

Chap. 3. Contributions of Wolf Wolfensberger to the Lives of People with Disabilities.

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Abstract: Wolf Wolfensberger (1934-2011) emigrated from Germany to the United States at the age of 16 years. He had a great influence as a psychologist, researcher, professor of special education and rehabilitation, and specialist in intellectual disability. Wolfensberger became one of the most influential intellectuals and thinkers in the field of intellectual disability in the 20th century, thanks to his development of the normalization principle, his articulation of the theory of social role valorization, the creation of the tools PASS and PASSING for assessing the quality of services, and the vast knowledge mobilization undertaken by his Institute for Training at Syracuse University (USA) for nearly 40 years. This article describes his major contributions and still relevant influence.

Abstract: Mit 16 Jahren wanderte Wolf Wolfensberger (1934-2011) von Deutschland in die USA aus. Als Psychologe, Forscher, Professor für Sonderpädagogik und Rehabilitation sowie als Experte für geistige Behinderung war er von wesentlicher Bedeutung. Sowohl dank seiner Entwicklung des Normalisierungsprinzips, seiner Ausformulierung der Theorie über die Aufwertung der sozialen Rolle, als auch dank der Schaffung der Schlüssel PASS und PASSING zur Qualität Beurteilung von Dienstleistungen, sowie die enorme Mobilisierung von Wissen, die von seinem Trainingsinstitut an der Syracuse Universität (USA) über eine Zeitspanne von fast 40 Jahren aufgewendet wurde, gilt Wolfensberger als einer der einflussreichsten Intellektuellen und Denker des 20. Jahrhunderts im Bereich Geistige Behinderung. Dieser Aufsatz beschreibt seine wichtigsten Beiträge und seine andauernde Relevanz.

In this paper, I will try to do three things. First, in the main section of the paper, I will describe the late Professor Wolf Wolfensberger's main theoret-

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ical and applied but also personal contributions to the lives of persons with disabilities, primarily in the field of mental retardation (the latter now often referred to as “intellectual and developmental disabilities”) but also in other areas of human services, including mental health and aging. Second, I will provide evidence in support of the broad consensus among many people in a number of countries that Wolf (as I will most often refer to him here) has been one of the most influential thinkers of the last half-century or more in mental retardation. And third, in the concluding section, I will suggest why Wolf’s contributions are better known in the English-speaking world and, to a lesser extent, in Scandinavia than in the French-speaking or other countries of continental Europe

Wolf Peregrin Joachim Wolfensberger was born in Mannheim, Germany, on July 26, 1934, and died in Syracuse, New York, USA, on February 27, 2011, at the age of 76. During 1973-2011, he was Professor and then Emeritus Professor in the Division of Special Education and Rehabilitation at Syracuse University as well as Director of the affiliated Training Institute for Human Service Planning, Leadership and Change Agency that he founded upon arriving in Syracuse in 1973. Previously, in 1966-1971, he had been a Mental Retardation Research Scientist and Associate Professor of Medical Psychology at the Nebraska Psychiatric Institute at the University of Nebraska in Omaha, Nebraska, and, in 1971-1973, a Visiting Scholar at the National Institute on Mental Retardation, in Toronto, Ontario, Canada.

After emigrating from Germany to the United States in 1950 at the age of 16, Wolf completed his BA in Philosophy in 1955 at Siena College in Tennessee, his MA in Clinical Psychology and Education in 1957 at St. Louis University in Missouri, and his PhD in Psychology and Special Education in 1962 at George Peabody College for Teachers (now part of Vanderbilt University) in Tennessee. The PhD program at Peabody appears to have been the first anywhere in the world to prepare doctoral-level psychologists for research careers in the field of mental retardation (Wolfensberger, 2008). Wolf was the 15th student to have been enrolled in the program (Wolfensberger, 1991a).

I had the good fortune to study with Wolf for three years (1973-1976) at his Training Institute during my doctoral studies at Syracuse University. He used his time more productively than any person I have ever known, with

the possible exception of Susan Thomas, who worked with him between 1973 and 2011 as the coordinator of training and as a frequent co-presenter at the Training Institute. Susan is now carrying on his work, in collaboration with many former students and colleagues who were previously trained at the Institute in Syracuse. Wolf considered time the most precious non-renewable resource, which explains the prolific scholarly output that Raymond Lemay (2011) noted in his moving eulogy at Wolf’s funeral: 47 books, 63 chapters and partial monographs, 231 articles, 27 reviews, 6 poems, and 2 books that were ready for posthumous publication.

