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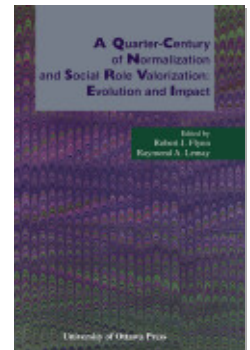
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The impact of Normalization and Social Role Valorization in the United Kingdom

TONY WAINWRIGHT

1 INTRODUCTION

This chapter discusses the contributions from Kristjana Kristiansen (chapter 18), Michael Kendrick (chapter 21), and Jacques Pelletier (chapter 25) from the viewpoint of a clinical psychologist from the United Kingdom. Before approaching the main topics that they raise, I would like to set the U.K. scene and give some personal background that I bring to this critique.

I have worked in human services for the past 15 years and for most of that time, Normalization has been something of a guiding framework for me. I have worked in community settings and in large institutions. I now work at St. Lawrence's Psychiatric Hospital in Cornwall, which still has over 200 people living there. This hospital started its career in the 12th century, when it served people with leprosy. It is located on what was historically a good begging route and while begging for alms may be thought of as belonging to history, it is alive and well in the UK as it is in most other parts of the world. Leprosy, too, is still a major disabling illness and this should provide a reflective context for any positive statements we can make about service improvements or optimism in the UK and elsewhere.

These three papers broadly agree that there have been some improvements in the lives of people with disabilities in the countries they have surveyed, and many of these developments are also to be found in the

UK. I would have liked to have devoted more space to the many achievements of the U.K. scene, but my purpose is to specifically discuss selected issues raised by these three papers.

In particular, I will not be discussing the extensive training program of PASS and PASSING, which Alan Tyne and Paul Williams have led throughout the 1980s through the auspices of the Campaign for Mental Handicap Education and Research Association (CMHERA), nor with this and other organizations that are continuing training and consultation in this area. The impact of this training initiative should not be underestimated, as a very large number of influential workers in human services have been exposed to Normalization and SRV through its agency. I will also not discuss the very considerable movement toward more normalized settings such as the development of ordinary housing as a service form. Finally, I will not be covering any of the issues that center on the advocacy movement.

2 THE U.K. CONTEXT

Some major milestones in the development of the "ordinary life" ideas and the introduction of Normalization and SRV into the UK are shown in Table 23.1, and the context in which Normalization has been operating in the UK is presented in Table 23.2. I will set out four main points here.

TABLE 23.1

SOME MILESTONES IN THE INTRODUCTION OF NORMALIZATION AND SRV INTO THE UK

1957	"Brooklands" (see J. Tizard, 1960) moving young people from hospital into "ordinary housing"
1958	Establishment of adult training centers
1963	Architecture for the disabled is the hot topic
1964	Wolf Wolfensberger working with Jack Tizard et al.
1965	Wessex 25 place hostels developed
1971	Campaign for Mental Handicap (CMH) established
1975	Visits from/to Danish and Swedish services
1976	Visits to ENCOR/COMSERV
1978	CMHERA established
1979	First Normalization and PASS workshops held in UK
1979	Ordinary life initiatives at King's Fund begin
1979	Jay Report on "Mental Handicap Nurse Training" published
1980	Supported house in Skelmersdale opens
1981	NIMROD opens/Andover experiment begins
1982	First PASS workshop held in Dublin
1983	All Wales Strategy for mental handicaps services published
1983	CMHERA participates in first PASSING in US
1984	First PASSING workshop in UK
1985	Speak Out starts
1987	First Moral Coherency workshop held in UK
1988	First Sanctity of Life workshop held in UK
1989	Campaign for Mental Handicap becomes Values Into Action
1989	First SRV workshop in Belfast
1990	NIMROD evaluated using PASS

