Normalisation and social role valorisation

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Introduction

In the 1990's normalisation was, for many involved in supporting people with a learning disability, a framework for understanding and influencing service values and practices. It was the foundation stone for *Valuing People* (2001) the Department of Health's Green Paper which set out the principles of how people with a learning disability should be supported – offering rights, independence, choice and inclusion. In recent years the term has fallen out of regular usage. However, the core of normalisation theory, ensuring people who have historically been devalued are restored to the heart of society by actively seeking to afford them the same opportunities in life as are enjoyed by all 'valued citizens', remains to be developed some 45 years on.

This PBS Practice Paper sets out the background to the development of normalisation theory, the key concepts that underpin the model and suggests a compelling contemporary relevance.

The background

Normalisation theory originated in Denmark when in 1959, Bank Mikkelson introduced legislation designed to make the benefits of living in a wealthy modern democracy available to all members of Danish society. In 1969 Bengt Nirje, a director of the Swedish Association for the Mentally Retarded (that was the terminology used at that time to describe people with a learning disability), developed the idea and defined the concept of normalisation. Nirje described the disability in terms of:

a) the factual impairment
b) other people's responses to impairment
c) the awareness of being different

Nirje also talked about expectations and routines and rhythms of ordinary life. Nirje (1982) defined the normalisation principle as *"… making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society"*.

An American psychologist called Wolf Wolfensberger elaborated Nirje's work and in 1972 the book *Normalization: The principle of normalization in human services* was published by the National Institute of Mental Retardation in Toronto. This publication laid out the foundations for advancing the support of individuals with a learning disability including those who display behaviours of concern. Normalisation principles required that individuals with a learning disability be supported to live in ordinary houses, in ordinary sized groupings, be supported by ordinary people and to engage in ordinary activities of daily living at ordinary times of the day and week.

Most of all, normalisation principles required that services be organised to maximise opportunities for the people using them to function with the greatest level of autonomy possible and to have ordinary relationships with the rest of society.

It is important to note that the principles of normalisation were concerned with normalising the living conditions, experiences, expectations and aspirations of people at risk of being devalued, and NOT forcing people into an arbitrary stereotype of being normal. The 'making people normal' misunderstanding was a source of confusion for many years and partly why in 1983 Wolfensberger and colleagues adopted the term *Social Role Valorisation* (SRV). To valorise is to esteem. So, the label social role valorisation clearly describes the normalisation goal of supporting people (who are at risk of being devalued) to create and maintain a range of valued social roles. In fact Wolfensberger's last definition of the normalisation principle was as "*the enablement, establishment, enhancement, maintenance, and/or defence of valued roles*".

Key ideas and concepts

Central to Wolfensberger's work was the idea that groups of vulnerable people in society, for example those with a learning disability, are likely to experience systematic devaluation. This means that once people are seen as being different in ways that are negatively valued, it is more likely that specific consequences will follow. Such consequences might include:

- relegation to low social status

- rejection – perhaps by family, neighbours and communities

- living in segregated and congregated settings

What can also accompany such processes is a loss of personal control and limited opportunities in life. The events at Winterbourne View (BBC, 2011) encapsulate many of these consequences.

For Wolfensberger, such processes and their consequences, are not 'accidental' but are the result of deeply held societal beliefs which find their expression in many ways. For example, it is taken for granted that most children with 'severe' learning disabilities will attend 'special' schools. For Wolfensberger, this is an example of a service system 'acting out' society's belief that such children *should* be segregated, in the mistaken belief that these arrangements are 'better' for them. Here Wolfensberger would point to the importance of an organisation 'unconsciously' putting into practice particular societal beliefs, but in a way that renders them as 'natural'.

