

A TRIBUTE TO WOLF WOLFENSBERGER

Paul Williams

Introduction

Professor Wolf Wolfensberger, Director of the Training Institute for Human Service Planning, Leadership and Change Agency at Syracuse University, New York, died at the end of February 2011. He was 76. He had leukaemia and had been unwell for some time, though he continued his hard work schedule at the Training Institute as much as he could.

His influence on services for people with developmental disabilities has been one of the greatest of any single individual over the last 40 years. This influence has been on a global scale, with particularly strong (though sometimes unacknowledged) adoption of his perspectives and ideas throughout North America, in Britain and other European countries, and in Australia and New Zealand.

Early development

He was born in Germany in 1934. Wolf was his given name and not an abbreviation or nickname; his full name was Wolf Peregrin Joachim Wolfensberger. He witnessed the war as a child and was evacuated for several years to the German countryside. In 1950 he and his mother emigrated to the USA, where he

completed his schooling and went on to obtain university degrees in philosophy and psychology. He developed an interest in special education and achieved a much sought-after place to study for a PhD at Peabody College, Tennessee, at the time the only college in the world offering specialist non-medical teaching and research opportunities on mental retardation at the doctoral level. All his life Wolf kept copious notes of his thoughts and activities, enabling him to write a detailed account of his time at Peabody over 50 years later (Wolfensberger, 2008). During his time there, he worked in several institutions for people with developmental disabilities and visited many more.

In 1962, Wolf obtained a post-doctoral research fellowship to study in the UK for a year with Jack Tizard and Neil O'Connor. Part of his work involved a study of day services for people with developmental disabilities. The earlier work of Tizard and O'Connor (e.g. O'Connor and Tizard, 1956) had led to many such services being oriented towards sheltered work. The work environment was felt to be quite compatible with people's need for social education as promoted by Herbert Gunzburg (1960) and others. Wolf was particularly impressed by seeing people similar to those he had witnessed living in degrading situations in institutions,

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having the self-dignity and the respect of others conveyed onto them by work. During this time, Wolf also visited some pioneer services in other parts of Europe.

Development of key concepts

On his return to the USA, Wolf worked for a year in another institution for people with developmental disabilities, before obtaining a research and teaching post at the University of Nebraska in Omaha. Vehemently opposed to institutional care, much of which he described as a 'snake pit', but inspired by the analytical approach he had learned at Peabody and from Tizard, Wolf began researching the history of institutions to try to understand why treatment of people with developmental disabilities was so bad. He also sought a sound ideological and empirical basis for developing new pioneer services. In 1969, he was offered the opportunity of jointly editing, and contributing to, a review of the latest thinking on future directions for services, commissioned by the President's Committee on Mental Retardation and intended to be widely distributed by them.

The resulting book (Kugel and Wolfensberger, 1969) contained a rich series of insightful articles by some of the foremost progressive thinkers, practitioners and researchers in the field. They included Bengt Nirje, who gave the first systematic written account of the principle of 'normalization' as it was developing in Scandinavian services, and Jack Tizard, who described his ideas for developing comprehensive community-based residential services. Wolf himself contributed two chapters. The second, entitled 'A new approach to decision-making in human management services',

ends with the words: "problems related to mental retardation can only be considered in relation to other human problems generally."

Wolf's first chapter in the book was a *tour-de-force* that set the pattern of his ideas and work for the rest of his life. It was called "The origin and nature of our institutional models". At the instigation of some people in Britain who read the chapter, Wolf prepared a shortened version of it which was published in the British magazine "New Society" (Wolfensberger, 1970). In the chapter, Wolf analyses six negative perceptions of people with developmental disabilities that could be found in historical literature, and also in current attitudes of both professionals and the public, with evidence of how these perceptions underlay many features of institutions. The perceptions are of the retarded person as: subhuman, a sick person, a menace, an object of pity, a burden of charity, and a holy innocent. These are contrasted with the positive perception of the retarded person as a developing person.

