

DEINSTITUTIONALIZATION AND PEOPLE WITH INTELLECTUAL DISABILITIES: IN AND OUT OF INSTITUTIONS

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Notwithstanding its rather intimidating title this book deserves to be read by all who are involved in seeking to improve services for people with intellectual disabilities. The book is divided into four parts: Living Inside; Moving Out; Living Outside; and Moving On. The first part documents the lives of people with intellectual disabilities who were placed in institutions and who spent most of their lives there. It also seeks to challenge views about the nature of intellectual disability and how it has been historically defined. The purpose of institutions is questioned. The second part is concerned with the usually unreported experience of people with an intellectual disability moving out of institutions and the way in which their wishes when choosing where and with whom to live are either casually overlooked or deliberately ignored.

The third part notes the erosion of initial enthusiasm and energy that often sets in after leaving the institution. The biographies of people with an intellectual disability, which are included in this book, confirm that while life in the community is better than life in the institution, it rarely matches the hopes or the realities

of the lives that most of us live. The final part considers some of the problems that are currently emerging in relation to deinstitutionalization and community life. It is noted that the old issues of control and surveillance that permeated institutional life have been reconstructed in 'homes in the community'. Attention is drawn to a serious lack of new ideas about how to create alternative options for people with intellectual disabilities.

In his chapter entitled '*The institutions are dying, they are not dead yet*', Steven Taylor critiques the continuum model of services for people with intellectual disabilities and the associated principle of least restrictive environment (LRE). This continuum is conventionally represented by a line running from the most restrictive environment (public institution) to the least restrictive (independent living). While Taylor identifies a number of conceptual flaws with this model, he fails to acknowledge the fact that deinstitutionalization is not a form of linear progression but is a *social process* that impacts upon the individual. In other words, the kind of institutional features identified by Goffman (1961) - block treatment, loss of autonomy, depersonalisation, psychological isolation, social distance between staff and residents - can as easily be found in purpose-built 'homes' located in ordinary neighbourhoods. The LRE continuum model also fails to take account of village communities which may appear superficially to possess the characteristics of an institution but which in fact provide a distinctly non-institutional pattern of care. This fact has been confirmed by the findings of a comparative analysis of quality and costs of village communities, residential campuses and dispersed

housing schemes (*vide* Emerson, Robertson, Gregory, Hatton, Kessissoglou, Hallam, Knapp, Järbrink, Netten and Walsh, 1999).

The discussion on the origins of institutions in the 19th century, which are described in this book, ignores a number of factors. It is not generally appreciated that the purpose of many of the early institutions was rehabilitative and integrative and to that end they were deliberately kept small and thus were responsive to the individual needs of residents. Their rural location, often represented by critics as a form of self imposed physical isolation/segregation, was quite intentional. Given that involvement in horticultural and agricultural work formed an important part of the rehabilitative programme, it was necessary to have easy access to land – not a resource in ready supply in urban centres! Over time institutions became victims of their own success and despite the protestations of the superintendents, more and more people were admitted. Inevitably with increasing populations the role of the institutions changed from being rehabilitative to being custodial. Unsurprisingly the kind of negative institutional features identified by Goffman began to take hold.

The book points to a number of current developments which should give cause for concern. The marketisation of care services through the introduction of the purchaser-provider model is one example. It is noted that local authorities have been progressively withdrawing from providing residential services for people with intellectual disabilities. Not-for-profit organisations and private commercial companies have increasingly taken on that task. Over time competition is likely to favour those commercial companies which can maintain their competitive edge by keeping staff costs low largely through engaging part-time and poorly qualified

staff. Given the limited financial resources available, purchasers are likely to select the cheaper options. The likelihood is that not-for-profit organisations will be slowly squeezed out leaving the commercial companies to dominate the market. In such a process the individual needs of people with intellectual disabilities will be ignored, as the first obligation of the companies will be to shareholders and not 'service users'.

An inevitable consequence of the commercialisation of social care provision is that 'successful' companies will start to swallow up the less 'successful' ones. The result is likely to be the creation of a few monolithic companies which will be in a position to dictate terms to the purchasers, for the balance of power will have irretrievably shifted in favour of the providers. The only impediment to such a development would be the introduction of restraining legislation but that seems unlikely given the present government's commitment to free market principles.

This may all seem an alarming prospect but as this book illustrates there are signs that it is already happening. In other words, we are witnessing a form of re-institutionalisation where because of poorly paid and under-motivated staff, the lives of people with intellectual disabilities are becoming increasingly impoverished. One does not have to be an apologist for institutions to recognise that some former institutional residents were less lonely, bored and restricted than those currently living in 'homes in the community'. Limits on the operational freedom of staff resulting from resource constraints combined with the existence of a risk-averse climate means that homes in the community are likely to turn into mini-institutions.

One crucial element in the lives of many former institutional residents, which is

now missing and which this book properly highlights, is the opportunity to undertake some form of work. Whilst much of the work undertaken in institutions may well have been exploitative in the sense that workers were inadequately remunerated, nevertheless the opportunity to work did give a sense of achievement and self worth.

Although the book does not do so, it is worth briefly comparing the situation in the social care sector with that in the National Health Service. Whilst there has been almost universal opposition to any idea of the NHS becoming privatised, one is witnessing precisely that process in the social care sector. There are a number of reasons why this process is likely to go unchecked: firstly, there are few powerful voices or organisations with the necessary political clout to champion the cause of social care; and, secondly, social care does not enjoy a strong and positive public or professional image. There is yet another factor which cannot be overlooked and that is the increasing medicalisation of the social care sector. This is likely to impact on the social care ethos – in particular on the way in which people with intellectual disabilities are perceived by medicalised social care staff. Wolfensberger (2005) has recently drawn attention to the dire predicament of members of societally devalued classes – in particular people with intellectual disabilities - in the health care system in the USA. Medicalisation leads to re-institutionalisation by another route.

This book is to be welcomed for it encourages the reader to look more closely and critically at the concept of deinstitutionalization and it raises a series of important issues that need to be addressed if the quality of life of people

with intellectual disabilities is to be significantly enhanced.

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