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Ageing and SRV-- A challenge for the future

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> *It is common knowledge that the conditions of old people today are scandalous... we must try to understand how it is that society puts up with it so easily.*

This quote came from Simone de Beauvoir in 1972 (p243) but applies equally 30 years on. This highlights that the treatment of older people is already a challenge for our community but will be an increasing challenge for the future.

This paper will examine the challenges facing the SRV movement in influencing public policy on the support of older people. It is based on a thesis written with reference to Australia. While I do not claim to be an expert on global ageing issues, I believe there are many similarities across Western countries. Judging by the move to "export" aged care knowledge from Australian to Asian countries, many of those countries also seem set to follow this trend.

While there is an increasing emphasis on community care there is tradition that promotes the institutional care of older people and entrenched practice that prevents a move towards total deinstitutionalisation. Aged care is well behind other fields in moves to close large congregate care facilities.

The scope of the issue

In 2001 the proportion of Australians aged over 65 years is 12.5% (2.4 million people), this will increase to 18% by 2021 (4.2 million). At the same time by 2020 the number of working aged people will not increase. (Myer Foundation Report, 2002). Life expectancy is increasing and people are remaining healthier until later years.

In an international analysis of ageing trends, Brink proposes three phases of responses to population ageing. The first is where the proportion of elderly is between 7 and 10% of the population, the second between 11 and 14%, and the third where the proportion is over 15%. At this third stage she proposes that the amount of time spent in collective institutions declines as people move there mostly at the end of life (Brink, 2002).

The increasing dependency ratios (proportion of those over 65 years to those of working age) and increased workforce participation by women (who are the main providers of informal care) has reduced the capacity for informal care in the community. These trends will increase into the future. Coupled with that is a decline in the sense of "community" which has been acknowledged by many commentators (Hamilton, 2003; Putnam, 2000, Bellah, 1985).

Ageing policies in Australia and many other countries were developed at a particular point in time and, if in fact they were relevant at the time, may no longer be relevant to current situations. For example, aged pensions were introduced for people over 65 years in Australia at a time when they did not live many years past this age. Many of the original institutions for older people in Australia developed out of an initial response to a shortage of housing for retired people on modest incomes.

In Australia the average size of institutions is actually increasing in order to improve their economic viability. A recent report by the Myer Foundation cites as a problem the fact that "more than half of the residential providers operate facilities with less than 50 residents" (Myer Report, 2002, p 35). A facility for 90 people is considered a "viable" size. The commercial sector also continues to build large retirement complexes that congregate and segregate older people.

Despite the long history of institutional solutions for many groups considered "in need" there has been an increasing move in recent years to deinstitutionalise these groups and examine other alternatives.

In the field of mental health the seminal work done by Goffman (1961) and others in exposing dehumanising practices in mental health facilities began the questioning of the role of institutions in this field. In Australia in 1993 the Human Rights and Equal Opportunity Commission conducted an inquiry into the human rights of people with a mental illness. A number of scandals in mental health facilities led to this inquiry, and Commissioner Burdekin explained that the report "documented numerous examples of serious violations of the most basic human rights of mentally ill people". (Opening Address by Commissioner Burdekin, 1993, p 4)

There has been no shortage of criticism of the deinstitutionalisation process in the mental health field (some examples include Barber, 1985; Tomlinson, 1991) with good cause. Difficulties have been created by community attitudes and by underfunding and poor planning of the change process. While there are occasional calls by the public to reverse the trend, policy makers in Australia at least have accepted the principle that people with a mental illness have the right to live

outside of institutional settings.

Wolfensberger (1975) analysed the evolution of institutional models in the United States, with a focus on the field of intellectual disability. The earliest institutions, around 1850, were designed to educate the impaired, and were not meant to become long term custodial care. In the early 1900's, society's view of intellectual disability changed, and greater concern was expressed about the potential dangers of having "feeble-minded" people as part of the community (Wolfensberger, 1975, p33). The institutions, which had begun expanding in size, were now seen as protecting society from the "deviants". This led to a greater likelihood of exploitation and dehumanisation, which eventually led to the push for deinstitutionalisation in the United States in the 1960's and later in Australia.

