

Book synopsis and review

Raymond Lemay

January 2004

You were right: Things are pretty bad out there for handicapped individuals and their families, and here's what you can do about it:

A Review and synopsis of:

Wolfensberger, Wolf (2003). *The Future of Children with Significant Impairments: What Parents Fear and Want, and What They and Others May Be Able to Do About It*. Syracuse, New York: Training Institute for Human Service Planning, Leadership & Change Agency (Syracuse University).

A must read for parents and professionals.

Before telling you about this book, I think it's important to provide you with a brief note about the author. Wolf Wolfensberger was born in Germany in 1934, and immigrated to the US in 1950. He has a PhD in psychology with a specialization in mental retardation. From 1971 to 1973, he was a visiting scholar with the Canadian National Institute on Mental Retardation of the Canadian Association for the Mentally Retarded (now the G. Allan Roeher Institute). Since 1973, he has been a Professor in the School of Education at Syracuse University in Syracuse, New York, and is currently Professor emeritus at Syracuse University. Since 1973, he continues to be the Director of the Training Institute for Human Service Planning, Leadership and Change Agency.

Wolf Wolfensberger, along with other prominent individuals such as Burton Blatt, G. Allan Roeher, André Blanchet, and Gunnar Dybwad, played leadership roles in the reform of human services, particularly those for mentally retarded persons that led to the community living movement. His book *The Principle of Normalization*, published in Canada in 1972, is world famous and, indeed, in 1991, his peers voted it the most important published work in the field of mental retardation in the past century. His more recent article on Social Role Valorization (SRV) was seventeenth on a list of the fifty most important works. He is in fact the only author with two citations in this very important list of influential works in developmental disabilities.

Wolfensberger is also the developer of two widely used program evaluation tools, PASS and PASSING, which assess the quality of services provided to vulnerable persons.

Wolfensberger is a controversial figure in the field of mental retardation and in human services generally. Though, in many ways, he has assumed a leadership role in the reform of human services, he is far from being satisfied with the results. In fact, he continues to be a very strong and vocal critic of how services are provided to the most vulnerable members of our communities. I had the honor and pleasure of being Wolf Wolfensberger's student and continue to collaborate with him.

In 1983, Wolfensberger wrote for the Canadian Association for the Mentally Retarded a monograph on the kinds of guidance, education, and supports that should be organized for the families of handicapped individuals.

In the year 2000, as our organization contemplated its merger with four other community groups that included services for the developmentally disabled, we asked Professor Wolf Wolfensberger to update his advice and to write it in a way that would be useful for both parents and professionals. Our organization is very pleased to be associated with this enterprise.

A synopsis and review of the Future of Children with Significant Impairments

The book is divided into three major sections, including the first part that reviews the conditions that are likely to arouse concern for families of an impaired family member, the second part which covers some of Wolfensberger's thoughts on parental responsibilities, and a third section on five common mistakes made by parents of children with impairments.

The book is first and foremost written for parents, with some reference to research but mostly through the telling of vignettes and short stories about how families have fared with the responsibilities for raising and supporting impaired family members. Written as it is for parents and coming from one of the foremost authorities on community services for mentally retarded persons in the world, this brief monograph is also important reading for professionals.

Part 1: Conditions that are particularly likely to arouse concern in families for the future of an impaired family member

This is the part of the monograph where Wolfensberger talks about the fears that parents have concerning the future of their impaired children. By and large, he validates these fears. Through a number of illustrative vignettes and studies, Wolfensberger points out that there is cause for concern. This first part of the book is fairly sobering and, as is his wont, Wolfensberger doesn't gloss over the bad news. Wolfensberger recalls that in the "bad old days," people institutionalized their children because there really was nothing else out there in the community. Institutions have the patina of permanence and security though they didn't do much to provide, let alone improve, good life experiences and conditions for disabled residents. However, in the 1950s parents mobilized and organized parent groups with the aid and support of reformers like Wolfensberger to eventually make important inroads into education, and other social service areas. Generally, they sought to set up services so that their children would be able to live in their communities and with their families. But as Wolfensberger points out, "the community living revolution that started in the late 1960s has opened up innumerable opportunities to impaired persons, and has conveyed many of the good things of life to many of them, but one of its greatest shortcomings has been that a large proportion of adults who have been impaired since childhood do not have much integrative community participation: they have few or no real friends, or they associate almost entirely with other people who are societally devalued themselves, and/or with paid caretakers. This has been the conclusion of study after study in North America. (For just a single one of many research reviews, see Flynn and Aubry, 1999). Some people have no one who will touch them who does not get paid. When parents are still alive to perceive this, then their fears are fed that there will not be a competent and reliable person around after they are gone who will love and support their son or daughter, and see to it that no bad things get done to him or her" (p. 17).