At the outset, I want to acknowledge my debt to several other individuals who have faced the same challenge of capturing succinctly the impact of Wolf the thinker and the man, especially Raymond Lemay (2011), John O’Brien (2011), and Glenys Mann and Christa van Kraayenoord (2011). Anyone interested in a much lengthier analysis of the influence of Wolf’s thinking on the English-speaking and French-speaking worlds and Scandinavia may wish to consult a book that I edited in 1999 with Raymond Lemay, *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*. The book includes a comprehensive bibliography (St-Denis Flynn, 1999) of some 800 items published in English or French during 1969-1999. Also, Wolf’s interesting teaching style and flair for the dramatic are readily accessible via the Internet², thanks to the foresight of the Minnesota Governor’s Council on Developmental Disabilities. The Council recorded a two-day workshop that Wolf and Susan Thomas presented in September, 1998, at Millersville University in Pennsylvania. Day 1 of the workshop consisted of a fascinating “Interpreted Pictorial Presentation on the History of Human Services”, with an emphasis on the origins of current service forms and the lessons that can be drawn from this history. Day 2 was devoted to “Reflections on a Lifetime in Human Services”, in which Wolf discussed what, in his opinion, had gotten better, what had gotten worse, what had remained the same, and what the future was likely to hold.

² Retrieved on <http://www.mnddc.org/wolfensberger/index.html>

1. Wolfensberger's theoretical contributions

i. Normalization

The principle of normalization was originally a Danish and Swedish innovation in the field of mental retardation in the 1950s and 1960s. Wolfensberger's essential contribution in the 1960s and 1970s, especially in *The Principle of Normalization in Human Services* (1972), was to show the theoretical applicability of normalization to other disabilities and, indeed, to virtually any condition in which individuals or groups were at serious risk of social devaluation (e.g., homeless people or many elderly persons). In Denmark, Neils Bank-Mikkelsen, the head of the Danish Mental Retardation Service and apparently the first to disseminate the concept, defined normalization as "letting the mentally retarded obtain an existence as close to the normal as possible" (cited in Wolfensberger, 1972, p. 27). Bank-Mikkelsen had succeeded in having normalization written into Danish legislation governing services to mentally retarded persons as early as 1959. In a chapter in the influential volume that Kugel and Wolfensberger edited for the President's Committee on Mental Retardation in 1969, *Changing Patterns in Residential Services for the Mentally Retarded*, Bank-Mikkelsen described the implications of normalization in practical, service-related terms (whose successful implementation, more than four decades later, is unfortunately incomplete and uneven in Canada and many other countries): "The purpose of a modern service for the mentally retarded is to "normalize" their lives. For children, normalization means living in their natural surroundings, playing, going to kindergartens and schools, etc. Adults must have the right to leave the home of their parents, to be trained and taught, and to pursue employment. Children as well as adults need leisure and recreation as part of a normal life. We are trying to integrate the retarded into the community in the best possible way. We help them in making use of their abilities, no matter how limited these may be. The mentally retarded have, along with other human beings, a basic right to receive the most adequate treatment, training, and rehabilitation available, and to be approached in an ethical fashion." (Bank-Mikkelsen, 1969, p. 234).

Building on Bank-Mikkelsen's definition, Bengt Nirje (1969), executive director of the Swedish Association for Retarded Children, formulated the first systematic elaboration of normalization in the international liter-

ature. He did so in another chapter of *Changing Patterns*: "[T]he normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. "This principle should be applied to all the retarded, regardless whether mildly or profoundly retarded, or whether living in the homes of their parents or in group homes with other retarded. The principle is useful in every society, with all age groups, and adaptable to social changes and individual developments. Consequently, it should serve as a guide for medical, educational, psychological, social, and political work in this field, and decisions and actions made according to the principle should turn out more often right than wrong." (Nirje, 1969, p. 181)

Wolfensberger's own best known and most influential contribution to normalization was in the form of a book, *The Principle of Normalization in Human Services* (Wolfensberger, 1972). The normalization book sold an estimated 100,000 copies and was translated into Japanese, with portions also reprinted in other books in the US and Israel (Wolfensberger, 1999). Wolf defined normalization as the "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (p. 28). His definition went beyond the Scandinavian definitions of Bank-Mikkelsen and Nirje in three main ways (Wolfensberger, 1999). First, Wolf generalized the applicability of normalization beyond mental retardation to all conditions that a given society considered "deviant", that is, socially devalued and a potential source of rejection. Such devaluation and even exclusion might be based on appearance, level of intelligence, age, race, nationality, religion, etc. Second, Wolf's definition included both means and goals, with a clear preference for human service means and behavioural and appearance-related goals that are culturally appropriate, typical, or valued (i.e., "normative") for persons in that culture of similar age, gender, or other characteristics. Third, Wolf's definition was parsimonious, in subsuming numerous actions on the individual, small group, and societal levels that could aim at enhancing the person's or group's behaviour and image as well as improving the attitude of the wider society towards people at risk of devaluation. As I will note in greater detail in the later section on Wolf's overall impact, the clarity, universal scope, and forward-looking

nature of his conceptualization of normalization made of his 1972 monograph the most influential publication in the field of mental retardation in a half-century.