Again the results of deinstitutionalisation in the field of intellectual disability have been equivocal. Many of the processes have created smaller institutions in the community, or resulted in the isolation of people. I do not have space here to discuss the research relating to the outcomes for people, but make the point that the overall trend in Australia and many other Western nations is to support community living for people with intellectual disabilities, or at lest recognise the desirability, even though institutions remain.

This is also the case for people with physical and multiple disabilities. We could also examine other areas such as substitute care for children. While institutions still remain, there is general agreement that they are not desirable for many groups.

Why is it then that large scale institutional care is considered acceptable and even a desirable form of support for older people who are frail or cognitively impaired and in need of support? Segregation and congregation is even considered acceptable and desirable for fit and healthy retirees. Older people themselves seek out these forms of support.

This dilemma is highlighted by the plight of people with disabilities who are ageing. They have fought all of their lives to live a typical life in the community away from institutions, and then may find themselves back in residential care if their support needs increase with age.

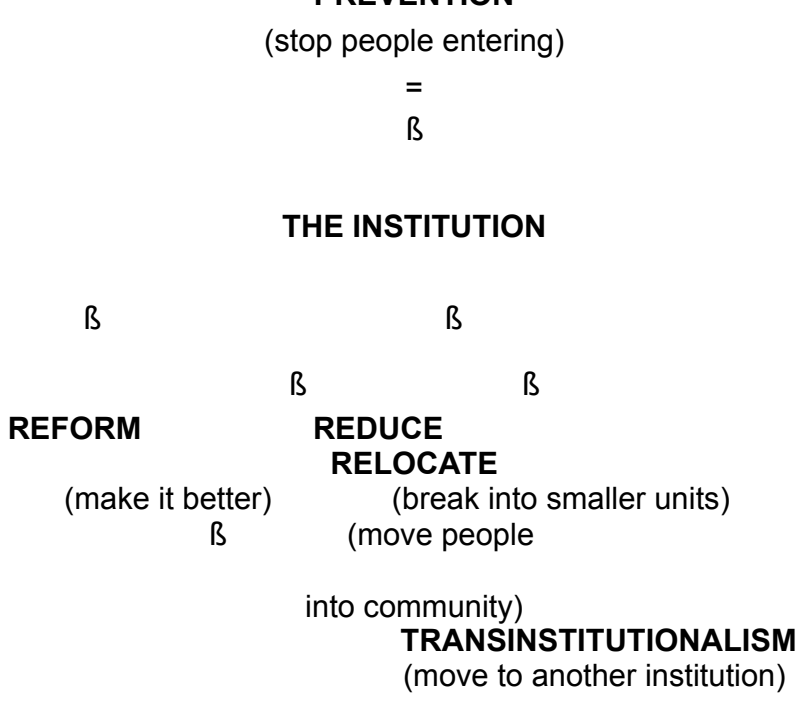
What are institutions and what is deinstitutionalisation?

In the field of human services the concept of "institutional care" is generally accepted as a method of organising care for those with a particular support need which involves large scale residential accommodation. The term "institution" has come to have negative connotations, although this has not always been the case. The term "asylum" was seen as a benevolent response to human need, protecting the "destitute" from an unkind society.

The definition of **deinstitutionalisation** which will be used in this paper is the process of closing large residential "whole of life" services that have been designed for particular groups in our society considered to be "in need", and moving the people into non-institutional settings that are integrated in the community.

If the object of deinstitutionalisation is to release people from the negative impacts of living in large scale institutions, then there are a number of processes which could bring this about. It is also important to distinguish between what happens to people and what happens to buildings.