Firstly, Normalization did not arrive in the UK into a theoretical or practice vacuum. As Wolfensberger has noted in chapter 3, his work with Jack Tizard and Neil O'Connor at the Maudsley Hospital in London in the early 1960s was very influential in his thinking. Tizard and O'Connor continued with their work throughout the 1960s and 1970s in collaboration with such people as the Clarkes, Albert Kushlick and, more recently, David Felse and Norma Raynes (see, for example, Tizard, Sinclair, & Clarke, 1975; Kushlick, 1975;

Raynes, Pratt, & Roses, 1979; Malin, 1987). This was an established, extensive, and robust knowledge base. Furthermore, international exchanges took place between U.K. workers and our colleagues from the Scandinavian countries. The reason for making this point is that it sometimes seemed that when Normalization or SRV were being presented, the world started thinking about the need for services to change to reflect new ideas in, say, 1972, when the Normalization book was published (Wolfensberger, 1972). This was not the case.

TABLE 23.2

THE U.K. CONTEXT

- Strong clinical/community traditions
- mental hospital decline both mental health (since 1948) and learning difficulties (since 1970) although varied in different parts of the UK
 - radical right-wing government since 1979 with powerful ideology
 - commercialization of welfare
 - managerialism purchasers and providers of care
 - consumerism—user power
 - cash crisis—recession
 - value for money—targeting of resources—rationing
 - health divide widening (see Phillimore, Beattie, & Townsend, 1994).

The second contextual point is that the rundown of the large asylums began in England quite early. Indeed, 1948 saw peak occupancy just before the establishment of the National Health Service and the new welfare state. The novel availability of benefits outside institutions, together with the optimism of the therapeutic community movement, led to a sharp decline in numbers, and deinstitutionalization literature began to accumulate in both the mental health and learning disability fields. By the mid-1960s it had become government policy to close the old asylums, with speeches by ministers arguing that the dreadful conditions had to end. While we know this is a complex story, taking a different route in England from

either Wales, Scotland, or Northern Ireland (and the learning disability population in fact grew during the two postwar decades) the rhetoric of community care was well under way. Indeed, some community services had already developed, and this led to the formation of a separate community mental health ideology with a different history to that of SRV.

A third pivotal issue is the political and ideological context of Mrs. Margaret Thatcher's first administration, around which Normalization had to grow. As noted in Table 23.2, the notion of individual responsibility was central to this ideology, and the oft-quoted statement that there is no such thing as society highlight the difficulties SRV as a manifestly competing set of ideas would have. I have noted in Table 23.2 some positive and negative consequences of the Thatcher agenda.

The final contextual issue has been the strong evidence from census and other data, and particularly from the work of Peter Townsend (see, for example, Phillimore, Beattie, & Townsend, 1994), that the poor have gotten poorer and sicker and the rich richer and healthier over the last decade or so. As devalued people are, almost by definition, overrepresented in or, some would say, coextensive with the poor, the service improvements that we have undoubtedly seen are perhaps more marginal than we sometimes like to believe. It is noteworthy that the Health of the Nation initiatives do not mention poverty as a cause of ill health (see HMSO, 1990).

3 COMMENTS ON THE CHAPTERS

3.1 COMMENTS ON CHAPTER 18 BY KRISTJANA KRISTIANSEN

Running through this chapter is a theme concerning the significance of high-level social policy and law concerning disabled groups and the influence Normalization has had on these. So, an important system issue is the legislative framework surrounding the entitlements, rights, and protection afforded to disabled people. As she sketched in her paper, there

are a range of laws in this area. This is also covered more briefly in the other two chapters. While it is emphasized that the presence of such laws does not guarantee their effectiveness, their absence and the intensity of opposition—particularly ideologically powerful opposition—to such laws may be seen as an indication of the low legal standing of disabled people.