Earlier, Wolf had contributed a lengthy chapter, *The Origin and Nature of Our Institutional Models* (Wolfensberger, 1969), to the *Changing Patterns* volume. This chapter served to shape his thinking about the normalization principle, including the core issues of integration versus segregation and developmental, community-based versus institutional models. The chapter became a classic that was later reprinted as a separate monograph (Wolfensberger, 1975). In it, Wolf identified several negative, historically damaging role perceptions of the person with mental retardation as key determinants of institutional models: the retarded person as a sick person, sub-human organism, or menace. In the chapter, he also depicted several other role perceptions that, while still negative, were more benign: the retarded person as an object of pity, burden of charity, or holy innocent. In sharp contrast, Wolf also described a positive, developmental role perception – subsequently known as the “developmental model” – that became a major foundation of his interpretation of the principle of normalization: *the retarded person as a developing person*, who required age-appropriate opportunities for learning and growth, which only culturally appropriate and physically and socially integrating community services could adequately provide. This insight, that high-quality services had to communicate positive role perceptions about the people receiving the services, was a forerunner of his later reformulation of normalization as Social Role Valorization. Wolf’s developmental model was a breath of fresh air that emphasized the capacities and similarities of people with intellectual disabilities with rather than differences from other people. Combined with a strong emphasis on physical and social integration and positive imagery, the developmental model made Wolf’s articulation of normalization very attractive to a large North American audience, which made of his *Normalization* (1972) book the single most influential publication of the 1941-1991 period (Heller, Spooner, Enright, Haney Schilit, 1991).

In sum, for Wolf, normalization was aimed at supporting (but not imposing) culturally valued behaviours and imagery in persons who were at risk of being seen as “different” and thereby devalued. The fact that the process of social valuation was to take place on three increasingly complex

levels, the individual person, primary and intermediate social systems (e.g., the family, school, work place, service agency), and society as a whole, anticipated Bronfenbrenner’s (1979) social-ecological, multi-level, multi-sectoral model that is now pervasive in many service fields, from child welfare to population health. Also, Wolf saw the physical and social integration of those who were devalued as a major corollary of normalization. Integration was not only a precondition for learning and development; for Wolf, it was even more fundamentally an ethical imperative.

ii. Social Role Valorization

In a widely cited paper in 1983, *Social role valorization: A proposed new term for the principle of normalization* (Wolfensberger, 1983), Wolf reformulated normalization as “Social Role Valorization” (SRV) because of what he felt were persistent misinterpretations of normalization both as a term and a service principle (Wolfensberger, 1980). Thomas and Wolfensberger (1999, p. 125) defined SRV briefly as “the application of what science can tell us about the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people”. In a subsequent article, reprinted in a posthumous volume (Wolfensberger, 2012a), Wolf explained the implications of SRV in more concrete terms, as follows: “The key premise of SRV is that people’s welfare depends extensively on the social roles they occupy: People who fill roles that are positively valued by others will be afforded by the latter the good things of life, but people who fill roles that are devalued by others will typically get badly treated by them. This implies that in the case of people whose life situations are very bad, and whose bad situations are bound up with occupancy of devalued roles, then if the social roles they are seen as occupying can somehow be upgraded in the eyes of perceivers, their life conditions will usually improve, and often dramatically so.” (Wolfensberger, 2012a, p. 14)

Finally, in 2002, the following formal definition of SRV was adopted by Wolf and other members of what was then known as the North American Social Role Valorization Council: “Social Role Valorization is a theoretical framework that, based on empirical knowledge, and drawing on multiple theories in sociology and psychology, (a) posits a relationship between the social roles people occupy, and how these people are then perceived, evaluated, and treated; and (b) affords the formulation of predictions of how

shaping the social roles of individuals, groups, or classes will influence how perceivers of these roles respond to, and treat, these respective parties, and of a great many strategies for doing so." (Wolfensberger, 2012b, p. 78-79).

As with normalization, SRV is a social-ecological approach (Lemay, 1995), with action implications on the levels of the individual person, the individual's primary and intermediate social systems, and the larger society (Thomas, 1999). Such actions are meant to enhance the impaired individual's personal competencies (e.g., through integrated education or work) as well as his or her social image (e.g., through age-appropriate modes of dress and daily activities).