And, of course, parents know this. Not only are they struck by the great vulnerability and dependence of their handicapped offspring, they also intuitively know that community services are not as permanent, stable and secure, as they should be. Wolfensberger goes on then to document “extremes to which worried family members may be driven”, which include mercy killing. Wolfensberger tells us that we shouldn’t be surprised that things are coming to this because despite a lot of good intentions and a lot of money, and community services, a number of bad things continue to happen to people who are impaired. For instance handicapped adults are at great risk of having poor vocational prospects, of ending up in poverty, of having problematic and fragile residential situations. Study after study has pointed out how they are lonely, they are at risk of being preyed upon, and how they sometimes get into trouble because they keep bad company. Handicapped individuals are often on life long regimens of psychiatric drugs, very often in poor health, and end up dying earlier than they should.

Wolfensberger is very critical of what he terms the radical self-determination movement where choice, self-advocacy and empowerment are the preeminent values. “As a result of these ideologies, millions of people who are impaired in mental competency are today turned loose without any, or without sufficient, supports, guidance, tutelage, or outright controls where that is what they need, and this accounts for a very large proportion of the kinds of disasters listed above” (p. 27). What is really important here is that Wolfensberger validates the fears and concerns of parents by documenting research and many vignettes to support their intuitive grasp of the situation. “I also suspect that parents really begin to worry big-time when the impaired son or daughter reaches the twenties, “ages out” of what school systems are allowed or mandated by law to provide, and the parents discover that there is not much available to such adults in the way of good work training, work settings and options, or even reassuring residential options” (p. 29).

Wolfensberger goes on then to describe and critique some of the strategies that are currently used to reassure parents about the futures of their impaired and dependent family members. In this section, he gives a brief two-page history of residential services and how community services evolved in the 1950s and 60s. Governments were then interested in passing laws to develop guardianship schemes, which for the most part have been dismal failures. Wolfensberger doesn’t put much hope in government-sponsored schemes as these are dependent on funding and prey to whatever current professional fad seems to be around. Rather, in the next sub-section, Wolfensberger describes a number of measures that families and parents can take to improve an impaired person chances in life. Firstly, he suggests, in keeping with Social Role Valorization (SRV), that “... vulnerable people need to hold social roles in society that are valued. Many things can be done that (a) increase the number of positive roles that a vulnerable person gains and holds, (b) increase the value of whatever roles the vulnerable person holds, and (c) decrease the likelihood that a person ends up in social roles that are generally devalued. The reason for all this is very straightforward and obvious: people who hold roles that are socially valued are more likely to actually be valued themselves by others, and others are more likely to do good rather than bad things to people whom they perceive in socially valued roles. The opposite happens to people who are perceived to occupy roles that perceivers devalue” (p. 43).

The second important thing is to ensure that handicapped children and youth develop those important competencies that make it possible for them to interact successfully with other members of the community. Wolfensberger spends a few paragraphs describing the importance of developing

social graces in the handicapped individual so that others will be more willing to interact with them. “The reason why social graces in particular can be of decisive importance to what happens to an impaired person in the future is that – like it or not – people will respond more positively to others whom they perceive and experience positively; and among the things that people perceive and experience positively are other people’s social skills, including courtesy, generosity, welcoming, compassion, politeness, thoughtfulness, unselfishness, good manners, and personal cleanliness. The more social graces a handicapped person learns and practices *as a habit*, the more are other people likely to be willing to engage themselves with the handicapped person. And getting other people to engage with the handicapped person, in a benevolent and even protective manner, greatly improves the odds that good things rather than bad things will happen to, or be done to or for, the handicapped person” (pp. 44-45).

