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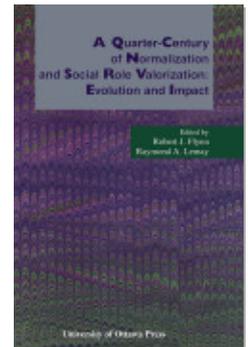
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Normalization and Social Role Valorization in Australia and New Zealand

PETER MILLIER

1 HISTORY

Normalization and Social Role Valorization have had a comparatively short history in Australia and New Zealand. There has not been a culture of PASS such as that which influenced policy, practice, and research in North America and the United Kingdom in the 1960s and 1970s. PASS was used sporadically for research and evaluation in Australia in the 1970s by researchers at the Schonell Institute in Queensland and by some workers in the Commonwealth Rehabilitation Service (part of the Commonwealth Government Disability Services). It was not underpinned by any systematic or sustained presentation of (then) Normalization theory or training in the conduct of PASS such as had occurred in the US and Canada and, as a consequence, both the content and process of PASS events were probably incompletely understood and articulated. There were a number of evaluation instruments that derived from PASS, such as Community Health Evaluation of Service Systems (CHESS), which were quite widely used in Australia in the mid-1970s, and the "Blue Book," which was developed by the then New Zealand Institute of Mental Retardation and published in 1980. The Blue Book focused on standards for residential services. CHESS did not acknowledge its indebtedness to PASS but the Blue Book did, one of the authors of the latter publication having been involved in PASS workshops in Canada during the 1970s. In turn, the Blue Book influenced the development of an interagency standards document in

Western Australia and subsequent intellectual disability service evaluation instruments now used by the Standards and Monitoring Service (SAMS) in New Zealand.

Until 1980 most of the attempts to use PASS or instruments derived from PASS were based on an emerging sense of the need for measures of service accountability and quality, but were not embedded in a broader strategy to change or develop the pattern of services for people with intellectual disabilities. However, there was a mood and a movement for change that was influenced by several factors. First, there had been a number of young, enthusiastic, and, in some instances, dissident professionals recruited into intellectual disability services during the 1970s. These workers challenged prevailing views about how best to provide services for people with intellectual disabilities and, in particular, the dominance of the medical profession. Second, there was a tradition in both countries of inviting progressive leaders in the field to visit. Thus, people such as Jack Tizard, Gunnar and Rosemary Dybwad, Albert Kushlick and the Clarkes had visited, lectured, met with key professionals, policy makers, and parents throughout Australia and New Zealand and communicated their ideas. Third, most of the key players had read and clearly been influenced by *The President's Committee on Mental Retardation* (Kugel & Wolfensberger, 1969) and *The Principle of Normalization in Human Services* (Wolfensberger, 1972). A number of people from Australia and New Zealand were also aware of

ENCOR in Nebraska and COMSERV in Canada. Indeed quite a few visited Nebraska and Ontario and some stayed on to work there.

The visit by Wolfensberger in 1980 was pivotal in the development of Normalization and SRV in Australia. For the first time, people were exposed to a full presentation of (then) Normalization theory by Wolfensberger and Lyn Breedlove, and a significant number also attended the first PASSING workshop in Adelaide. At that stage, the PASSING manual was still in draft form. During his visit Wolfensberger also conducted a workshop on Planning Comprehensive Service Systems, and a group of people who attended took copious notes, which were circulated, read, and extensively discussed. These, together with the COMSERV monographs, became the basis for much service planning and development in a number of Australian states as well as influencing and informing *New Directions*, the report of the Handicapped Programs Review, which was established by the Commonwealth government in 1983 and published in 1985.