In attributing many features of institutions to historical and current perceptions of what he calls the 'social role' of people, Wolf recognised that simply closing institutions was not going to improve the experiences of people, unless the negative perceptions were also changed. We can thus see several ideas emerging in Wolf's thinking in the late 1960s:

- An interest in the Scandinavian idea of 'normalization'
- The recognition that institutional care results from negative role perceptions
- The experience (for example from his visits to day services in Britain) that there are great benefits when people can be seen in positive roles, for example as learners or workers

- The need for new services to portray people in such positive roles, and actively avoid portrayal in negative roles
- The importance of empirical evidence to underlie policy and practice
- The generalisability of thinking and practice in mental retardation services to other groups of vulnerable people.

Practical projects

In Nebraska at the time, many people with developmental disabilities from Omaha were housed in the large institution 100 miles away that served the whole of Nebraska. Wolf was involved in a project to bring as many of them as possible back to live in small groups in more ordinary settings in the cities of their origin. The service, which became world-renowned for its pioneer work, was called ENCOR – the Eastern Nebraska Community Office of Retardation. As the new service was planned and developed, Wolf worked on three projects that reflected his thinking.

The first was the propagation of the concept of normalization, particularly amongst planners, professionals and academics. This resulted in a book which Wolf edited and to which he was the major contributor (Wolfensberger, 1972). In 1991, a survey was carried out asking 178 North American specialists in mental retardation which publications had had the most impact during the past 50 years (Heller *et al.*, 1991). Wolf's book came first; it has sold over 100,000 copies. While always greatly respecting and acknowledging his debt to the original Scandinavian concept of normalization, in his formulation Wolf developed the ideas away from a reliance on 'rights' towards a firmer basis in empirical evidence, and away from its focus on people with developmental

disabilities alone towards relevance to any group in need (Wolfensberger, 1999).

The second project was the development of an instrument to evaluate services according to the extent to which they were promoting normalization, with appropriate management and administrative mechanisms to safeguard this orientation. The instrument was called PASS – Program Analysis of Service Systems (Wolfensberger and Glenn, 1969). Initially designed to assess the eligibility of new community services in Omaha for funding, the instrument was refined to apply to any service for any people in need, reaching its final form in a third edition (Wolfensberger and Glenn, 1975), known as PASS 3.

The third project was the invention of a scheme to link individual people with developmental disabilities, particularly those coming out of institutions, with ordinary people who would assist their integration into the community and help the meeting of their needs, either directly or by assistance with negotiation. Wolf had been working on such a scheme, both theoretically and in practice in Omaha, since 1966 (Wolfensberger, 1977). He called the concept 'citizen advocacy'.

These ideas were popular amongst parents and radical practitioners in Omaha, but made Wolf unpopular amongst other professionals more allied to existing patterns of service. His position at the University of Nebraska was challenged and in 1971 he moved to a joint appointment as researcher and lecturer between the National Institute on Mental Retardation (sponsored by Canada's national parents' group) and York University, both located in Toronto. The 1972 Normalization book, PASS 3 and the first substantial text on citizen advocacy (Wolfensberger and Zauha, 1973) were all published by the NIMR.

The Training Institute

In 1973, Wolf was offered the opportunity to move to Syracuse University, in the north of New York state, to set up and direct an institute of his own to develop and promote his work. Situated within the University's Division of Special Education and Rehabilitation, in which Wolf was given a professorship, his base was called the Training Institute for Human Service Planning, Leadership and Change Agency. Here Wolf developed a programme of workshops, both in situ and at other venues worldwide, on normalization, PASS, citizen advocacy and many other related topics. One of the first people he hired, Susan Thomas, stayed on at the Training Institute and worked closely with him in writing and conducting workshops, right up until Wolf's death. In Syracuse, Wolf was able to establish a long-term home for himself, his wife Nancy and their three children.