Wolf identified the major role domains to which human services needed to attend in referring to or imaging the people served, given that they may be subject to or at risk of devaluation (Wolfensberger, 2012a). In the relationship domain, for example, the positive roles of *wife*, *husband*, *child*, *brother*, or *sister* can be juxtaposed to the negative roles of *orphan* or "*black sheep*" of the family. Role juxtapositions in other domains might include, in the residential domain, *home-owner* or *tenant* versus *homeless person* or "*street*" person; in the realm of employment, *wage-earner* or *apprentice* versus *long-term unemployed person* or *lazy person*; in education, *professor* or *student* versus *special-education student* or *school drop-out*; in leisure or sports, *athlete* or *winner* versus *klutz* or *loser*; in civic life, *citizen* or *taxpayer* versus *foreigner* or *social-assistance recipient*; in religious life, *pastor* or *parishioner* versus *sinner* or *apostate*; and in cultural life, *artist* or *music-lover* versus *philistine* or *boor*. Wolf also underlined why social roles are so important, both in life and in human services (Wolfensberger, 2012a). First, roles "situate" people in society in relation to others, in the role domains just described. Second, roles influence most aspects of people's lives, including their schedules, incomes, modes of dress, and individuals they associate with. Third, highly valued roles will tend to offset negative roles or characteristics that a person may have. Finally, on a probabilistic, long-term basis, people occupying valued roles are more likely than those in negative roles to receive the good things that life has to offer. For all of these reasons, SRV advocates that as many valued social roles as possible should be made available by human services to impaired or devalued people.

2. Wolfensberger's applied contributions

Wolf's theoretical and applied contributions were closely tied, as he united in his person an unusually incisive intellect with an uncommonly practical sense. He saw clearly, for example, that a revolution in values and ideology would be more crucial than new research findings in bringing about a better life for people with mental retardation (Wolfensberger, 2008). Accordingly, he directed his writings more towards people in the field – parents, direct-service workers, and service managers and policy-makers – than towards researchers, without ignoring the latter. Like a shrewd politician, he often spoke (and wrote) "over the heads" of gatekeeping journal editors, researchers, and institutional administrators, preferring to address directly those whom he deemed likely to make a difference in the real world. Wolf's practical contributions complemented his theorizing by focusing especially on issues of service quality, which he saw as the key to implementing normalization and SRV. In particular, he was keenly aware that theoretical frameworks needed to be made operational in the form of "social technologies" that would allow parents of children with intellectual disabilities, service workers, agency managers, or government policy-makers to understand the concrete implications of normalization and SRV and translate them into the practical terms of daily life and service delivery. Thus, Wolf constructed two well-known instruments for the assessment of service quality, *PASS: Program Analysis of Service Systems* (Wolfensberger Glenn, 1975), and *PASSING: A Tool for Analyzing Service Quality According to Social Role Valorization Criteria* (Wolfensberger Thomas, 2007). Use of these instruments over the last 40 years has consistently suggested that when services in many fields are evaluated against the demanding criteria of normalization (with PASS) or SRV (with PASSING), the overall quality of service programs, including those in the community, is frequently only modest (Flynn, 1980, 1999).

i. Findings with PASS: Program Analysis of Service Systems

PASS 3 (Wolfensberger Glenn, 1975), based on the normalization principle, was used between 1975 and about 2000 to assess the quality of services in several fields, including mental retardation, mental health, and of a range of types, such as residential, vocational, and educational services.

Detailed summaries of PASS research are available in Flynn (1980) and Flynn (1999).

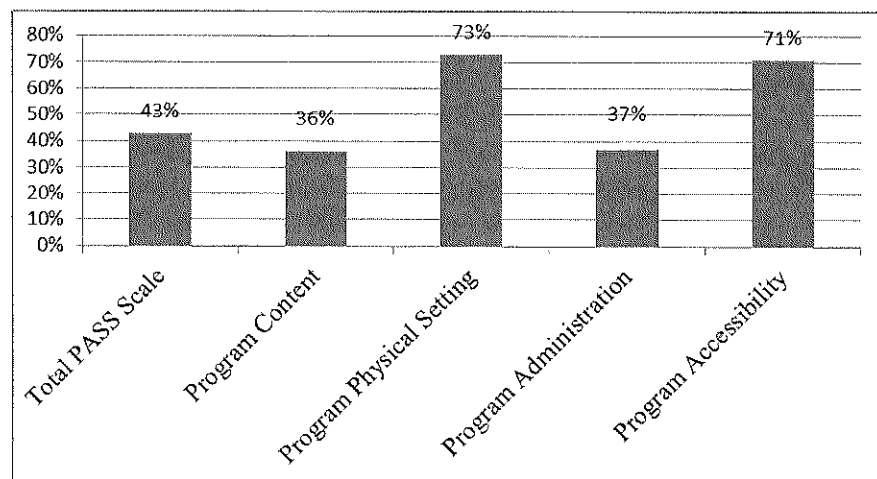


Figure 1. Mean total PASS and subscale scores as a percentage of the maximum possible score ($N = 626$).