What is the situation in the UK as far as the policy reforms and legislation are concerned, and how far has Normalization influenced them? While I am not a legal expert, my own reading of the situation is that there is virtually no legal framework protecting the rights of disabled people. One contemporary event in the UK highlights this situation, where a private member's bill in the House of Commons providing rights for disabled people (which has cross-party support) has just been blocked by a government minister "talking it out." It has been explicitly stated that the government is opposed to such a law as it would cost money and decrease the UK's international competitiveness. The Disability Movement won't let things go, however, and the European Court of Justice may make some interesting rulings in the near future. Liberty, the Human Rights organization in the UK, has also recently published a report (Liberty, 1994) framing the experience of disabled people in terms of the abuse of human rights and is submitting its report to the United Nations. While Normalization per se has not been a strong force in this area, it has played a part.

The only aspect of recent legislation that provides a specific role for consumers is the Community Care Act 1990, but this supports only weak involvement and more often is honored in the breach than in its observance.

One other device considered rather eccentric by many has been the Citizen's Charter. This did not emerge from pressure from below, but from the Prime Minister's efforts to make "public services more accountable." There is some debate over whether it is completely ineffective and simply gives the right to complain or is revolutionizing the way public services view their responsibilities to their "customers." Both might be true!

Two brief further pointers to the future can be seen. In one recent court case, children have been granted the right to sue education authorities if their educational needs are not met. The second point is that ordinary citizens now have a statutory right to see their

own health records. We are getting less secretive, but it is slow progress.

Some 15 years ago, however, things were different. The Jay Report on "Mental Handicap Nurse Training" had just been published (HMSO, 1979), with a chapter on a model service written by Derek Thomas (currently director of the National Development Team for Learning Disability Services). Still an excellent statement of the principles of the rights of people with learning difficulties, it was informed by visits to services such as ENCOR, which had been established using the Normalization principle. This report, together with the work of Alan Tyne and others on the "Ordinary Life" working group organized by the Kings Fund, led directly to the one national policy document firmly influenced by Normalization, namely, the All Wales Strategy (AWS). This document does not mention Normalization specifically, and is mentioned elsewhere in this volume as an example of Normalization being influential but too controversial to acknowledge explicitly. The AWS has been remarkable in driving services for people with learning disabilities in Wales toward patterns we would recognize as advocated by Normalization.

One example of this is in Clwydd, North Wales, where Grahame Harper has been able to develop comprehensive services for different client groups covering both Health and Social Services. He reports this to have been possible through the following mechanisms: the AWS; Normalization/SRV; frameworks for accomplishments that John O'Brien has developed; John McKnight's work on community building and competence; personal commitment by many people locally; and, finally, having the management clout to make things happen. These are all necessary for a successful enterprise.

In summary, despite the efforts of many groups, social policy legislation has not extensively incorporated Normalization ideas.

The next point concerns the notion of "alliances" developed in Dr. Kristiansen's paper and how SRV attracts and repels support: the U.K. situation is summarized in Table 23.3.

The picture is of rather weak alliances between SRV and other major organizations and ideologies in the field. As noted in Table 23.3, with some notable exceptions, there are no major organizations that have adopted Normalization. This may reflect the

overconcentration in SRV circles on learning disabilities, and this has perhaps not been helpful to either SRV as a set of ideas, or the groups of people who may have benefited from their application.

TABLE 23.3

SUMMARY OF THE U.K. SITUATION

1. SRV as a guide for social policy reform and protective legislation?
 - Virtually no legislative framework for disability rights
 - The Jay Report and the All Wales Strategy for learning difficulties services strongly influenced by SRV
 - Rather weak consumer-led planning as part of the Community Care Act 1990
 - Citizenship ideas through the Citizen's Charter having some weak impact
 2. SRV as a magnet for alliances?
 - Few if any major voluntary organizations have Normalization/SRV as their mission
 - Few if any service-user organizations or disability organizations have adopted Normalization or SRV
 - Strong local alliances built particularly in North West Region of England and in Wales
 - Links with political parties or other political organizations marginal if any
-

The voluntary sector has had a rather ambivalent relationship with these ideas. Among organizations for children, Barnardos (North West) and the Children's Society (see Williams & Race, 1988) have had strong connections with SRV, and their impact on the wider service field has not been insignificant.