In 1980, Wolf and Susan Thomas published a new version of PASS, with more emphasis on features of services that promote or damage valued social roles, and leaving out the wider management and administrative issues included in PASS. The new instrument was called PASSING – Program Analysis of Service Systems' Implementation of Normalization Goals (Wolfensberger and Thomas, 1980). A second edition was published by the National Institute on Mental Retardation in Toronto in 1983.

Social Role Valorization

Wolf wrote a seminal paper in 1983 giving his concept a new name: Social Role Valorization (Wolfensberger, 1983). There were two main reasons for this.

First, the Scandinavian concept of normalization was focussed primarily on the environmental conditions experienced by people, whereas Wolf's conception was of service features that promoted or damaged valued social roles. Second, there was massive misinterpretation of both formulations by very many people (Wolfensberger, 1980), by virtue of the word 'normalization' being assumed by some to be interpretable just by reading it rather than by studying the concept! From that time on, Training Institute workshops and publications on the concept used the term Social Role Valorization (SRV), PASSING was described as being based much more on this concept than PASS, and it became expected that other users of Wolf's concept or materials would use the new term rather than 'normalization'. The most up-to-date versions of Wolf's development of the concept are contained in Wolfensberger (1998) and Wolfensberger and Thomas (2007).

Global dissemination

People from all over the world began to attend Training Institute workshops, and Wolf and his associates began to travel widely to disseminate his work. Particularly in the USA, Canada, Europe and Australia, groups were set up to study and teach Wolf's concepts.

In Britain, an organisation was established in 1979 by Alan Tyne and others to introduce systematic teaching of Wolf's ideas. It was called the Community and Mental Handicap Educational and Research Association. In addition to other related training, that body ran over a hundred week-long workshops on the PASS and PASSING evaluation instruments, as a means of teaching

the detailed implications of Social Role Valorization, during the 1980s and early 1990s, before training resources in the UK were massively diverted to training on statutory issues such as Health and Safety and Risk Management. Both Wolf and Susan Thomas visited Britain several times in the 1980s and 1990s to run workshops on a variety of topics. Some of these visits were initiated and sponsored by The Children's Society. Other people closely associated with Wolf's work, such as John O'Brien, also played a major role in disseminating his ideas in Britain and elsewhere.

Wolf's global influence is further illustrated by the adoption of his concept of Citizen Advocacy in many parts of the world. In Britain, a consortium of voluntary organisations, including Mencap and Scope, introduced the idea in the early 1980s and there are now many schemes in the UK, some following Wolf's concept and others developing it in new directions.

The risks to vulnerable people

Wolf's realisation that negative perceptions of people are rife in society and need tackling directly and persistently, even after the 'snake pit' institutions have closed, led him to collect information on the wider experiences of vulnerable people in society. He became horrified by the evidence on the risk of early death to people with mental health problems (through excessive prescribing of drugs), to homeless people (from neglect, exposure and ill health), to people with developmental disabilities (through abuse or poor care), to older people (through abuse and neglect), to children (through abuse or abandonment). He formulated

a concept of 'death-making' to refer to all these causes of risk in society.

Following Jean Vanier, founder of the L'Arche movement for life-sharing with people with developmental disabilities, he described the negative experiences of vulnerable people as 'wounds'. He strongly objected to the prevalently used term 'quality of life', saying that we should never judge a person's life but should only be concerned with the quality of their experiences (Wolfensberger, 1994). A key publication on the topics of wounding and death-making is Wolfensberger (1992).

Wolf became convinced that in order to counter the negative forces at work in this respect, people needed moral strength. One of his most powerful and influential training workshops became that on 'How to Function with Personal Moral Coherency in a Dysfunctional World'. He also edited a regular newsletter, called TIPS – Training Institute Publication Series – which documented forces of wounding and death-making of vulnerable people in modern society.

