matters for the person is judged from the perspective of managing organizational risk. It pursues a good fit between personal preferences and the way available services are delivered.

Mainstream applications of person-centered planning function as tools in social care reform and are managed bureaucratically. Under administrative authority and with advice from stakeholders, social care systems typically define a form of person-centered planning, promulgate rules to govern its practice, tie the chosen form of planning into resource allocation and service coordination processes, set the tempo for planning events, incorporate planning into audited record-keeping routines, provide technical assistance, develop curricula, and require courses of training (e.g., NQF, 2020). Academic research centers and consulting firms usually play important roles in definition and implementation (e.g. HSRI, 2020).

A Network of Innovators

Implementation of mainstream person-centered planning practices are engineered by system logic. Senior authorities define specifications in consultation with interested constituents, their agents plan and implement the means to meet those expectations. Outside that logic, just at the outer edges of the social care system, there is another source of creative energy for improving the life chances of people who rely on social care. Beginning about forty-five years ago, in a decade of rapid service system growth, innovative practices, including person-centered planning, began to emerge at this edge. Emergence can't be commanded and controlled as engineering can, but it gives birth to unexpected possibilities.

Reaction to institutional scandals and skilled and tenacious advocacy by influential family voices and professional leaders brought cautious and qualified legislative and judicial statements of rights for people with developmental disabilities. Driven by court decisions, inquiries, and legislative action, public investment expanded. The service sector grew rapidly as money flowed to reduce the institutional census.* There were positive changes: residential services were smaller and located on ordinary streets, physical environments were upgraded, staff ratios increased, health care improved, there was more attention to developing skills, observing typical routines, and exposing people to local settings and activities. Interdisciplinary teams of professionals wrote

* In the US neither the move from institutions nor the mandate for special education have ever approached full funding. The leading deinstitutionalization case, *Olmstead v L.C.*, instructs states to implement alternatives at "a reasonable place."

individualized service plans and set goals that addressed their judgments of individual potential. When the team judged it appropriate, people with developmental disabilities and family members had seats at the table where plans were made for them and a say in goal setting.

Rapid growth also brought in new workers who carried seeds of further change. Demand for staff and front line managers attracted many from outside the professional identities typical of the field. Even in direct support positions more people held degrees in outlying fields of study than ever before or since. Many new workers were active in moments for civil rights and peace and had done terms of voluntary service in community development or were discharging their obligation as conscientious objectors to military service. Hope that activism would bring positive social and cultural change shaped their consciousness. Fans of Ken Kesey's *One Flew Over the Cuckoo's Nest* (1962; film in 1975), these young people were ill-fit to take subordinate places in the established social care hierarchy and unquestioningly follow orders and protocols. Everything was open to question and typical staff client boundaries often melted in shared life experiences.

Across organizational boundaries and outside of formal roles, networks formed among those who did not find a way to the future they desired in mainstream waves of local service growth. Informal networks brought together families with high expectations for support to community living, people with developmental disabilities seeking opportunities to live their lives in ways they valued, and dissident service workers. Those who created these self-organized networks saw themselves working for social justice. They spoke of walking with developmentally disabled people and their families who sought to experience life as citizens with publicly recognized dignity, agency, and capacity to contribute.

Different interests shaped loose and changing networks. Lawyers and their expert witnesses connected, researchers who assisted people with developmental disabilities to blow up professional underestimations of their capacity for learning and performing meaningful work connected, people committed to those whose behavior challenged existing community supports beyond the breaking point connected, family members and educators committed to creating inclusive schools connected. Multiple interests energized connectors among networks. Networks offered mutual assistance in attracting resources and shaped formal conference agendas and informal life in conference hotel bars.

The self-organized network that generated early approaches to person-centered planning took shape around the work of Wolf Wolfensberger. His thinking and the example of his unrelenting advocacy against the segregation of people with disabilities framed and provided a vocabulary for our inquiries into practical support for social integration. Wolfensberger deconstructed the thinking that produced institutionalization, articulated a corrective in his interpretation of the principle of normalization, and framed a range of implementing concepts, including locally governed comprehensive systems of community services, citizen advocacy, and new roles for parent organizations as social inventors (Race, 2003).