The training department of MIND, our major mental health campaigning organization, was developing Normalization as a central plank of its work but eventually rejected it.

In the learning disability field, MENCAP—a U.K. charity for persons with learning disabilities and their families—has had a very mixed view of Normalization and SRV, and on the whole has been rejecting it in fundamental ways, although more recently it has

adopted policies that reflect an awareness of the importance of image issues, particularly in its advertising.

Services for older people have been notable for the lack of influence by SRV.

As already noted by Michael Oliver (chapter 6), the disability movement in the UK is not closely allied with SRV either theoretically or practically (see also Oliver, 1990). The criticisms of SRV from this perspective are found in a number of chapters (see, for example, Oliver and Perrin in this volume, chapters 6 and 8, respectively) and they underline the task faced if common ground is to be found.

3.2 COMMENTS ON CHAPTER 25 BY JACQUES PELLETIER

but also there is a strongly held view that it is taught in too dogmatic a way, which leads to converts rather than flexible thinkers. There are some possible themes that may bear on this, which are outlined in Table 23.4.

3.3 COMMENTS ON CHAPTER 21 BY MICHAEL KENDRICK

The question "Are things going well or badly?" arises from the notion of "SRV consonant effects."

Two areas are illustrative of the U.K. situation. First, there is a mixed picture concerning public perception of disabled people. For those with mainly physical disabilities, there has been some remarkable progress. People with physical disabilities are routinely positively imaged in athletics (as "disabled athletes") and disabled people have radio and television programs presented by disabled people. However, there is often very devaluing press coverage of disabled people.

An example in the *Boston Evening News* (Grahame, 1994) has the headline "Caring for children who never grow up." The first paragraph reads: "Mums and dads cry at weddings when their offspring fly the nest. Some parents cry much oftener because they know their children will always be fledglings with broken wings."

This article/ad describes a new facility for adults with learning disabilities. We have a long way to go in getting the message across that devaluing imagery is damaging.

Second, I am also less than convinced that, taking the disability world as a whole, things are improving. One indication is in the field of services for older people. My own hospital, for example, has sold its 100-year-old Radial Building to a nursing-home-providing company that may develop a large nursing home on-site. Another is a recent decision by the U.K. government to change its criteria concerning allocation of NHS continuing care facilities, which may be the beginning of further exclusion of older people from services to which they should be entitled. It is in the elderly field that the scandals are likely to be seen, although children's services seem to be running them a pretty close second.

TABLE 23.4

POSSIBLE REASONS FOR IMAGE PROBLEMS OF SRV

- Association with death-making teaching
- Conservative service system
- The way we have done our training
- Its perceived cultural identity is alien (either Scandinavian or North American)
- Complexity leading to misunderstandings
- Lack of clarity about the status of the SRV "movement"

One particularly pertinent section in this chapter concerns how SRV itself is imaged, and the author makes the case that it is seen as radical rather than commonsensible. While this agrees with my own experience, it is also seen, as noted elsewhere in this volume, as being paternalistic, controlling, and judgmental. Considerations of how this imagery is dealt with and why it has developed are important issues for us in the UK, as SRV has not been a widely popular viewpoint over the past few years. This is connected with the lack of alliances mentioned above,

4 CLOSING REMARKS

Finally, it is clear that there are many areas where SRV has had a substantial impact on improving the lives of handicapped people. However, it is largely a first world ideology (but see Billimoria, 1993, for a

discussion of the application of Normalization to India) and can be seen as generally reflecting the concerns of these countries. As the world becomes a smaller, more interdependent place, the wider political and ideological context must not be neglected or SRV will become an interesting set of old ideas but not relevant to the real world of the 21st century.

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