

**AND
THE
WALLS
COME
TUMBLING
DOWN
JOHN ARMSTRONG**

Against the historical background of institutions, this author adds an interesting perspective to the debate on deinstitutionalisation. He maintains that the community needs to create networks which will share the responsibilities for integration rather than pouring resources into paid professional services, which he believes, can't deliver.

I first met Jim in 1984. He was 27 and lived with thirty-five other men who were aged between 27 and 73. His home was in a 'unit' (a euphemism for a ward) that was 130 years old and located on the very edge of the main institution buildings overlooking a cliff. Jim had lived in this place for five years, and apart from the daily routines of washing, dressing and eating, he did nothing. As I talked with him, it was apparent that his attention was focussed on his parents coming to take him home at 2.30pm that afternoon. But this afternoon would be like every other; there would be no parents at 2.30pm, no visitors, only solitude and his endless vigil for those who had abandoned him. Tomorrow would be the same, as it had always been, world without end...

I learned that Jim had been a student at a well-known Melbourne Grammar School to Year 10, and had then for a short time worked for PMG (now called Australia Post). It was unclear how Jim came to be in this 'service', but it was quite clear that his life and the lives of others in this institution were going nowhere.

How is it that our communities have come to see institutions as a 'service' and the solution to a 'problem'? The institution - a place where the major activities of life take place in a single location with others of the same class ⁽¹⁾ - is now a common and accepted phenomenon where individuals who because of illness, physical, sensory or emotional disability are isolated from the general community.

STEPS TOWARDS SEGREGATION

Prior to the 'Industrial revolution', institutional care was not commonplace. In fact, there is much evidence to support the view that before this period, people and communities accepted and supported disabled family members. The human services which did exist, mainly took the form of 'community houses' (similar to the special accommodation houses today) which were run as private enterprise; 'hospices' (catering for the poor, sick and disabled) were located in churches in the town centre and served by volunteers. It was not until about the 15th Century, that voluntary service workers were paid, thus qualifying them as the first 'human services workers'. ⁽²⁾

The changes wrought by the Industrial Revolution – the breakdown of extended family networks, the move away from cottage industries and the invention of concepts such as 'economic productivity' - brought the notion of community care into question, and a harsher attitude was adopted towards those who came to be viewed as economically unproductive. A new means for valuing human life was emerging.

THE EARLY REFORMERS

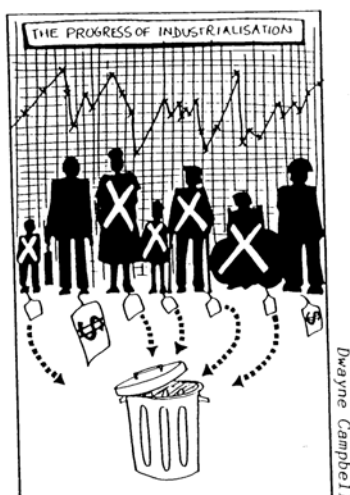
Between 1850 and 1880, within selected cities in the United States (US), a number of innovative reformers established residential schools for children with intellectual disabilities; these 'special schools' were centrally located in the communities which they served. These early pioneers recognised that communities had become uncaring places for their disabled members and that unless supported through education, people with disabilities would be destined to lead squalid and lonely lives. The reformers believed that

education could reverse the effects of intellectual impairment; their programmes were intense and focussed on the future needs of their students. The dreams of the reformers were not without some substance, and most children graduated, and were assimilated into their respective communities. Despite the impressive record, this period of optimism was short-lived, and soon gave way to an equally powerful pessimism, which swept through the US, England and Australia.

DISILLUSIONMENT AND PESSIMISM

Some students of the early reformist schools failed to acquire the desired level of competence, which was required for them to return to a supported community environment. This meant that an increasing number of more severely disabled children and adults were remaining in programmes which had never been intended to provide long-term support. Yet, the desire to protect such children from the harsh realities of the wider community persisted. As a result, the period 1870 to 1890 was marked by a growth in the number of larger institutions for 'the feeble-minded'. In order to effectively protect them from a harsh society, people with disabilities were removed from it. Victoria's larger institutions were built during this period and their locations - although remote - were strategically placed for the economic well being of country townships, and particularly in towns whose gold-rush days were coming to an end!