2 IMPACT

Normalization and SRV have had a considerable impact on legislation, policy, and practice in the areas of disability (particularly intellectual disability) and aged care, but the impact or influence has not always been obvious or given due recognition. It is not surprising that the principles underpinning Normalization and SRV (if not the theory) should find a certain resonance in Australia and New Zealand. There is a tradition of social democracy in both countries that inspired the original settlement ideals of justice and egalitarianism, although clearly this tradition did not necessarily extend to the original inhabitants. Both countries vied to be the first to give women the right to vote, and there is an equally long tradition of social welfare measures to provide a safety net for people who are unable to provide for or care for themselves. Thus, many people have found it easy to equate Normalization and SRV with (or to recast them in the language of) social justice, participation, and equity or, more colloquially, as a "fair go," which may in part account for some of the misunderstandings and misconceptions about the theory.

3 IMPACT ON DISABILITY LEGISLATION, POLICY, AND PRACTICE

It would be a mistake to assume that the impact of Normalization and SRV, or subsequent developments in legislation, policy, and practice in Australia and New Zealand (or even among Australian states and territories), have been the same everywhere. To a large extent, responses in various places are a reflection of the different histories of responding to the needs of people with an intellectual disability. For instance, the New Zealand Intellectually Handicapped Children's Society (IHC), the national voluntary association for people with intellectual disabilities, has been involved extensively in service provision, whereas in Australia, the National Council on Intellectual Disabilities (formerly AAMR) has not. However, many of its affiliated local and state voluntary associations do run services. Western Australia was arguably ahead of most Australian states in moving away from medical domination of services, and also away from large institutions toward smaller (albeit still quite large) hostels situated in local communities. In some states the government and voluntary sector worked together very closely, as did state and commonwealth funding agencies. In other places there was considerable tension and competition between the sectors, or state and commonwealth bureaucrats and workers did not talk to each other except through their respective ministers. New Zealand has only one government so it has largely avoided the problems of lack of coordination and overlap of responsibilities that have tended to occur in Australia.

In many respects, however, the scene was depressingly similar and familiar. There were many large institutions, mostly old and government-run, reflecting the history of the domination of those services by the mental health system. There had been some purpose-built institutions built in Australia during the 1960s for people with intellectual disabilities, but their newness did not mitigate the institutional thinking of the mental hospitals from whence most of those services had transferred. In New Zealand, the state institutions were known as "psychopedic hospitals," or "training schools," clearly reflecting the origins of the thinking and practices of the people who planned and ran them.

The period from 1976 to 1986 was one of great excitement and turbulence. There were many reports to governments concerning the need to reform and restructure services for people with disabilities. In Australia, the most influential of these were *The Law and Persons With Handicaps—Volumes 1 & 2* (Government Printer, 1979, 1981) prepared in South Australia by the Committee on the Rights of Persons With Handicaps, which was chaired by Sir Charles Bright, a retired Supreme Court Judge, and *New Directions* (Australian Government Publishing Service, 1985), the report of the Handicapped Programs Review, which had been established by the then Commonwealth Minister for Community Services, Senator Don Grimes. There were a number of reports to the various state governments including, among others, the McCoy Report (1981) in South Australia, the Beecham Report (1982) in Western Australia, and the Richmond Report (1983) in New South Wales, all of which charted new directions for disability services (and, in the case of Richmond, psychiatric services as well) in their respective states.

Normalization and SRV were clearly a major influence, either explicitly or implicitly, in all of these reports. Some reports used Nirje's definition of Normalization but Wolfensberger's concepts. Others mentioned Wolfensberger more specifically in relation to the need to develop Citizen Advocacy and other safeguards. Still others did not mention Normalization but made frequent reference to terms such as *least restrictive alternative, the developmental model, moral and legal rights, participation, and equity*. A number of the people involved in the various reviews and reports discovered that it was not strategic to use the language of Normalization/SRV, or to mention Wolfensberger, so they used other words to describe the principle or the concepts being discussed. One of the people closely involved with the Handicapped Programs Review said that there was a suspicion of jargon and things American. Participants in the review agreed for the most part with the principles underpinning Normalization and SRV but not the language.