Early in the 1970's, The Canadian National Institute on Mental Retardation (NIMR), founded to strengthen the family voice in policy and practice, adopted and promoted Wolfensberger's ideas through demonstration projects, policy development exercises,

multiple educational events, and publications. Wolfensberger maintained strong ties with NIMR when he moved to Syracuse University in 1973 to establish The Training Institute for Human Service Planning, Leadership and Change Agency. Both NIMR and the Training Institute were explicitly committed to advocacy for social justice and the development of services that would play a part in shifting the social status of people with developmental disabilities by relentlessly promoting social integration. Syracuse University was also home to The Center on Human Policy a setting where organizers collaborated with sociologists to campaign for community supports based on qualitative research that revealed the dark side of institutionalization and documented the benefits and workings of community alternatives (Ware & Story Sauer, 2021). These initiatives, and a number of innovative agencies and regions, provided multiple opportunities to strengthen our network by working on these organizations' agendas and strengthening relationships among their leaders.

Ground Level Innovation

Those who produced early person-centered planning approaches did not set out to engineer individual planning processes for systems. In fact, naming person-centered planning as a distinct form of practice came very late in the 1970s and early 1980s. Identified practices, such as Personal Futures Planning (Mount, 1984), emerged from assemblage of ad hoc practices to identify desirable changes in the organization of services.

Our network participants felt personal responsibility to accompany known people in their quest for a good life in a particular place. Some were members of families of people with disabilities. At work, some network members were responsible for developing and managing local day or residential services. Others assisted institution inmates to resettle. Others organized families and young people seeking a path from (usually segregated) special education into adult life in their community. Others offered support in crisis. A few were responsible for developing regional systems of social care services. A few were disabled leaders of early efforts to encourage people with developmental disabilities to speak for themselves. All wanted publicly funded services to offer better assistance than they currently did.

While we were by no means the only people to develop a critique of existing services, our network provided a platform from which we could observe ourselves as actors in a system we increasingly felt called to change. A powerful instrument for self-observation came in the unexpected form of a service evaluation instrument, *PASS* (Wolfensberger and Glenn, 1973), which operationalized 34 dimensions of the principle of normalization. While very few authorities ever used *PASS* to score the quality of the services they commissioned, investments in teaching *PASS* and applying it in consultations offered us multiple, intense opportunities to observe and reflect on snapshots of the day-to-day experience of people in services. The process of team debate produced knowledge that stimulated innovation. We named many ways that current service practices –our practices– reproduced social exclusion and restrictions of human rights and analyzed their causes. We noted the costs and limits that established service structures imposed. Most important our practical imaginations were lit.

Growing commitment to change in our own practices and structures introduced ambiguity into the roles of those of us who worked in social care. We felt responsibility to change the system that we worked inside and depended on. Very few of us had job descriptions that authorized us to be change makers. A growing number of us discovered openings for innovation at the edges of our formal responsibilities. Some found enough space to create individualized alternatives to group living, develop integrated employment and other supports to community participation, prevent social isolation and promote belonging, and discover strategies for accommodating differences rather than focusing exclusively on fixing diagnosed deficiencies. Many times these were one person innovations developed to interrupt a pattern of service failure that threatened a person with exclusion or to support a person and family with a strong vision and assets to invest in action. (For a variety of examples of such ground level innovations, see Meissner, 2013; O'Brien & Mount, 1991; O'Brien & Mount, 2015).

Our purpose, individualization of support for meaningful community roles, demanded a guiding and motivating narrative that expressed each person's identity, capacities, requirements for assistance, and personal images of a desirable community future. Otherwise we risked reproducing the institutional practice of classifying and managing people in groups. Identified approaches to person-centered planning emerged to invite people with different perspectives to come to a shared understanding of a desirable future that was strong enough to motivate and guide action. From its origin person-centered planning was inseparable from the work of discovering community opportunities and developing new ways to organize support.

The context of ground level innovation shaped these forms of person-centered planning differently than mainstream reforms would have done. Through years of development these enduring qualities of person-centered planning at the edge took shape. At their initiative or with their permission, innovators join a person in an effort to improve life chances for themselves and other people with developmental disabilities. The person is addressed as a citizen seeking more opportunity to live a community life that they value. Those involved recognize themselves as engaged in an action learning process. They explore new ways to push back limits on what is possible, rather than following established practices to produce more of the same. They will meet resistance, both in the world outside and within themselves. The purpose of meetings is to organize action and learning by all those involved, not to write orders, wishes, or demands for others to fill. Family, friends and other citizens are seen as allies and agents of change as are direct support workers. The number of people involved will change: a bigger circle of people will be involved in big changes; fewer when things are stable. Social care services are means to support citizenship. It is right that the person is in effective control of supports, though this can be complex in practice. The person's desired future defines the context and limits for applying clinical expertise, technologies, and strategies that increase a person's capacities to perform desired community roles. Because the social innovator's effort is grounded in responsibility to a person they know, feedback on what is working and what is not is rapid, situated, and open to quick response and real time revision.