Figure 1 displays the mean total PASS 3 scores and sub-scale scores of a cross-validated short form of the instrument that Flynn, Guirguis, Wolfensberger, Cocks (1999) derived on an international sample of 626 service programs that had been evaluated with the full PASS tool between 1975 and 1987. Of the programs, 56% were located in the United States, 32% in Canada, 10% in France, and 2% in Switzerland and Mauritius. Some 38% were community residences, 18% vocational programs, 16% institutional residences, 9% child-development programs, 5% counselling, therapy, or day-treatment programs, 3% recreational programs, and 4% were other types of programs. Finally, 54% served persons with mental retardation, 10% persons with mental health difficulties, 7% elderly persons, 4% persons with physical disabilities, 4% youths in difficulty with the law, 2% persons with alcohol or drug abuse, 6% persons with other conditions, and 12% persons with "mixed" (different) conditions. As shown in Figure 1, the mean total PASS score was only modest (i.e., a mere 43% of the maximum possible score), and the physical aspects of the program, that is, the physical setting (73% of the maximum possible score) and accessibility (71%), were of much higher quality than either the content of the program (36%),

which is the clinically most important service dimension as it assesses what happens to clients in the program, or administrative processes (37%).

ii. Findings with PASSING: A Tool for Analyzing Service Quality According to Social Role Valorization Criteria

Having formulated Social Role Valorization to replace normalization on the theoretical level, Wolf created PASSING to replace PASS on the applied level. PASSING is based on SRV criteria and continues to be used in several countries to evaluate service quality. A summary of PASSING studies may be found in Flynn (1999).

Figure 2 shows the mean scores on the total scale and subscales of a cross-validated short form of PASSING that Flynn et al. (1999) derived on a second international sample. The latter comprised 633 programs that had been evaluated with the full PASSING instrument between 1983 and 1995. Of the programs, 54% were located in the United States, 37% in Canada, 6% in Australia, 2% in the UK, and 1% in New Zealand. Forty-two percent of the programs were community residences, 25% vocational services, 13% institutional residences, 10% adult day programs, 5% child-development programs, 3% school-based educational programs, and 1% other types of programs. Four in ten (39%) of the programs served persons with mental retardation, 10% persons with mental health difficulties, 7% elderly persons, 3% persons with physical disabilities, 5% with a range of other conditions, and 36% persons with mixed (different) conditions.

Figure 2 shows that the mean total PASSING score was only 32% of the maximum possible score. Once again, as with PASS, the physical dimensions of the program – the physical setting (47% of the maximum possible score) and accessibility (55%) – were of much better quality than the most crucial service aspect, the content of the program (21%). (There is no Program Administration subscale in PASSING.)

The fact that the average level of service quality on the Program Content subscale was so low is problematic, given that the subscale assesses the extent to which the service program is rated by the PASSING evaluation team as actually promoting and supporting important client outcomes or service processes: autonomy and rights; life-enriching and socially integrating interactions with others; individualization; socio-sexual identity; the address

of clients' most important service needs; and the intense and efficient use of clients' time. In a recent SRV-based study of the relationship between housing settings and the community integration of 73 people with psychiatric disabilities who were receiving intensive case management, Aubry, Flynn, Virley, and Neri (2013) found that people living in housing settings that scored higher on the Program Content subscale of the PASSING short form also had higher scores on measures of physical, psychological, and social integration. Housing environments that supported client individualization and autonomy and rights were found to be associated with client competencies that enabled them to live independently. Moreover, the people with psychiatric disabilities who were residing in housing settings that were rated higher on the Program Content scale also had higher levels of psychological integration and, in turn, greater life satisfaction.