It was hardly surprising then, that *New Directions* and the Disability Services Act (1986), should be imbued with the language of rights and equity although it is worth noting that the Objectives of the Act contain specific reference to the use of culturally valued means, meeting individual needs, promotion of image

and competency enhancement, physical and social integration, autonomy and rights and advocacy, which are all Normalization/SRV concepts, or derive from the theory.

Notwithstanding the impact of Normalization and SRV on disability policy and legislation in Australia, their impact on practice has been much more oblique. There appear to be some close parallels with the North American and Scandinavian experiences as described by Michael Kendrick and Kristjana Kristiansen in their papers. For example, implementation efforts have been impeded by confusion about Normalization/SRV, not just in the definition and exposition of the Nirje and Wolfensberger formulations, but more especially by the lack of a systematic, coherent articulation of Normalization/SRV in legislation, policy, and practice. Normalization, SRV, and social integration have been seen as synonymous with deinstitutionalization or, for political reasons, have been a hidden or covert aspect of policy and practice, often concealed under the banner of rights and social justice.

On the other hand, Normalization and SRV appear to have made a much greater impact at the local and personal level. Thus, certain services or agencies, usually discrete and small, together with some parent, consumer, and advocacy groups, have embraced, not just the rhetoric, but also the reality of what it means to support a person with an intellectual disability, to advocate on his or her behalf, or to provide services to a group of people using Normalization/SRV principles. For the most part, the people involved are part of the SRV network in Australia.

In New Zealand, the link between Normalization/SRV and disability legislation, policy, and practice, while acknowledged, has also been covert. The IHC, which today provides services for 3,000 people throughout New Zealand, was apparently well ahead of its government counterpart in developing a philosophy and standards for services in the late 1970s, of which the Blue Book formed an important part. There has also been a tradition in IHC of involving families and people with intellectual disabilities in decisions about service provision and evaluation, and this tradition has been continued in the evaluation sphere by the now independent Standards and Monitoring Service. However, there seems to have been less willingness among key leaders in services in New Zealand to acknowledge the extent to which

Normalization and SRV have influenced policy and practice. As has been the case in Australia, there is a strong aversion to the jargon, if not the concepts, and perhaps in the case of New Zealand, there has been an even stronger resistance than in Australia to the perception of a hegemony of ideas and language emanating from North America.

In both Australia and New Zealand, Normalization and SRV are taught as part of basic and postbasic courses in colleges of education and universities with varying degrees of understanding and competence. Generally speaking, the more closely the people teaching these courses are linked to the SRV network, the better are the course content and processes. In some instances people who are teaching courses seem to have had very little exposure to SRV and PASSING, nor do they appear to have much contact with people with intellectual disabilities in their personal or professional lives.

4 IMPACT ON AGED CARE LEGISLATION, POLICY, AND PRACTICE

Normalization and SRV have also had a significant impact on developments in aged care in Australia. Between 1980 and 1989 there were four reports and reviews conducted by, or on behalf of, the Commonwealth Department of Community Services (the Department has since changed its name several times), which have led to substantial changes in aged care policies and practices. The McLeay Report (Australian Government Publishing Service, 1982) focused on the high cost of nursing home care and the way funds were distributed in favor of institutional care. This led to changes in aged care residential programs to ensure more equitable distribution of funds to home and extended care support and to nursing homes and hostels. The Giles Report (Australian Government, 1984) and The Rees Review (Australian Government, 1986) focused on the goals of nursing home care and the provision of appropriate and quality care. Although cost was clearly a consideration, standards of care were also addressed by both Giles and Rees and, among other things, led directly to the development of standards for nursing homes and a process for evaluating nursing home care. Ronalds