From its earliest days person-centered planning has contributed to ground level social innovation in two ways. It brings a person and their allies together to form a circle that

collectively holds and updates an understanding of the person's identity and images of a desirable future that are powerful enough to activate, focus, and sustain each circle member's contribution to positive change in the person's experience of community. And, it builds habits of conversation that encourage deep listening, creative imagination, and courageous action when obstacles, failures, conflicts, and breakdowns of trust threaten the person.

Different Patterns of Thinking

The era of deinstitutionalization shifted large numbers of people with developmental disabilities into a growing inventory of local services. Most of this growth transferred dominant patterns of thinking and established forms of power along with the people. True to the facts and their professional perspective, expert voices convinced judges and legislators that institutional deficiencies resulted from failure to implement known good practice. They diagnosed the cause as woefully insufficient public investment resulting in overcrowding, substandard professional and care staff ratios, and impoverished physical environments. They persuasively recommended substantial staff increases, new buildings, rapid increase in the number of service providers, and higher standards of care.

Our network developed a different, more disruptive perspective. As we learned to listen better to people with developmental disabilities and their families and observed our own practice more critically it became clear that the services we operated were not organized to support desired futures in community life outside service settings. As trust grew, more of the people we served voiced desires for a job, a home where they were not one of a client group, intimate relationships, and opportunities to pursue personal interests. These ordinary desires far too often ran aground on the structures of our group based, professionally controlled services, especially when people required more than a little assistance. Other people with developmental disabilities communicated inadequacies in the support we provided by harming themselves or others, actions that pushed us into increasingly restrictive practices including retreat to institutionalization. We realized that these were not just problems with implementing known, technical solutions. Along with the people we served, we were trapped in an insufficient pattern of thinking.

Many of our organizations could be said to take for granted a professionally distanced view of people as isolated, embodied deficiencies to be objectively classified and systematically managed. This perspective cast people with developmental disabilities in passive roles as objects of professional assessment, surveillance, and prescribed intervention. Assessment sorted people into group program models for treatment and supervision. Services were delivered in environments designed to facilitate staff surveillance and implementation of prescribed routines. When compliance with treatment regimens mitigated deficiencies, and a person better matched a professional template of normalcy, that person earned a greater measure of supervised independence. Failure to progress consigned a person to a lifetime of social exclusion in a group of people with similar status, and very few made enough progress to achieve discharge from supervision. This distanced way of knowing and resulting structures of exclusion and control

too often persisted as people with different qualifications and titles moved to the head of the individual service planning table and the executive offices of organizations.

We wanted a richer pattern of thought, one that took direction and inspiration from the voices of people with developmental disabilities, their families, and their allies among service staff. Wolfensberger was an important source of vocabulary and critical practices that opened up better ways of thinking. In the late 1960s he turned from the form of clinical psychology that focused on testing and treating individual deficiencies and adopted a social psychological and sociological perspective. This turn informed his work as one of the leaders in the creation of a comprehensive system of services in Eastern Nebraska that became an international model of a local service system that was sufficient to make institutions unnecessary (Casey, 1985). He focused on discovering practical means to create systems of services that would, over generations, shift the social status of people with developmental disabilities by promoting social integration. In Wolfensberger's vision of a desirable long term future, differences would remain, assistance in various forms would remain, but social devaluation of those differences would diminish significantly and reduce the risk of social exclusion. This vision stretched our network's horizons and motivated us to work for changes in people's community roles and relationships far beyond those measured by an increase in positive checks on a skill inventory.

We were inspired and informed by other creative resisters to the dominant pattern of thinking. Early in the 1970s physically disabled activists labeled the medical model of disability; theorized a replacement social model that names discriminatory practices, enforced inequality, and inaccessible environments as primary causes of disability; organized politically to demand physical and social accessibility; and offered one another practical assistance and advice to control their own services (Heumann, 2020).

Burton Blatt and Seymour Sarason engaged the emerging field of Community Psychology to shift the focus of inquiry from treating individual pathology in service settings to creating social settings that enable flourishing lives in diverse communities (Sarason, 1972). Their work reinforced the application of aesthetics, story, and politics in our efforts to think better about our work. Their colleagues at Syracuse University's Center on Human Policy introduced us to qualitative research methodologies and a perspective on disability as a social construction and the development of a sociology of acceptance grounded in their careful listening to people with disabilities and close observation of service and community settings (Bogdan & Taylor, 1975).

