

Celebrating the Genius of Wolf Wolfensberger

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For 50 years, people with intellectual disabilities, their families, and their allies have participated in a profound, if incomplete, shift in how their place in society is valued and understood, in the ways their possibilities for development and contribution can be imagined, and in the means available to assist them to lead good lives. As the persistent shadows of eugenics and Social Darwinism have diminished and practices of segregation and bureaucratic control have increasingly been supplanted, it has become possible to meet growing numbers of people with disabilities who live good lives in ordinary communities. Until his death on 27 February 2011, Wolf Wolfensberger poured his genius into the entire half-century of this shift.

Exceptional Ability

A good case can be made for Wolf's genius in the contemporary sense of exceptional ability. The scope of his thinking cannot be captured at less than book length. Beginning in 1958, and most recently (though not finally) in the month of his death (Wolfensberger, 2011), he produced nearly 300 publications ranging from experimental studies of learning to a book collecting his writing on theology and disability (Gaventa & Coulter, 2001). Fortunately, Race (2003) has surveyed much of his thought in a beautifully edited and annotated collection of readings, which earned Wolf's enthusiastic endorsement. This body of written works shows Wolf's intellectual gifts of analysis, theory building, and strategic thinking (he held the U.S. Chess Federation rank of Chess Expert, one grade below National Master): He articulated the principle of normalization in operational detail and then refined it into the similarly operationalized theory of social role valorization; he presented and refined a set of principles and specifications for designing, implementing, and governing a comprehensive system of community services; he developed a schema for understanding and developing protection and advocacy and redefining the role of voluntary associations; and he produced a closely argued case for a growing societal tendency toward deathmaking of vulnerable people and a systematic approach to support moral behavior in the face of social dysfunction and destructiveness (Wolfensberger, 1992). In each of these efforts, he looked for and continually refined his presentation of fundamental principles and the rigor and clarity

with which their implications were deduced and presented. He demanded disciplined review of the extent and effects of their implementation and continually revised the details of their presentation.

Wolf was a charismatic presence with a great love of life. He was a gifted and demanding teacher (Note: Thanks to the Minnesota Governor's Council on Developmental Disabilities, it's possible to view Wolf and his long-time associate Susan Thomas teaching two-/one-day workshops at <http://www.mnddc.org/wolfensberger/index.html>). He intentionally built networks of people in the United States, Canada, the United Kingdom, Australia, New Zealand, and Norway whom he considered potential leaders by engaging them in intensive and rigorous workshops, recruiting them into team experiences, and assigning them responsibility for presenting and writing about the foundations, content, and implications of the theories that he judged would best respond to the real needs of marginalized and vulnerable people. Especially in the 1970s and 1980s, this strategy multiplied the influence of his ideas as more and more members of this network moved into positions of authority in developmental disabilities services. Few agreed with all of Wolf's positions and practices; many more were moved by moments of clarity generated by his person and his ideas.

Generative Power

This capacity to move people brings me to the less common sense of genius that I want to celebrate in Wolf. In classical times, the word genius was closer to its root, which means to generate, and refers to an individual guiding spirit, a unique pattern of sensibilities and powers that constitutes a person's way of relating to the world. Wolf identifies important elements of this pattern in himself as he reflects on his doctoral study in the first program dedicated to training research psychologists in what was then labeled mental deficiency (Wolfensberger, 2008).

My mentors seemed to think that I was a little on the crazy side, and in a sense they were right, except it was a craziness that protected me from surrendering to the innumerable normative crazinesses of a professional or service practice nature.

At the 2004 Peabody reunion, my advisor admitted that the faculty would not have rated me as one of their more promising students. However, I stayed in the field, was indefatigable in addressing real-life

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challenges there, and worked full-time even after my supposed retirement, the same as my friend and mentor Gunnar Dybwad had done. Also, I formed extensive informal personal involvements with retarded people, some lasting for decades until death parted us. (p. 77)

A heart open to the lives of people with developmental disabilities gave him purpose and a lifetime of insights. From his first encounter with institutions as a psychology intern, he was outraged at the way people were treated and by the moral complacency of those responsible for their management. Experience convinced him that communicating trust and high expectations reliably elicited growth, even among those he met and served in the most violent and degraded environments (Wolfensberger, 1999). Two summers as a psychologist at Muscatatuck State School during graduate study “bonded me to a commitment to mentally retarded people for the rest of my life” (Wolfensberger, 2008, p. 67). This commitment channeled Wolf’s natural gifts of intellect and power of will into the discipline that sustained more than 50 years of hard work engaged with the real-life challenges in living and supporting good lives in a society that devalues people with developmental disabilities. In the service of this bond, he developed the critical faculties and self-possession to hold and vigorously communicate positions that sometimes imposed serious personal cost and that more than occasionally led others with differing perspectives to mark him as at least mildly crazy (or severely irritating).