The role of such 'unconsciousness' beliefs and their enactment is one of the core themes in normalisation theory. The others are:

- living in segregated and congregated settings

- the relevance of role expectancy and role circularity on deviancy making

- the 'conservatism corollary' (meaning that we need to urgently compensate for and counter devaluation)

- the power of imitation

- the importance of social integration

- the dynamics of social imagery

- the developmental model and associated personal competency enhancement

In 1983 Wolfensberger and colleagues grouped the principles of normalisation (*social role valorisation*) according to whether they related primarily to image or competence. Issues to do with social imagery encompasses everything from how a person dresses and how they are spoken about, to the image that is projected by the physical appearance of the service (residence, school or workplace) and the social imagery associated with other people with whom a person spends most time. All of these, and more, project and embed powerful messages both to local communities and to the person themselves. The combined effect of such imagery can often reinforce the notion that people have low social status and are 'different' in ways that are negatively valued in society. Consider the physical and other features of the

services you know and whether these support the images associated with valued social roles or (unknowingly) if some of them perpetuate the process of devaluation.

The second group of principles is organised under the heading of competence. Most services nowadays claim to have a positive approach towards an individual's developmental potential and would also claim to develop a person's skills and independence. This is sometimes encapsulated in the rubric of 'personalisation' and a cursory examination of many (if not all) mission statements prepared by human services reveals how such claims are made.

According to normalisation principles, competency enhancement is *precisely* what (alongside other strategies) services should be striving to achieve. The more competencies a person has, the less they will be perceived as different, and the more opportunities will open up for that person. The problem is, on close examination, many services fall far short of the aspiration to maximise a) how service users spend their time, and b) the degree of appropriately challenging activities necessary for skill development. For example, adults in day services for people with learning disabilities are often found undertaking the same routine and tasks year after year.

This brings into play another key theme in normalisation – that of role expectancy and role circularity. This is concerned with the ways that all of us tend to live up (or down) to the expectations placed upon us. The role expectancies placed upon people with learning disabilities tend to be negative – people may be seen as objects of pity, as someone to be feared, or even as sub-human. It then follows that the way in which someone's life is arranged will often mirror these expectancies.

For example, if you think about the roles you occupy it is likely that this will include parent, worker, partner and so on. You also will be clear about the responsibilities, behaviours, and expectations that accompany each role (although none of us would claim to get this right at all times). Now, think about the roles (and concomitant expectancies) associated with people with learning disabilities. The primary role is that of 'service user', 'client' or something similar. Think then about the expectations that arise from this role, and also the self-generated expectations that then flow from being seen and acted upon as a 'service user'. These might suggest dependency, powerlessness and marginalisation. In short, what can develop is a self-fulfilling prophecy in which, as a result of low expectations, little is accomplished, which in turn reinforces the negative perception that people are incapable of significant personal development. Consequently, and in contrast to negative roles, normalisation suggests that services should be striving to attain valued roles for people such as worker, citizen, tenant, home owner, consumer, and friend.

This is what Wolfensberger means through advocating that people with a learning disability should live lives "*as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics that are as culturally normative as possible*". The easiest way to understand this further is to *use yourself* as a reference, and point of contrast to the lives of people who rely upon services. Think hard about the choices you have, the experiences you have, how you spend your time and so on. Then think about people you support and map, in detail, the differences. What accounts for these?

All of us like to believe that we, and the services we work in, are always doing the best and there is no doubt that the vast majority of paid staff *do* strive to give their best. However, good

intentions are rarely enough and Wolfensberger has designed a workshop to test out service quality and outcomes, and this is described in the next section.

PASSING (Programme Analysis of Service System's Implementation of Normalisation Goals)

This workshop, which typically runs over a week, enables participants to understand some of the detail of Wolfensberger's work, and then apply his ideas to a real service. The 'manual' which accompanies the workshop contains 42 criteria against which to judge service quality. Participants gather evidence from the chosen service, and with the help of a team leader (someone very knowledgeable about normalisation) then rate the service (ratings go from 1-5, where 1 is very poor, through to 5 which is excellent or above) against each of the 42 normalisation criteria. These criteria are wide ranging, but broadly fall into two groupings – those concerned with the image and imagery of the service, and those concerned with competency. Examples include:

The physical setting of the service:

- *Is the service located in close proximity to ordinary resources within the community which can act as settings for positive contact between users and valued citizens*? Does the location increase or decrease the likelihood of the people living within it to be able to build strong positive relationships with their neighbours and local contacts? Does the house back onto similar attractive properties or an industrial estate?