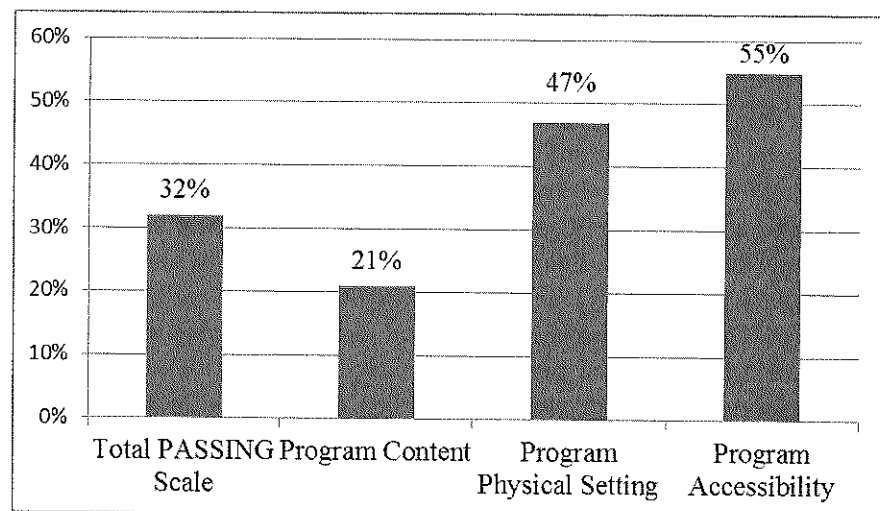


Figure 2. Mean total PASSING score and Mean PASSING subscale scores as a percentage of the maximum possible score ($N = 633$).

iii. Other Applied Contributions

ENCOR: Eastern Nebraska Community Office of Retardation.

Wolf was an innovative and self-directed thinker who, as Lemay (2011) emphasized, was quite willing to champion unpopular causes. One of the

first such causes that he tackled, in the 1960s and 1970s, was the need to replace large residential institutions with small-scale, dispersed residential and other services in the community. This kind of thinking, now conventional wisdom throughout most of the western world, was bitterly opposed at the time as "too radical" or "unrealistic" by proponents of large institutions. Wolf's ability to conceptualize new service models and to argue persuasively in their favour enabled him, during his time in Nebraska (1964-1971), to take a leadership role in the creation of ENCOR (Eastern Nebraska Community Office of Retardation). ENCOR, the world's first comprehensive community-based service system for persons with mental retardation (Wolfensberger, 2002), enabled the traditional large, single-campus institution to be replaced by a well-coordinated system of services in the community, composed of family support, integrated early education, supported employment and work stations in industry, and small homes and apartments (O'Brien, 2011).

Citizen Advocacy.

The same spirit of innovation and practicality led Wolf, while still in Nebraska, to create, for people with mental retardation or other impairing conditions who often lacked close social ties outside the family, a new form of mentorship which he called "citizen advocacy". Citizen advocates were competent volunteers who represented as their own the interests of impaired "protégés" who had major unmet instrumental or expressive needs (Wolfensberger Zauha, 1973). Many cities in North America now have citizen advocacy offices, which help to initiate and support long-term relationships between advocates and protégés that sometimes last a lifetime (Hildebrand, 2004).

Training in human services.

Wolf reached many thousands of people not only through his stream of publications but also through hundreds of workshops delivered over a 40-year period by him and his collaborators and students at the Training Institute at Syracuse University. Susan Thomas and her colleagues are now continuing this training effort. In her account of normalization and SRV-related training, Thomas (1999) estimated conservatively that some 10,000 individuals had participated in training events that had lasted for two days or more and had been conducted by the Training Institute itself. By 1992, 4,000 oth-

ers had been trained in the United Kingdom alone in normalization-based service-evaluation methods. Finally, thousands of others had attended training sessions presented by parties other than the Training Institute in the UK, Australia, Ireland, and New Zealand, as well as in France, Belgium, Switzerland, Spain, Norway, and Iceland (Thomas, 1999). The workshops of the Training Institute, originally focused on normalization, SRV, PASS, PASSING, and service planning, took on an increasingly ethical focus during the last 25 years of Wolf's life, dealing with issues such as personal relationships with impaired persons, morally coherent action, the sanctity of life, and personalism.

3. Wolfensberger's Personal Contributions

i. Unity Kitchen and L'Arche Syracuse

Wolf often urged his students, collaborators, and workshop participants to maintain personal, unpaid ties to vulnerable people, especially ties that would cost them something. He also practiced what he preached. He was a member for many years of Unity Kitchen Community of the Catholic Worker in Syracuse. As part of this lay Catholic group, he rendered weekly personal service to poor and "street people." He was also personally involved in the establishment of a l'Arche community in Syracuse in the 1970s. In the more than 120 l'Arche communities that now exist in 30 countries, people with intellectual or other disabilities and non-impaired volunteer assistants share their lives on a long-term basis (Vanier, 1995). Wolf was greatly impressed by Jean Vanier, a former philosophy professor who founded l'Arche in France in 1964. I remember Wolf saying, many years ago, that he found in the life-sharing model of l'Arche what he had been attempting to discover for many years in the professional world as a psychologist and researcher. It is no doubt this same life-sharing core that explains the fact that of the hundreds of completed PASS or PASSING evaluations in my computer file, the l'Arche communities assessed in Canada or the US tend to have service-quality scores that are much higher than the average for typical community residences.