(1989a, 1989b) investigated and made recommendations regarding the rights of residents in nursing homes and hostels. As important as these reviews and reports were to developments in aged care, probably of more importance was the environment in which they were conducted. At that time there were a number of key people within the Commonwealth Department of Community Services, including the state director in Adelaide, who, together with leaders in several aged care services in South Australia and Victoria, had attended Wolfensberger's 1980 workshops. Subsequently they formed a group, together with some people working in the disability field, that initially concentrated on learning more about Normalization/SRV and PASSING through a series of small-scale evaluations, informal discussions, and some introductory events for people with whom they worked. This in turn led to the development of embryonic Normalization/SRV groups in Adelaide, Melbourne, and Sydney but, more importantly, it helped develop a small core of people who were able to influence changes in policy, practice, and legislation throughout the 1980s. A strategic alliance was forged that has influenced many subsequent developments. Initially, many of the efforts at reform using Normalization/SRV principles and concepts were focused on improvements in the environments and conditions in nursing homes and hostels, but since the late 1980s there has been much more focus on programs to support and assist elderly people in their own homes and neighborhoods. As in disability, there was much enthusiasm and many mistakes. Some agencies have fallen away but others have continued to develop policies and practices that have Normalization/SRV as their basis. One agency in South Australia has been working at this for the past 14 years and is clearly regarded as a leader in the field of aged care by many, although the agency is also regarded as a "slightly eccentric relative" by some agencies and workers.

There are many parallels between developments in aged care and disability, but there are some differences. There has tended to be less involvement or commitment by service recipients and their advocates in aged care than in disability. On the other hand, reform in disability may be more difficult given its longer history and whole-of-life implications than in aged care. While more people in disability seem to have an understanding of, and commitment to, reforms

based on Normalization/SRV, few have full agency or organizational support. While both disability and aged care are beset with increasing formalization and managerialism, some people in the Australian SRV network believe that there may be more lasting reform in aged care than in disability.

5 SRV NETWORK IN AUSTRALIA AND NEW ZEALAND

There is a network of SRV training and interest groups throughout Australia and, more recently, in New Zealand. There have been several phases in the development of these groups. Initially, the focus tended to be on meeting informally to learn more about the theory and its implications; then, gradually, to establish larger groups, many of which have been sponsored or supported by agencies for the purpose of conducting training workshops and sponsoring visits by people from overseas. Most of the groups, whether formally or informally constituted, have moved away from agency auspice to individual membership, although it would be foolish to pretend that these groups would be able to function as well as they have without the support of agency benefactors. The various groups have been assisted in their development through regular visits by people in the North American network especially, including Michael Kendrick, who has been most influential, Bruce Uditsky, Judith Sandys, A. J. Hildebrand, Zana Lutfiyya, and Darcy Elks. Wolfensberger and Susan Thomas have visited Australia twice recently (in 1989 and 1992), during which they have conducted many of the events offered regularly in North America by the Training Institute.

A significant number of people from the Australian network have also visited North America to study services and service developments, to attend various workshops and training events conducted by the Training Institute and its associates, and to spend time with various people in the North American network. Two people have spent extended periods at the Training Institute to develop their SRV training leadership skills and now act as senior trainers at SRV and PASSING workshops throughout Australia and New Zealand.

A national SRV group (ASG) was established in Australia in 1993. It is composed of individual members who either are working as independent SRV trainers or are working to achieve this status; also people who promote and develop SRV training. The goals of ASG are: (a) to develop an Australian SRV training culture with the development of SRV as a central function; (b) to safeguard and enhance the quality of SRV training and development in Australia; and (c) to provide a forum for problem-solving issues related to the implementation of SRV principles. Among a series of strategic objectives for ASG, the development of SRV trainers, together with the identification promotion and development of potential leaders, are undoubtedly the most important.

Strategic alliances and affiliations have been formed with consumer, parent, and advocacy groups, both nationally and in various Australian states. These alliances have been reinforced by consumer, parent, and advocate participation in Wolfensberger's workshops in Adelaide in 1992, as well as participation and involvement by various members of ASG in workshops and training events conducted by Zana Lutfiyya and A. J. Hildebrand at the National Citizen Advocacy Conference in Sydney in 1993, and in early 1994 in a series of workshops for parents conducted throughout Australia by Darcy Elks on behalf of the National Parent Information Project.