New concepts - economic rationalism and productivity - guided social attitudes and effected the nature and development of institutional care



for well over a century. This was partly due to the widespread belief that disability resulted from immorality and could be remedied in part, through hard work - such as smashing and moving rocks! At the same time, it was felt that if residents of institutions were to be protected from society, their reduced dependence on that society was an advantage. Institutions turned their attention and activities toward the need to achieve autonomy and self-sufficiency. This new philosophy, however, was never extended to the clients who were not encouraged to work towards either autonomy or self-sufficiency, but were 'employed' in all aspects of the institution's operations. The future welfare of people with disabilities thus remained intimately bound to the maintenance of the institutional setting.

THE ERA OF INDICTMENT 1880-1925

Two major events heralded a new era for people with intellectual disability. The first was the theory of evolution; the second was the invention of I.Q. testing and with it, the discovery and understanding of mild intellectual disability. Together, these events led to a range of new conclusions about people with intellectual disabilities. The condition was viewed as a moral and genetic menace, which posed a serious threat to the future of the human race. This era, often known as the 'Period of Indictment' or the 'Eugenics Alarm', had a fundamental influence on the nature of service provision, whose purpose became one of protecting society from the 'deviant'. In order to achieve this aim, it was necessary to 'contain' the members of this dangerous class and to segregate the sexes to prevent reproduction, through legislation to prevent couples marrying, and through sterilisation. Although these measures fell short of genocide, such ideas were not entirely discounted by some sections of the community⁽³⁾ who used Darwinian theory to justify fanatical (and often racist) views based on genetic purity⁽⁴⁾. In Europe during World War 1, for example, such views were given a political force which was vented towards a range of groups including Jews, blacks, homosexuals and people with disabilities.

The death toll for people with disabilities was not only limited to Europe:

“Less than a third of those committed to the care of the Elwyn School in the United States lived to the age of twenty. Eight out of 625 made it to forty.”⁽⁵⁾

This was due in part, to the spread of diseases like tuberculosis, but also to the appalling conditions which characterised institutional care including over-crowding, lack of sanitation and poor diet. As the number of people ‘needing’ placement increased, the cost of running these places of death needed to be reduced. This goal was achieved by reducing the number of institutional staff. It was not uncommon to find entire wards without staff and people with severe disabilities being cared for by less disabled ‘inmates’. Scull reports ⁽⁶⁾ that in one hospital in England, people were tied to their beds (made from pallets of straw) from Friday evening until Sunday evening when staff returned, as a cost cutting measure!

The Great Lull (1930 - 1950)

The social and genetic menace associated with disability began to subside and was replaced by more important social concerns – The Great Depression and World War II, to name a few. Advances in genetics and the review of earlier ‘pedigree’ studies threw established ‘truths’ about mental retardation into question. Yet with all of this renewed insight, life for people in institutions changed very little. Though society accepted that these people were no longer menaces, how else was it to treat them?

“Court actions ... by people with disabilities... added pressure... to re-evaluate... institutional care...”

The 1950’s and 60’s witnessed a revival of political, academic and medical interest in mental retardation. The civil rights movement forced governments and institutions to examine service provision to people with an intellectual disability, and resulted in public disclosure of life in institutions. Court actions brought against institutions by people with disabilities in the US and Australia, placed added pressure on the authorities to re-evaluate the effectiveness and impact of institutional care on people’s lives.

Persistent revelations about life in institutions, forced governments to seek alternative methods for providing residential care. The process of closing institutional settings with the intention (though not always the result) of providing alternative service, is often referred to as ‘deinstitutionalisation’.

This brief historical discussion leads us to a number of significant observations.

- 1) Irrespective of the condition being treated - physical disability, age or psychiatric disorder - the aim of treatment has always been the same: the condition must be cured, reversed, prevented, isolated or destroyed ⁽⁷⁾.
- 2) During each era, proponents of existing services regarded their actions as benevolent, and were unaware that the system they supported might also have a detrimental purpose.
- 3) When first established, the institution aimed to reverse the effects of disability in response to the



harshness of the wider society.

4) Once the disastrous nature of the institution was discovered, it was assumed that its dismantling would eradicate the 'evil', which it had produced.

5) Today, a commonly held assumption is that any alternative to the institution (particularly if it is located in the community), will automatically be 'good', or at least better than what the institution offered!