Fig. 1: Forms of deinstitutionalisation



In relation to older people in Australia, there have been attempts at prevention" and "reform" and much "transinstitutionalism". There has been little relocation of older people into the community, and any dismantling of institutions has been for reasons of viability rather than ideology.

Is deinstitutionalisation desirable?

Institutionalisation is both underpinned by, and perpetuates a negative view of ageing. There is considerable evidence that institutionalisation in its many forms is both damaging and dehumanising for older people. While there are attempts to prevent older people entering institutions, or moves to reform existing institutions, there are few calls to close them completely

The "wounding" process as described in Social Role Valorisation Theory (Wolfensberger, 1995) applies equally to older people. Attaining a particular age (such as the notional age of 65 years in Australia) does not in itself trigger the wounding process but events such as retirement, ill health or the onset of disability can be the first step. Any deviation from the characteristics that society values that is viewed negatively can lead to devaluation, which in turn can lead a group to be treated differently by society.

There are many aspects of the wounding process that may be experienced by older people living in the community, such as rejection or branding and labelling. However, the process of leaving home and living in congregate institutional settings can result in many negative consequences for older people. These may include:

- loss of control
- loss of freedom, independence and individuality
- institutional routines and dehumanisation
- loss of dignity and privacy
- medicalisation
- loneliness and lack of meaningful activity
- segregation and dispossession
- abuse and exploitation
- lack of secure tenure and fear of reprisal

While government approaches to monitoring the quality of institutional care may have improved conditions (at least in Australia), many of these experiences still remain. Devaluation may be more subtle, such as not being given enough time or assistance to eat. This is well summarised by Friedan when she talks of her experience in visiting many nursing homes:

> Over the years, I have visited some of the very best nursing homes, sparkling clean, where neither physical or chemical restraints were used, and the halls and rooms did not smell of urine and faeces or that awful all-pervading sweet smell of disinfectant... some were doing their best to give the residents some 'choice'-- over the food they ate, which movie to see - and some control of their day, at least the illusion of some choice over when they wake or sleep or eat. But basically the institutional paradigm remained: They left the larger community of which they were part, and their identity in it, when they entered the nursing home.(Friedan, 1993, p488)

We are also becoming increasingly aware of how older people who remain at home do not necessarily remain part of the broader community. Hazan (1994) discusses how knowledge about ageing is produced and reproduced. He believes there are two conflicting modes of reference in relation to ageing. One is the forces which remove older people from the rest of society and assign them to an enclave. The other is the awareness that most of us will eventually occupy that enclave. He explains how the language we use serves to "construct a wall around ageing" (p13) especially the terms "old" or "ageing". He argues that:

> ...the problem is not that of the aged themselves but of those who relate to them, and similarly, that 'solutions' to the 'problem' do not address the aged at all but serve those for whom they are a burden. (p22)

The types of solutions that are suggested are classified in terms of two axis, the first ranging from integration to segregation, the second from humanisation to dehumanisation.

This then leads to four possible combinations:

- 1. *Integration and humanisation*, where elderly people are both well integrated into their social environment and viewed as acceptable human beings. This is more common in rural societies, especially where information is transmitted orally.
- 2. *Integration and dehumanisation*, where the aged live in the midst of society but are no longer regarded as valued human beings. An example of this may be the abuse of older people in their home or the home of a family member.
- 3. *Segregation and humanisation*, where the elderly are distanced from the community but preserve their social identity. The "new communities of the aged" are an example of this, in retirement villages or suburbs that have ageing populations.
- 4. *Segregation and dehumanisation*, where the elderly are both alienated and no longer regarded as valued human beings. The elderly people who live in large institutional settings are at grave risk of being part of this category.

Figure 2: Two axis of ageing leading to four possible combinations of approach.