Network members reached outside human service fields for ideas and planning practices. Connections between the Canadian National Institute on Mental Retardation and the Environmental Studies Program at nearby York University linked us to Eric Trist and his colleague David Morley. We explored the search process, a participatory planning method that supports diverse voices to develop images of a desirable future strong enough to guide sustained efforts to learn new ways in a complex, changing, and unpredictable environments (Emery and Emery, 1976). In the search process, an image of a desirable future is not a fixed goal to be analyzed into targets to hit. It is a tentative, narrative synthesis of differing expressions of human purposes that correlates action in a common direction of travel. The shared image is reshaped and renewed to adapt action to rapid and unpredictable environmental changes.

Learning the socio-ecological systems theory behind the search conference clarified another pattern of thinking that limited our work (Ackoff, 1974). Individual planning in social care was commonly built on mechanistic assumptions. Based on their diagnoses, professionals predicted attainable goals for an individual, set objectives, and prescribed procedures. We came to see that this (attempt to) predict and control approach had four defects. First, the assumption of predictability was false to our experience: unpredicted skills and interests showed up in unexpected ways as people had access to new opportunities, and so did unexpected problems. Underestimation of a person's capacities was far and away our most common error. Second, it reinforced institutional power relationships by setting the professional voice above others and subordinating the person to staff assigned to implement the plan. A person's access to desirable experiences, like a visit with family, might be made contingent on compliance with staff orders. Third, it closed off discovery of new possibilities. It confined attention to the person in service settings when attention to the person in community settings produced better questions and liberated new ways of knowing and acting. Fourth, it divorced the work from a principle source of meaning: learning to move, however haltingly, toward the ideal of a more just and inclusive community. Experience showed that goal setting by people with developmental disabilities themselves and family members could also be entangled by these limitations.

Approaches to person-centered planning took shape as our network gained experience of social innovation and developed new ways of thinking. Methods grew through adaptation of procedures developed while teaching and applying Wolfensberger's thinking and applying the qualitative methods in use at The Center on Human Policy. Windows into people's current and desired lives opened as oriented ourselves to supporting valued human experiences: being respected, belonging, choosing, contributing, participating. An empathic reconstruction of personal history could highlight both the burdens imposed by social exclusion and restricted freedom and the forms of resilience the person employed. The concept of Model Coherency – aiming to harmonize an account of the most important human needs of people an organization served with the way services are conceived, organized, and delivered– formed the core of thinking about how to support movement toward a person's desirable future. The idea of modeling methods on those valued outside the human service world took us to adapt techniques sources like Richard Bolles' *What color is your parachute?* (Bolles, 1970), an approach initially designed to reveal hidden interests and capacities of engineers changing jobs.

Methods took shape as we folded in practices from other fields. The search process framed collaborative effort to visualize a desirable future. Group Graphics (Sibbet, 1977) introduced visual methods to energize the dance between imagination and action by setting forth graphic templates to guide thinking and capture emerging ideas and images. Interactive planning (Ackoff, 1974) specified methods for generating idealized designs that surfaced and challenged limiting assumptions. Organizational development provided new maps of change (Weick, 1979). New approaches to community development (Kretzmann and McKnight, 1993) expanded our tactics for discovering community opportunities and strengthened our focus on planning as an active process of revealing people's gifts and potential opportunities through community exploration.

Conclusion

The network chronicled here has expanded, divided, contracted and reformed over the decades since early forms of person-centered planning emerged. Some of us original participants are still at work, glad to be joined by new generations. Wolfensberger's legacy remains, transmitted by a loyal group of teachers and woven into our thinking. Many more ideas and practices have been incorporated to enrich our thinking and shape our action. The voices of people with developmental disabilities have grown stronger and better organize. Experienced families invite others into leadership. The network's core endures in a shared commitment to carry on the unfinished work of social inclusion, particularly by creating practical supports that resist unjust structures. The work remains at the social care system's edge where boundaries are fluid.

The edge can contribute modestly to the center. Person-centered planning situated in self-organizing networks of ground level innovators whose purpose is to join with people with developmental disabilities to work for social justice can never scale to meet the demand for mainstream planning practices that aims to increase the benefits that thousands of people experience from social care. Current conditions make it very hard to make the changes necessary to realize the promise of stated values, such as those expressed in *The UN Convention on the Rights of Persons with Disabilities*. Those who shape mainstream person-centered planning can adapt techniques from ground level innovators, recognizing that they will have different effects. More fruitfully, those responsible for operating the social care system can learn from and find non-intrusive ways to support self-organizing innovators. The most benefit to the whole social care system will come through expanding mindful engagement with the patterns of thinking and relationship that emerge from individual and organizational innovations. As network learning about more liberating patterns of thinking becomes the subject of serious conversation in wider circles, available perspectives on what is possible will expand and large scale changes will be better grounded.

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