A third important strategy is for parents to band together in voluntary associations and to act as action groups. This collective activism is really the only thing that ensures that government and professionals will pay attention. There will be no long term fixes with this strategy but rather the continuing monitoring of service quality and service initiatives to ensure that they are in keeping with the needs of families with handicapped children.

Another important strategy is personal advocacy on behalf of the impaired person. Wolfensberger reviews a number of other important strategies including, where feasible, the arrangement for life-long income and developing, early on, residential options.

The most important strategy, however, is in response to the great risk of social isolation that afflicts so many mentally retarded adults. We tend to take for granted our own social networks of family, friends, colleagues, neighbors and other acquaintances. Experience tells us, and research confirms that social networks keep us well and protect us in times of adversity. But if you are a mentally retarded adult, other than aging parents, and a sibling or two, the only people you can depend on are paid staff. Wolfensberger proposes that parents must be actively involved in recruiting, amongst family, neighbors, friends and acquaintances, as many voluntary personal commitments as possible that will serve as a long term protective social network for their handicapped offspring.

Part 2: Some thoughts on parental responsibilities, with special reference if one has an impaired child

This section is particularly geared to parents with handicapped children and youth; however, it would generally apply to any parent of any child. Now one of the themes in this part is the fact that parents are part of a broader society and culture. Historically, Western culture has been organized around the concept that children are not only the responsibility of parents and their families but also of the community and society. Once again, Wolfensberger gives a brief history lesson on this and then goes on to describe how our society and culture has evolved to the detriment of family life generally, thus increasing the risks to handicapped individuals. “However, in recent decades, there has developed a mentality of entitlement to all the good things in life. In the minds of many people, this totally irrational entitlement mentality has overridden their intellectual knowledge of the realities of life” (p. 69). This brief part of the book tells parents that, like it or not, how their handicapped offspring will be viewed is very much dependent on the values of the majority culture and these values are not very sympathetic. Moreover, since we are products of this culture, we will

have to face the challenge of fighting off some of these values in order to adopt positions that are in keeping with our responsibilities as parents and in the best interests of our children.

Part 3: Five mistaken, maladaptive or dangerous mind-sets or child-rearing patterns that are commonly encountered in parents of children with impairments

There is a sense in which the second and particularly the third parts are a bit of counseling for parents. Not counseling in the passive non-directive way that is now in our days somewhat the norm for professional counselors, but rather a bit of wise counsel coming from someone who has a great deal of experience with the human service system and government on the one hand, and parents of handicapped individuals on the other. Wolfensberger identifies five mind-sets or ideas that parents often hold and that are a major danger for children with impairments.

- a) *Somebody else carries the major or ultimate responsibility for my child* - In this mistake, maybe inspired in a sense by one's feeling of entitlement, the parent assumes or delegates much of his responsibility to the state or to others. This is certainly an unreasonable position, given the fact that children generally are first and foremost the responsibility of their parents but it's also maladaptive because in any event professional services and government funding and the like are at best fragile and tenuous. For children, this can be tragic of course because like it or not they have to depend on their parents first and foremost.
- b) *The "my child syndrome"* - "It is expressed by a consuming fixation, and even a mental obsession, with the situation of one's own impaired child, far beyond what the special situation of the impaired child and of the family would really and objectively warrant" (p. 77). It's important for parents to quickly get beyond their own crisis and their difficulties and see that the problems they face go beyond the needs of their own child. Thus, it's not only about them and their child, but rather it's about others including their spouse, siblings, other members of the extended family, and the community, all of whom are affected either negatively or positively by having a handicapped person near by. Wolfensberger heartily suggest that parents need to get involved in parent groups not only for their own child but for the benefit of handicapped children generally and also for the benefit of society.
- c) *The "my-child-here-and-now syndrome"* - Parents going from one crisis to another are oftentimes unable or unwilling to look at the future and plan for it. This is indeed understandable because they are busy enough dealing with the day-to-day challenges and crises that often come up and are related to having a child whose handicap requires all sorts of special attention. However, if anybody needs long-term planning, it's children and youth who are handicapped. Their developmental road is not well trodden and a community's generic resources and structures are not really amenable to their handicaps and dependence. Special provisions need to be made. When the handicapped child is born, parents already have to be thinking about enrolling them in school, and once in elementary school need to think about secondary school, and already at the beginning of secondary school they need to plan for post-secondary education or work. Early on, parents need to think about residential options for their children, their future security, and the like. There is no doubt that the possibilities are greatly enhanced when parents band together and work collectively at ensuring better futures for their children.