- *Is the setting comfortable and relaxing*? Many services are delivered within small domestic settings and by the very nature of the support being offered often mean these settings become quite crowded with both users and staff, especially at handover times. Could we do more to minimise such overcrowding situations with staggered staff shifts etc and thus make the home more restful, relaxing and more personalised to the people who live in it?

- *Does the setting avoid over and under protection?* Typically, we would suggest, we over protect and thereby are potentially either depriving users of their freedom to access all aspects of their own home or equally disempowering, causing them to be overly reliant on staff support.

User groupings and relationships in service:

- *Is the service located in close proximity to other services for people at risk of devaluation or does it congregate people with dissimilar devaluing characteristics on the same site*? If the answer to these questions is yes, then Wolfensberger would see this as a significant negative as we are arguably perpetuating a devalued groups 'ghetto'.

- *Does the size and composition of the groupings of service users within a service provide the optimal conditions for service users to acquire valued characteristics?* It could be argued that any grouping that caused an individual to have to share

accommodation with another, who was not either their partner or their close friend, would mark them out as a devalued member of society.

- *Does the service support its users to participate in valued activities, in valued settings with valued citizens*? This is a fundamental question and encapsulates all the values we now see as part of Positive Behaviour Support and should cause us to question closely any activities that we promote for our service users that perpetuate them remaining on the fringes of society.

- *Do service workers talk to and about users in respectful ways?* Do we ensure that all staff avoid using childlike names for service users (Timmy, Mikey, etc.) and derogatory expressions such as "he kicked off again last night", when what we mean is the service user became distressed or anxious?

Those that have been involved in PASSING workshops for many years have found that contemporary services score reasonably well on some imagery ratings (many people now live in ordinary houses as opposed to settings with a more institutional appearance), but that the day to day life experience of many service users remains far from the aspirations set out by Wolfensberger. The outcomes from recent PASSING workshops run in North West England have been written up by Race, D (2014).

Those who have attended PASSING workshops can be left with unanswered questions about how to implement Wolfensberger's theory with regard to the individuals they support, as the task of change can seem overwhelming. Here, person centred planning (*but underpinned specifically by social role valorisation*) can be useful. One such approach has been developed by John O'Brien, and is called *The Five Service Accomplishments*. This sets out – in terms that can be readily applied to an individual – what a service should be trying to achieve. This includes community participation (but in a meaningful way), developing a valued role for a person and so on. This model does not present shortcuts to overcoming devaluation but does require us to think hard about what a desirable future looks like for a person and helps identify some of the important actions that will take the person in that direction over a number of years.

A further paper to be published in this series by CAPBS will also look in some detail at person centred planning and the relationship to social role valorisation.

Conclusion

This practice paper has described the key components of normalisation, and provided examples of how this approach can be applied to contemporary services. Wolfensberger's critics have claimed that his ideas are too 'prescriptive' and therefore force service users into particular ways of behaving that negate individuality or choice. Based upon your reading (and further reading) of normalisation and social role valorisation theory, you will reach your own conclusions on this issue. In doing so, remember to use yourself as the referent and then think about the lives of those who depend on services. At the very least, such contrasts will reveal that we still have a considerable way to go to counter systematic devaluation, and that normalisation theory provides a valuable benchmark to judge progress.

Suggested discussion points

- How relevant is the concept of normalisation today?
- How important is the social image of people with learning disabilities/intellectual disabilities?
- How could you use the PASSING checklist in your service?

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