Religion and science

Part of Wolf's motivation for pursuit of these issues was a deep religious conviction. Indeed, one little-known area of his publications is in the field of theology (Gaventa and Coulter, 2001). For example, one of the papers reproduced in that collection is entitled 'The prophetic voice and presence of mentally retarded people in the world today', originally written for L'Arche in 1978. One expression of Wolf's commitment to Christianity and to citizen advocacy was his personal involvement as a regular member and volunteer at a Catholic service for homeless people in Syracuse called Unity Kitchen.

Because of his religious commitment and his powerful views on ‘death-making’ (claiming in his 1992 monograph that the latter amounted to genocide), Wolf’s work on SRV, PASSING and citizen advocacy were sometimes attacked as constituting an ideological moral crusade. However, much to his credit in my view, Wolf was always very careful to present his workshops in a secular, scientific context, not at all in a religious or moral one. In fact, he did run workshops for people who shared his religious beliefs, but the vast majority of his teaching was done outside any particular religious or moral context. For example, SRV was taught as a set of scientifically-based principles, which one has to make up one’s own mind whether to apply in particular situations, on the basis of one’s own values and beliefs which are completely separate from the scientific evidence.

Wolf’s output

Two accessible books in Britain on Wolf’s work are those written or edited by David Race (1999, 2003). The latter contains a complete bibliography of Wolf’s published writings as of that time, illustrating the great extent of his output as an author. The list contains 42 books and monographs, 62 contributions to books or monographs edited by others, and 116 articles in scientific or professional journals. There have been many more since 2003.

Illustrating the great variety of topics which he researched and wrote about, his last published paper, dated February 2011, was entitled ‘Idiocy and madness in princely European families’ (Wolfensberger, 2011). A favourite of Wolf’s was Charles II of Spain, a member of the

‘princely European family’ of Habsburgs. He ruled on the Spanish throne for 35 years, from 1665 to 1700, despite having quite severe developmental disability – a classic, if very unusual, example of SRV.

In addition, Wolf taught literally hundreds of workshops in an intense, didactic manner with meticulous research and preparation. His workshops were challenging, with long hours of lecturing on complex topics. Some people, unused to this form of teaching, or opposed to didacticism or the terminology Wolf used, would walk out, but for those who stayed it was often a life-changing experience.

There were always critics of Wolf’s ideas and teaching, some of them – particularly those from academia – quite vicious in their condemnation. For example, SRV was accused of being authoritarian (because it was perceived by some – and indeed implemented by some – as prescriptive) and conservative (because it was perceived as failing to challenge conventional cultural values). To these particular criticisms Wolf responded with two papers, explaining that SRV is intended to be predictive rather than prescriptive (Wolfensberger, 1995a) and is radical rather than conservative (1995b).

Postscript

Wolf was an expert chess player, loved singing and wrote poetry, some of it published (see Race, 2003). He also had a strong sense of humour. His letters always had a standard introduction: ‘Please select an appropriate salutation for yourself, such as Sir, Madam, Ms., dear, dearest, you worm, hello there, etc.’!

As illustrated in his work on citizen advocacy, his commitment to protection of vulnerable people, his own good

relationships with many individual people in need that he knew, and his volunteer work at Unity Kitchen, Wolf was not an arrogant person but rather a humble one. He saw his work, however, as following in a proud tradition of pioneer developments in thinking about and serving vulnerable people, such as those by Itard and Seguin in the history of developmental disability services. At the end of his account of his time at Peabody College (Wolfensberger, 2008), he describes how he had met pioneers in the late twentieth century who had known the pioneers of the early twentieth century, who in turn had known the pioneers of the nineteenth century. "So a handshake with me is only three handshakes away from that of Seguin, and four from Itard. But if you want to shake their hands indirectly through shaking mine, you had better not tarry!"

Sadly, we only had a few short years to tarry. I am proud to have shaken his hand. His global influence, in ours and in other fields, is unlikely to diminish even though he is no longer with us.

Acknowledgements

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Terminology

I have used the term 'mental retardation' in several places where that was the terminology in use at the time, especially in the United States. Elsewhere, more up-to-date terminology is used.

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