A Field Breaking Open

With a new doctorate, Wolf entered a field in the earliest stages of reformation after a long period of inertia that left the worst practices of the Eugenic era grinding mindlessly and soullessly on in institutions. Outside institutions, parent leaders built local voluntary services and created practices based on a sense of their son’s and daughter’s potential, influenced increased state and federal investment, shaped recognition of the rights of people with intellectual disabilities to education and to humane treatment, and began to attract the attention of lawyers concerned with civil rights. The efforts of national leaders including Elizabeth Boggs and Gunnar and Rosemary Dybwad were accelerated by President Kennedy’s appointment of the President’s Panel on Mental Retardation in response to the relentless advocacy of his sister, Eunice Kennedy Shriver. Progressive postwar policies in Scandinavia and parts of Britain defined a new and positive policy foundation and the related practices set a new standard of service and demonstrated new possibilities. Allan Roeher created Canada’s National Institute on Mental Retardation as a national center to stimulate change. Burton Blatt courageously broke the code of professional silence, exposed the institutional horror of *Christmas in Purgatory* in *Look* magazine and

lent his gifts of heart, mind, and political skill to energizing the professions for genuine reform.

There were plenty of opportunities to learn, and Wolf was open to having his mind repeatedly blown (as he put it) by the gaps between demonstrated European possibility and even the best North American practice. Following post-doctoral study with Jack Tizard in England and a tour of Swedish and Danish services, his publications take a sharp and final turn away from such topics as “the oral vocabularies of severely subnormal patients” (1963) and move into the dissemination of lessons from Europe (1964) and a stream of papers and books that strongly influenced the development of community services for people with developmental disabilities over the next 20 years.

A Distinctive Way of Knowing

This turn marks a decisive shift from a form of research that depends on experimental manipulation to the disciplined way of knowing that Wolf developed through the rest of his life. This form of research combines direct observation and documentation of the real-life conditions of people with developmental disabilities in many different circumstances (in addition to voluminous and meticulously detailed four-color-coded notes, he took thousands of slides of developmentally disabled people’s life circumstances, studied them with care, and used them to powerful effect in teaching); historical retrieval of the portrayal, management, and assistance of people with disabilities (he amassed a huge collection of relevant historic texts, documents and images, including a history of institutions through postcards); and broad search for nuggets of knowledge in the literature of general and social psychology, sociology, politics, administration, and philosophy to define valid principles of assistance, organization, and social change. These studies underwrite the development of rigorous theories that form the basis for the large-scale creation of new settings and new forms of organization. Careful measurement of the fidelity of implementation to the theory led to development of both practice and theory.

Leadership for Social Change

By the time *The Principle of Normalization in Human Services* was published in 1972, Wolf’s intention was clear. No longer content with manipulating variables that could be controlled in a psychological laboratory, he aimed to lead a process of social change to develop community settings and service practices that would simultaneously greatly improve the lives of people with developmental disabilities and their families and contribute materially to the longer-term process of making deep positive changes in the social perceptions of people with developmental disabilities. He was willing to invest his energies in the messy business of making opportunities to implement his theories at the local and state or provincial levels to provide those theories an adequate test.

(Those who understand Wolf's theories will be critical of my repeated reference to people with developmental disabilities because he held that his theories were valid for any socially devalued group. I don't disagree, but, in fact, his early focus was on people who would otherwise be in institutions for mentally retarded people, and, unfortunately, his ideas have yet to gain much traction outside services to people with developmental disabilities.)

I want to sketch my understanding of Wolf's working through the first full iteration of this way of knowing through leading social change in Nebraska between 1964 and 1972 (this account is based on many conversations and presentations with Wolf and checked against his own account in Wolfensberger, 1999). I have chosen this initial episode from many because I think it illustrates a pattern of thought and action that characterized his career and because it suggests how much of the taken-for-granted background of services for people with developmental disabilities was largely absent at the beginning of this period and available at the end of it.

Appointed to a research position at Nebraska Psychiatric Institute, Wolf saw and was moved by the waste of life and the indignity of his state's institutional provision, the bankruptcy of institutional practices, and the impoverishment of all but a very few ideas for institutional reform. There was no coherent account of what good community support for people who otherwise faced institutionalization might look like, so he and his friends and allies created one and started it running in Omaha.

Wolf worked simultaneously on several tracks. He deepened understanding of institutional realities by undertaking an intellectual history of North American institutions, which was published in 1969 as "The origin and nature of our institutional model". His analysis showed the powerful circuit between how people with developmental disabilities are seen and understood and the imagery, architecture, staffing, practices, and life conditions that surround them and reinforce their interpretation. He identified dehumanizing role perceptions of people as subhuman or menace, demeaning role perceptions of sickness, burden of charity, object of pity, or holy innocent, and a positive role perception of developing citizen. This crystallized the insight that any meaningful change depends on seeing, imagining, and treating those served as developing citizens and whole persons, an idea whose disruptive power could be estimated by the derision it attracted from many of the professional leaders of the time.