- d) *My situation is unique* - Parents in this situation take exceptionality to its ultimate expression by suggesting that their situation or the child's handicap is totally unique and unlike anybody else's. Early on, Wolfensberger tells us that handicaps occur in about 5% of the population; one in 20 children is born with some degree of difficulty or handicap that will require some kind of special attention. Though there seems to be a new syndrome, or illness, or handicapping condition discovered everyday, the reality is that what professionals are doing is dividing handicapped individuals into more and more distinct groupings that will, if trends continue, be limited to one individual per group. The "*my situation is unique*" mentality only leads to isolation. Such parents feel that nobody else has anything to tell them of value because others haven't experienced the same thing as they have. "This kind of attitude can lead to a virtual mystification of the parenting experience that excludes other people completely – even to the point where associations formed on behalf of a class of impaired people actually exclude persons who are not either of that class, or parents of a member of that class" (p. 88).
- e) *Expecting either too much or too little* - Expecting too much, particularly in the short term, leads to failure and frustration. Expecting too little means that much individual potential lies wasted and underdeveloped. This brief section, in and of itself, is worth reading on its own and provides parents with wise counsel as to what are appropriate expectations. Finally, Wolfensberger tells us that handicapped individuals suffer greatly from poor and low expectations that do not allow them to develop the skills and competencies that they have, leaving them that much more vulnerable when they become adults. At the other end of the spectrum, however, one must be cognizant of the fact that learning and development will often require special support and special effort.

Conclusion

This brief monograph validates the fears that parents often have and express about the futures of their handicapped children. It's a sobering little book that should be read by parents so that they will know better what they are up against. Professionals should also read it so that they have a better understanding what parents are going through. Throughout this book, there is a clear invitation for parents and professionals to work in concert with each other to build better services one person at a time. There is no suggestion here of reforming services or putting faith in the structures we set up today, however good they might be. The unfortunate fact is that the community services are fragile and ever changing informal structures such as the family, the community, friendship, and acquaintanceships are more likely guarantees of long-term security. This little book is about 120 pages long and is written by one of the world authorities on developmental disabilities and parent movements. It's not a good news little book but it does provide wise counsel. If it's heeded, it might lead to a better future for your child.

References

- Flynn, R. J., & Aubry, T. D. (1999). Integration of persons with developmental or psychiatric disabilities: Conceptualization and measurement. In R. J. FLYNN & R. A. LEMAY (Eds.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact*. Ottawa, ON: University of Ottawa Press.
- Heller, H. W.; Spooner, F.; Enright, B. E.; Haney, K.; and Schilit, J. (1991). "Classic Articles: A Reflection into the Field of Mental Retardation." *Education and Training in Mental Retardation*, 26, 202-206.
- Lemay, R. (1995). Normalization and Social Role Valorization. In A.E. Dell Orto & R.P. Marinelli (eds), *Encyclopedia of Disability and Rehabilitation*. New York: Macmillan. 515-521.
- Wolfensberger, W. (1972). *The Principle of Normalization in Human Services*. Toronto: NIMR.
- Wolfensberger, W. (1983). *Normalization-based guidance, education and supports for families of handicapped people*. Toronto, ON: National Institute on Mental Retardation & Georgia Advocacy Office.
- Wolfensberger, W. (1998). *A brief introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services*. (3rd ed., rev.) Syracuse, NY: Syracuse University, Training Institute for Human Service Planning, Leadership and Change Agency.
- Wolfensberger, W. and Glenn, L.(1975). *Program Analysis of Service Systems (PASS): A Method for the Quantitative Evaluation of Human Services*. 3rd ed. Toronto: NIMR.
- Wolfensberger, W. and Thomas, S. (1983). *Program Analysis of Service Systems' Implementation of Normalization Goals (PASSING): Normalization Criteria and Ratings Manual*. Toronto: NIMR.
- Wolfensberger, W. (1983). Monograph on the kinds of guidance, education, and supports. *Canadian Association for the Mentally Retarded*.

RL:yf
03-11-21