ii. Wolfensberger's Theological Voice

Wolf elaborated on his ideals of closeness to vulnerable people and communality in a volume expressing what Gaventa and Coulter (2001) have called his "theological voice". The book includes seven of Wolf's religiously oriented papers, first delivered as occasional talks to Catholic or other Christian audiences. The themes covered in these papers were quite diverse: the prophetic voice and presence of people with mental retardation in today's world, the theology of social integration of devalued and handicapped people, the meaning of mental retardation from a Christian perspective, ministry with handicapped people at the parish level, urgent issues facing Christians concerned about handicapped people today, the good life for people with intellectual disabilities, and the lack of communality in Christian congregations as an obstacle to relationships with needy members.

4. Impact of Wolfensberger's Contributions

i. Impact of Wolfensberger's Normalization and SRV Writings

Heller et al. (1991) conducted a landmark study that showed the remarkable degree of intellectual influence exercised by Wolf, especially in the field of mental retardation. The researchers were interested in identifying publications that had "made a difference and affected many professionals over time" (Heller et al., 1991, p. 203). Heller and his colleagues first identified a panel of 432 experts in several sub-areas of special education (e.g., mental retardation, learning disabilities, or behavioural disabilities) by asking co-editors, associate editors, and others connected with the journal *Teaching Exceptional Children* to nominate three persons whom they considered qualified to identify classic or seminal publications. Of the 432 experts, 178 were associated mainly with the field of mental retardation. Next, in the initial round of a Delphi procedure, each of the 178 experts was asked to nominate articles that he or she thought had made a major impact in mental retardation. Finally, in a follow-up Delphi round, the 178 experts were asked to rank what they thought were the five most influential works (books, chapters, or articles), with their top choice receiving a score of 5, their next choice a 4, and so on. Of the 25 top-ranked publications, all published during the previous 50 years (i.e., during the period 1941-1991),

Wolfensberger's (1972) book, *The Principle of Normalization in Human Services*, received the highest ranking of all, with 175 votes. In addition, his more recent article, *Social role valorization: A proposed new term for the principle of normalization* (Wolfensberger, 1983), was ranked 17th out of 25, with 55 votes. Wolf's influence as the author of the top-rated publication is underlined by the fact that the Education Resources Information System (ERIC) had registered no fewer than 11,330 publications in the area of mental retardation since 1966 (Heller et al., 1991).

ii. *Impact of Wolfensberger's Work According to the 20th Century Project*

Further evidence of Wolf's impact was furnished by the 20th Century project of the National Historic Preservation Trust on Mental Retardation (a consortium of seven major mental retardation organizations). The project honoured him as one of the 36 most influential persons in the history of mental retardation in the 20th century (Other honorees included Alfred Binet, creator of the first intelligence test; U.S. President John F. Kennedy, apparently the first head of state to concern himself with mental retardation; Jerome Lejeune, discoverer of trisomy 21, the cause of Down Syndrome; and Burton Blatt, a critic and reformer of institutional care and the person most responsible for bringing Wolf to Syracuse University as a professor in 1973). Regarding Wolf's contribution, the 20th Century project had this to say: "Wolf Wolfensberger, Ph.D., has made many contributions to the field of mental retardation. In the late 1960's to early 1970's, Dr. Wolfensberger spearheaded the normalization reform movement. His efforts at teaching normalization helped forge the way for de-institutionalization and the development of services and supports for people in community settings. In the 1980's, Dr. Wolfensberger realized the limitations of normalization and abandoned it for his social role valorization theory. Both normalization and social role valorization courses have been taught throughout the United States, Canada, Great Britain, France, Germany, Scandinavia, and Australia. Dr. Wolfensberger's normalization and later social role valorization work were [sic] intended to assist people to better understand how to provide quality services to persons who are disabled. To even better accomplish this work, he developed, with associates, the PASS and PASSING evalua-

tion tools based upon the social role valorization theory, which measures human service quality from atrocious to ideal. These tools help determine whether a service meets the genuine needs of an individual." (National Historic Preservation Trust on Mental Retardation, 1999).

5. Concluding Comments

A recent article by a team of researchers from the five Nordic countries, Norway, Denmark, Finland, Sweden, and Iceland (Tossebro, Bonfils, Teitinen, Tideman, Traustadottir, Vesala, 2012) showed that normalization has continued to guide, over a 50-year period, the development of Scandinavian services and policies for people with intellectual disabilities. The article also displayed a good awareness of Wolfensberger's normalization thinking, although no mention was made of SRV. In English-speaking countries, Wolf's contributions continue to influence thinking on several themes (Mann van Kraayenoord, 2011): the nature of disability, social integration and valued community participation, government policies and agency practices in social, educational, and health services for people with disabilities, and advocacy work by families, community organizations, and ordinary citizens.