1.	***Integration***	**2.**

Humanisation	***Dehumanisation***
3. ***Segregation***	**4.**

Source: Hazan (1994)

The segregation and dehumanisation of older people in SRV terms is a clear consequence of the social devaluation of older people. However, is the devaluation of older people at all tempered by the knowledge that we may also one day find ourselves in a similar position? Do we attempt to humanise the institutions in order to make ourselves feel better about institutional responses? Or do we promote integration and community care that may still be dehumanising (through isolation or neglect) to convince ourselves that we are promoting the "right" approach? Do we adhere to the theory of "disengagement" (Cummings & Henry, 1961) that convinces us that older people prefer less contact with the world and choose to live segregate lives? Or are we convinced that older people are happier living with 100 strangers as at least they will have some company. Or in the end, are we more afraid to confront the unconscious devaluation of older people because of the knowledge that we may at some time occupy that place in society?

The consequence of Hazan's analysis is to understand that any response to the wounding of older people needs to aim for both integration in the community and real inclusion that is "humanising" for older people. This is a particular challenge in relation to people with cognitive impairments, such as those suffering from dementia, who now form the majority of residents in many forms of institutional care, despite the deinstitutionalisation of mental health institutions where people with dementia once resided. Many believe they must be confined "for their own safety".

There are also clear economic factors that continue to promote the provision of large scale institutional care for older people. Governments and providers argue economies of scale are required in order to provide the care people require at an affordable cost. Providers also have a large investment in their properties and wish to protect their assets.

There is also the argument that as countries move into phase three of population ageing, that institutions become more of a palliative care service that an alternative home, therefore it is acceptable for them to be more like a hospital than a home. Australia has certainly not yet reached that stage, with 61.8% of residents in 2001 having lived in residential services 8 years or more (18.3% over 5 years) (Australian Institute of Health and Welfare, 2002).

The challenges outlined earlier also mean that supporting older people in the community will become more difficult over time. The provision of freely given support is impacted by higher dependency ratios, the greater engagement of women in the paid workforce, the mobility of families, and the general decline in the sense of community. Australia also faces challenges in finding the workforce required to provide community care. This is also an issue facing institutional services, although work in this area tends to have greater security and continuity.

What are the challenges facing the SRV movement?

There are organisations that have utilised SRV principles to change the way in which services are delivered in order to promote more valued roles for older people. This has included increasing the focus on community care, enabling those with higher levels of disability or frailty to remain at home, improving the image of facilities and using developmental approaches in delivering rehabilitative and social programs. However, there are few countries or states in which SRV principles have more widely influenced policy to the extent of changing entire service systems. In recent years policy has been driven by the fear of increasing numbers of older people needing support because of longer life spans and improved medical care. This has led to "demand management" and economic rationalist approaches dominating policies regarding older people. There is a risk that institutional care for older people will decline due to the costs of providing such care, rather than through a recognition of the shortcomings of the model. This could result in the situation that alternative models of support could be similarly dehumanising, such as we already find with some models of community care and the subsequent isolation an dehumanisation of older people in community settings.

For the deinstitutionalisation of older people to occur on a large scale, there is a need for a new policy "frame" and a systemic strategy to implement it. There are many challenges for the SRV movement and other groups operating from a clear values perspective in influencing this area of social policy. These challenges exist at the individual, community and systemic level.

The ideal future is that all older people will be valued and have full citizenship in our community. They will be encouraged to stay fit, well, active and involved. However, if support is needed, it should be provided in the location of their choice, in a way that supports their roles in the community, and allows them to have control. There may be a need for some residential services for rehabilitation and palliative care, but these will be short term, homely and part of local communities. Paid services will work alongside families and communities, not taking over but working in partnership so that those networks are encouraged to support the inclusion of the older person.

Supporting individuals

SRV principles would predict that any changes in community attitudes towards older people will depend on the ability to maintain and increase the valued roles older people are able to undertake in our community. In Australia the compulsory retirement age has been abolished, but there are still attitudinal barriers to workforce participation by older people. Older people make a significant contribution to the volunteer workforce and in caring for family members such as grandchildren. The challenge comes when frailty or cognitive impairment means that older people are no longer able to be involved in those roles that society views as "productive". There is a need to support older people to have valued roles that involve "being" as well as "doing".