Mounting evidence demonstrates that devalued groups will still experience isolation, rejection and dislocation, even when they are physically located in the community. The emotional discomfort and social rejection exhibited towards these groups and their members - in contrast to 'valued' members of society - continues to be the norm. Indeed, society's growing emphasis on materialism and intolerance may mean our attitudes to disadvantaged groups have worsened.

A society, which creates this kind of moral environment inevitably, deals with disadvantaged groups by designing services to support them. We have in fact, come to view the good life for devalued groups, as being surrounded by an endless array of human services and human service workers. Is it not surprising, that as a result, people who have been 'deinstitutionalised' lead unfulfilling, isolated and lonely lives.

It seems to me that as a community we have come to expect paid services to deliver the kind of human contact and support which was once provided by local communities competently and on a voluntary basis. We live in an age where human services have professionalised and technologised those activities, which were once performed by communities for the mutual benefit and enrichment of their members. John McKnight⁽⁸⁾ refers to the massive take-over and expansion of the human service sector as "Community Busting" - the replacement of voluntary, caring interactions with paid, professional service. Thus we have created a society in which those experiences that are a natural part of human existence now require a professional 'fix'. All human and community needs are reinterpreted so that they become human service needs.

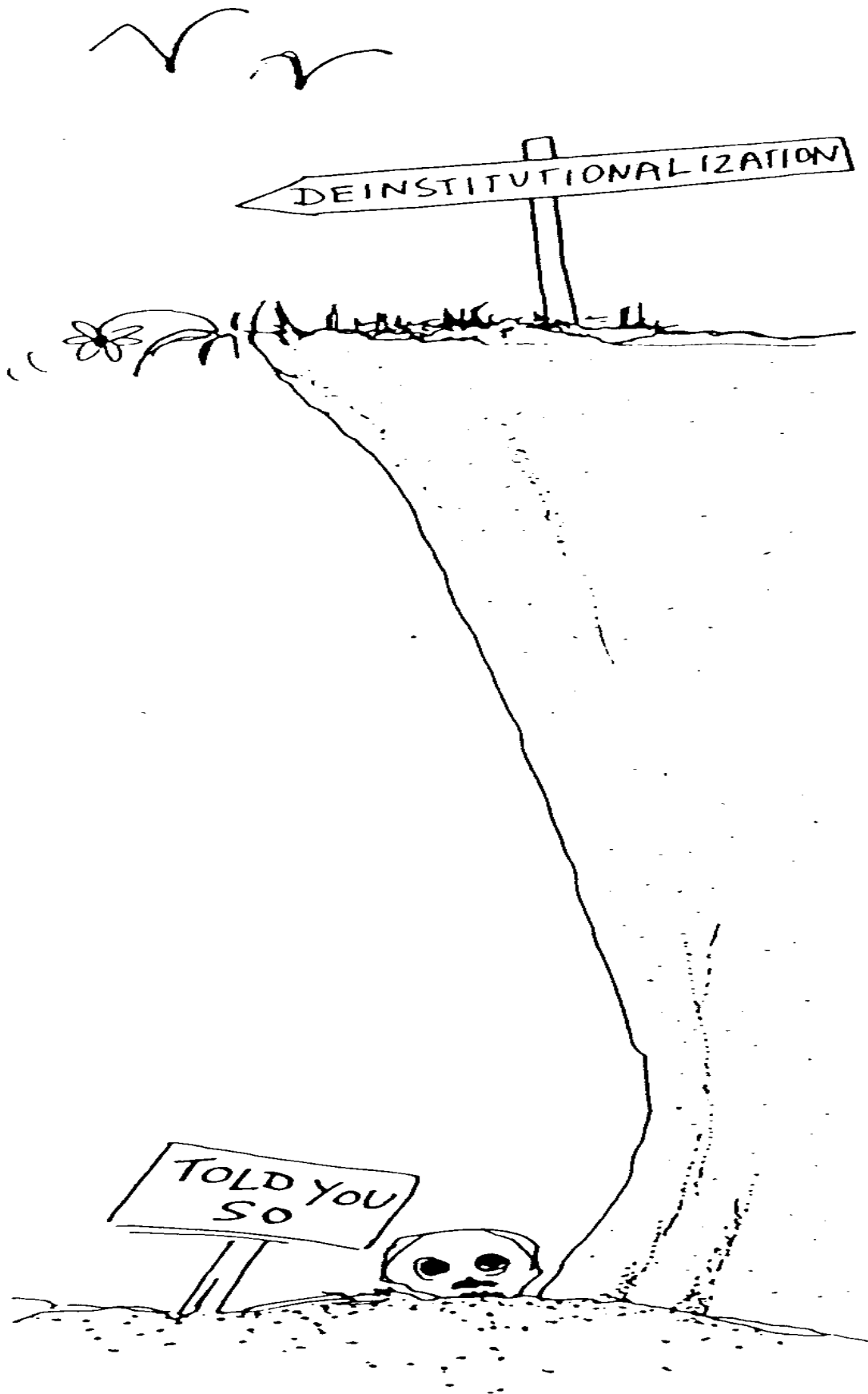
For instance, people don't need a friend, they need home help; not a shoulder to cry on, but a bereavement counsellor, not support to stay at home, but a geriatric assessment team, not a group, club or association, but a developmental day programme; not hope for the future, but a general service plan, and so on.