In the French-speaking world, normalization, SRV, PASS, and PASSING were introduced via Canada and Quebec (Pelletier, 1999). An organization known as CEDIS (Comité Européen pour le Développement de l'Intégration Sociale) disseminated normalization and SRV through PASS training sessions between the mid-1980s and roughly 2000. To respond to opportunities presented by new French legislation that required periodic external and internal evaluations of community social and health services, CEDIS also produced two new evaluation tools that were inspired by PASS and PASSING: EVA, in 2002 (*Manuel d'évaluation de la qualité d'hébergement pour personnes âgées dépendantes*), and VALORIS, in 2004 (*Évaluation de la qualité des services à l'usage des dispositifs sociaux et medico-sociaux*). CEDIS has recently become even more active than previously, carrying out frequent evaluations of service quality that are inspired by normalization and SRV values and principles.

According to Pelletier (1999), the impact of normalization and SRV in France has been limited because these intellectual currents have had no na-

tional profile. Their influence has been confined to certain regions, including the Dunkerque area in the north, Lower Normandy, La Charente, and Lot and Garonne in the southwest, for several reasons. First, pedagogical materials in French appeared later than they did in English. Although normalization and SRV were introduced into francophone Europe in the early to mid-1980s, Wolf's *Normalization* book was never translated into French. *PASSING* was published in French only in 1988 and *PASS* only in 1989, and the key publication on SRV, *La valorisation des rôles sociaux* (Wolfensberger, 1991b), became available only belatedly (Pelletier, 1999). Second, normalization and SRV were sometimes seen as based on "American" values and culture, despite the Scandinavian origins of normalization. Third, normalization and SRV did not enjoy the sponsorship of national voluntary or parent associations or high-ranking public servants, as had been the case in North America. And fourth, residential institutions tended to be smaller and of better quality in France than the large institutions that had been the targets of relentless criticism and legal advocacy in North America.

Overall, Wolf's many contributions are likely to remain conceptually, practically, and ethically relevant in many countries to the task of improving the lives of people with intellectual or other disabilities. I leave the final word to Professor Steven Taylor, the former editor of the journal *Intellectual and Developmental Disabilities* (formerly *Mental Retardation*) and a longtime colleague of Wolf's at Syracuse University. The last issue under Taylor's editorship, in December, 2011, was a posthumous tribute to Wolf. Taylor reprinted 9 of the almost 40 articles that Wolf had published in the journal between 1964 and 2011, introducing the issue with the following words: "Wolf was always thought-provoking and often provocative and controversial. One does not need to agree with everything Wolf wrote to recognize his tremendous contributions to our field. He stands among a small group of leaders in the 1960s and 1970s who radically changed how we think about people with intellectual and developmental disabilities and how we treat them." (Taylor, 2011, iv.)

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Chap. 4. Verletzbarkeit und Scham. Ein ethischer Versuch über "unpassende" Körper.

Regina Ammicht Quinn¹

Abstract: This contribution reflects on bodies, that do not fit – they do not fit the social norm, the self perception or the way the environment is designed. Tiffanie, with a condition called "diastrophic dysplasia", a rare type of "dwarfism", chooses to undergo multiple and excruciating bone-lengthening surgeries. What does it mean to fit? What is the role of shame, we have to reflect on identity, the gaze of the "other", and the difference between situations we are ashamed and acts that put someone to shame.

Abstract: Dieser Text fragt nach "unpassenden" Körpern – nach Körpern, die weder gesellschaftlichen Normen, dem Selbstbild, noch der Gestalt der Umwelt entsprechen. Tiffanie ist kleinwüchsig und unterzieht sich mehreren langwierigen und schmerzhaften Operationen, die die Knochen strecken. Was also heißt es, "unpassend" zu sein? Welche Rolle spielt Scham in den Diskursen über "unpassende" Körper? Wenn wir nach dem moralischen Wert von Scham fragen, geht es um Identität, den Blick "des anderen" und um den Unterschied zwischen Scham und Beschämung.

1. Tiffanie

Etwa zeitgleich mit dem Start des neuen "Hobbit"-Film Ende des letzten Jahres ist Tiffanie Di Donato durch eine Fernsehsendung und ein Buch für eine Weile berühmt geworden. Sie hat öffentlich ihre Geschichte erzählt, eine Geschichte, die durchaus nicht "normal" ist. "How One Women Fought for a Body – and a Life – She Was Never Supposed to Have" steht groß

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