Another development that looks potentially fruitful has been the link with training courses at universities around Australia and New Zealand. Several members of the ASG are involved in teaching and/or administering courses in special education and disability studies, and they are meeting together to develop and coordinate strategies for teaching and conducting research projects related to SRV and PASSING.

Bengt Nirje and John O'Brien have both visited Australia (indeed, John has been a regular visitor over a number of years) to conduct various workshops, seminars, and consultancies. These have been conducted mainly on behalf of the National Council on Intellectual Disabilities (NCID) or affiliated agencies in the various states. While these events have been arguably impactful and indeed have contributed significantly to agency thinking and practices, they have not been linked for the most part to the SRV network or to the goal of SRV leadership development.

6 CRITIQUE, ANALYSIS, AND RESEARCH

Undoubtedly, one of the weakest points in the development of Normalization/SRV in Australia and New Zealand has been the lack of informed critique, analysis, and research. Most of the Normalization/SRV critique in the literature in both disability and aging (e.g., Shaddock & Zilber, 1991; Branson & Miller, 1992; Stern, 1992, 1993; Graycar, Dorsch, & Mykyta, 1986; Fopp, 1990) has been of a very low level and characterized by many misconceptions and misunderstandings. Indeed, some critics (Branson & Miller, 1992) do not even provide references to suggest that they have read the basic Normalization/SRV texts. Others (Shaddock & Zilber, 1991) who do mention some of the readings do not seem to understand the profound differences between Wolfensberger's and Nirje's formulations of Normalization/SRV or much about the politics of change agency. They make a statement toward the end of their so-called critique that "the Handicapped Programs Review did not need to mention Normalisation to justify its *New Directions*" whereas, in fact, as mentioned in this paper, Normalization and SRV were widely discussed during the review and many Normalization/SRV themes were included in the Objects of the Disability Services Act (1986), but a strategic decision was taken not to mention Normalization/SRV or Wolfensberger. There have been responses to some of the critiques (e.g., Kendrick, 1992; Wolfensberger, 1994; Wolfensberger & Thomas, 1994) that address many of the incorrect assumptions and misconceptions raised by Stern (1992), Shaddock and Zilber (1991) and Branson and Miller (1992), respectively. These, in turn, raise strategic questions that the Australasian SRV network needs to consider. For instance, should we be responding to critics in this way or should we become

preemptive and create a climate of informed critique about some of the real issues, especially about the implementation of SRV in services and around individuals, or about the limits and limitations of services in areas such as relationships, autonomy, and rights, or indeed about the limits and limitations of SRV as a response to devaluation and wounding.

It is gratifying to see some research and writing beginning to emerge in the aged care area, and research is about to commence to analyze the results of PASSING evaluations in Australia and New Zealand, as has been done by Flynn, Lapointe, Wolfensberger, & Thomas (1991) in Canada and the United States.

7 SUMMARY AND CONCLUSIONS

Normalization/SRV in Australasia is young and vital but still fragile. The network in Australia has, for the most part, committed itself to SRV theory as propounded by Wolfensberger, which has been a surprise to some and a disappointment to others. The development of Normalization and SRV in the disability arena in Australia have in many respects mirrored developments in North America and Scandinavia. We have repeated many of the mistakes, but there have been some fruitful developments. The development of SRV in aged care policy and practice is unique. There has been a lot of mutual exchange between Australia and North America that has been beneficial. We have appreciated the need to form strategic alliances with consumer, parent, and advocacy groups. In Australia, in particular, we have been committed to working collaboratively and are strong as a group—there are no SRV hotshots. A major issue for us is not poor ideology but, rather, poor understanding, poor practice, and poor strategy. Normalization and SRV have had an impact, but the jury is still out.

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