Historical research and reflection on his study tours and observations of life in institutions took him beyond the most common reform agenda of the time: a system that continued to rely on more, smaller, better staffed, more comfortable institutions. He became sure that a locally governed system of specialized services offering intense developmental programming in ordinary community facilities would render institutions unnecessary and joined local and state allies to plan and implement a

comprehensive local service system. To guide his efforts, he consulted the social change and leadership literature and began to form and test in action his theories of what he called change agency.

Nebraska's planning efforts were energized and informed by an international network of reformers. Wolf accepted responsibility for co-editing *Changing Patterns in Residential Services for the Mentally Retarded* (Kugel & Wolfensberger, 1969), a publication commissioned by the President's Committee on Mental Retardation. This gave the local planners access to thought leaders from the United States and Europe, including Bengt Nirje, whose chapter on the normalization principle put Wolf's capacity for theory building into high gear. To guide the development of the new community service system, he worked with Linda Glenn to create *PASS* (Wolfensberger & Glenn, 1969, extensively revised in 1972 and 1975), a means of evaluating the likely impact of a service program's physical, social, and administrative features on the positive interpretation, developmental programming, integration, age and culture appropriate treatment, and appropriate specialization to meet the needs of the people it serves. Around the same time, Wolf compiled *The Principle of Normalization in Human Services* (Wolfensberger, 1972), a text that on its later publication stimulated the kind of vigorous and often heated debate that goes along with a major shift in the social imagination.

ENCOR, the local system that resulted from this planning effort, soon became a destination of choice for those interested in community services capable of replacing institutions. By the mid-1970s, it became a place where it was possible to see the effects of a system of services that combined family support, integrated early education, employment including individually supported employment and work stations in industry, an array of small residences specialized to provide a range of supports to meet individual needs in ordinary housing including an apartment living program (the single exception provided people labeled "medically fragile" with intensive developmental programming in a hospital wing) and a set of specialized initiatives such as a program for offenders with mental retardation.

Even the best system cannot sustain itself without safeguards, and Wolf's eye for the real challenges people with developmental disabilities face led him to generate two more big ideas as comprehensive local services were getting off the ground. In an international conference on guardianship, motivated by parent's deep concern for who will look after their son or daughter's interests when they are no longer able to do so, Wolf's experience of the importance of positive personal relationships in any effort to assist vulnerable people led him to conceptualize Citizen Advocacy in an intuitive leap. In this form of protection and advocacy, a competent citizen enters a freely chosen relationship with a vulnerable person and represents that person's interests as if they were his or her own. As he did with his other ideas in this period,

Wolf quickly pushed Citizen Advocacy to the test of implementation in Lincoln, Nebraska (Wolfensberger & Zauha, 1973).

A vigorous association life is essential to protect vulnerable people and drive continuing service innovation and community change. Projections of a likely future led Wolf to call on parent associations to enter a third stage of development, moving beyond service provision and developing their role as supporter and educator of families; monitor, innovator, and guardian of service quality; and advocate for individuals and continuing social change.

Themes of Action

These themes—supporting valued social roles in integrated settings by intensive and highly conscious service, continuous renewal and improvement through continuing and rigorous measurement of the fidelity of implementation to meticulously stated values and practices, mining history and empiricism for deeper understanding and practical examples, assuring safeguards through personal relationships with valued citizens and vigorous voluntary associations—run through much of the rest of Wolf's work.

One further theme emerged in 1972 when Wolf, a man already bonded to personal commitment to people with developmental disabilities and sensible of the importance of personal relationships, encountered life sharing in the life of l'Arche and its founder Jean Vanier (see <http://www.jean-vanier.org/info/en/>). Vanier's genius has generated a worldwide movement based on the recognition that the gifts of people with developmental disabilities show up best in deep and committed personal relationships, including relationships in which people voluntarily choose to live together and share their everyday lives with one another. This way of living had deep resonance for Wolf and opened his way to the philosophy of personalism as it is lived in l'Arche and in Catholic Worker communities.

One theme that defined the early years—the planning and implementation of comprehensive community service systems—held Wolf's attention into the early 1980s. It dropped from his active concern when he judged that social dysfunction has grown so strong that the conditions for implementing and governing an effective service system have been weakened to the point that it is almost infeasible to do so. More importantly, his recognition of the growing threat of deathmaking made it a much higher priority for him to teach and encourage ways that people can respond to social dysfunction in a morally coherent way.

A Personal Note

It was my privilege to assist Wolf with some of his teaching and writing from the early 1970s until the mid-1980s. Engagement with him and his work has shaped the way I see the lives of people with developmental disabilities and the relationship between services and community life, has given me language to make useful distinctions as I assist people to think about how to discover and pursue their purposes and possibilities, and has offered me a challenging personal model of deep commitment to seeking and speaking truth by combining disciplined inquiry and personal relationships. I am grateful beyond words for his life.

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Received: May 23, 2011

Final Acceptance: May 28, 2011

Editor in Charge: Martin Agran

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