"...all that is required is opportunity and commitment from individuals to make deinstitutionalisation work."

Devalued people have become the new resource for a faltering economy, and deinstitutionalisation, a vehicle for the creation and growth of a new branch of the human services sector. The role of caregiver has largely fallen to women in the past, and (perhaps ironically) it is largely women returning to the workforce, who are finding paid positions in this new growth area of professional community care.

McKnight⁽⁸⁾ believes that the resources, which are necessary for communities to perform supportive and caring roles are already in place; all that is required is opportunity and commitment from individuals to make deinstitutionalisation work. McKnight's writings explore the conditions, which are necessary for successful integration to occur. He maintains that people with disabilities are excluded from the groups, which operate in society, and that the challenge is to include people in these social structures. In some instances, this has occurred through the creation of networks, which share the responsibility of supporting less able members. Both Wolfensberger and McKnight argue that the society segregation of devalued people is thus due to factors other than a lack of resources.

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Dwayne Campbell

house'. He lived with four other men, went shopping and helped prepare meals. His days were still pretty empty, but some things had improved. He was later moved to a house in the suburbs, which was staffed and managed by an agency where he attended an adult programme with sixty other intellectually disabled people. He has his own room and a few personal items, which he has begun to purchase. However, his weekends are pretty empty and his holidays are organised by the agency and taken with other residents.

His major relationships are with other clients of the service and with those who are paid to relate to him - Jim still lives in a service, but it's their home, not his. It says a lot about the state of things when no one wants to be with Jim unless they are paid to do so! So he waits for his service to deliver the goods, and he waits to be a part of things; to have something useful to do, to be regarded as an adult; to have some friends and maybe a close friend; to learn some new skills that interest him; to look as good as he can and to have a place to call home.

Paid service can't deliver these things, but a well functioning community can. How much longer shall we pay dearly for something that can't deliver?

Training is available for people who want to understand the values and assumptions, which govern society's treatment of devalued people and the nature and quality of the human services they receive. A variety of workshops are held on a regular basis. Further information can be obtained by contacting the author on 651 6769, or by writing to:

Association of Advocacy and Change through Training

P.O. Box 561, Carlton South, 3053.,

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REFERENCES

- (1) Goffman, Asylums. Although this is not a direct quote, it is consistent with his definition of the 'Total Institution'.
- (2) Wolfensberger, W. The Origin and Nature of Our Institutional Models: Syracuse Human Policy Press & Scull A.T. Museums of Madness. The Social Organisation of Insanity in 19th Century England: Penguin. Harmondsworth 1982
- (3) Hollander, R. Euthanasia and Mental Retardation: Suggesting the Unthinkable in Mental Retardation: Vol. 27, No.2 1989
- (4) Wolfensberger, W. The Extermination of Handicapped People in World War II Germany in Mental Retardation: Vol. 19, No. 1 1981
- (5) White, W.D. & Wolfensberger, W. The Evolution of Dehumanisation in our Institutions in Mental Retardation: Vol. 7. No. 3 1969
- (6) Scull, A.T. Ibid
- (7) White, W.D. Wolfensberger, W. Ibid
- (8) McKnight, John L., Beyond Community Services in Journal of the Association of Severe Handicap, in publication.