The way in which support is provided to older people also influences how they are seen by the community. The ability to have control and influence over the supports provided retains the valued role of household manager. This is much less likely in institutional settings than if the person remains in their own home. Supports need to be individualised, developmental and promote real participation in the community not just living in community.

In order to support older people to remain in the community with increasing frailty, communities also need to respond in new ways. Accessible community facilities and transport are important supports for real community participation.

Older people are also at risk within the health system. Older people in Australia are known as "bed blockers", creating a "burden" on our health care system. Older people are highly likely to enter residential care following an admission to hospital. Programs are now being implemented to prevent the hospital admissions of older people. While this may advantage older people by enabling them to receive additional support at home, the risk is that deinstitutionalisation may occur through cost saving measures with few safeguards on the wellbeing of older people.

Systemic level change

Policy responses will inevitably balance the needs of older people with those of the broader society, vested interests and government. As Rein states:

> ...policy develops from compromise among contending interests, ideals and purposes so that an acceptable pattern contains the contradictions and limitations
>
> which make it politically acceptable. (1996, p25)

Given the essentially compromising nature of social policy, is it then possible to pursue the goal of deinstitutionalisation of older people? The moves to close large institutions for other groups has been driven by a strong value commitment to supporting the rights of people to leave the institution, and a belief that such a move would improve their quality of life. The limitations of the success of these moves have been largely to do with difficulties in their implementation, an unwillingness to move the associated resources from the institution to the community and the perennial barrier of community acceptance for people who are seen as different.

For older people, the commitment by society to the values which support a life outside of congregate institutional settings is essentially lacking. Even those who recognise the deficiencies of the current approach rarely recommend its dismantling. The voice of older people (particularly those who are frail or cognitively impaired) is relatively powerless amongst other interests in the system. The future older generation – the "baby boomers" are beginning to make their voice heard, although the response of the industry is to predict the need for better institutions to meet the higher expectations of this cohort.

The balance of care in the Australian community is heavily towards residential care. 74% of Commonwealth funding per capita goes to residential care. Real per-capita expenditure on community care has declined since 1993. (McCallum, 2001). As in many other fields, the rhetoric about changing the emphasis to community care is not followed by the resources.

The method of financing support for older people is also critical to the future policy frame. "User pays" is an increasing emphasis of governments and runs the risk of creating different systems of care for the rich and the poor. There is a risk that deinstitutionalisation will be achieved by making residential care so expensive that people cannot access it, without making planned provisions for alternative care. There is also a need for the financing system to be equitable across generations.

One of the key elements of a new approach to the support of older people is to separate the accommodation and care components of current services. In Australia there is only limited access to the same level of subsidy that would be received in residential institutions for care that is delivered in community settings, despite people with the same levels of need being located in both settings. If people with similar levels of need could access equitable funding for support services, this could be delivered to the accommodation setting of their choice.

Of course, the funding for support services is only part of the story in relation to supporting older people to have valued roles in our community. There needs to be a consciousness about how the current discourse about ageing devalues older people, and the continued segregation and congregation of older people reinforces that devaluation.

The influence of SRV theory

The influence of SRV theory

The theories of Normalisation and Social Role Valorisation grew out of the field of intellectual disability and have found application in other spheres. In Australia, SRV has influenced practice in a number of organisations, which in turn has had some impact on policy, mainly through the development of innovative programs, which were then more widely implemented. (Schultz, 1994). SRV principles have been used equally as a rationale for reforming institutions as for creating alternative forms of support. One state in Australia has utilised the principles as a basis for a Ten Year Plan for Ageing. However, the SRV "movement" as we know it has few members whose main interest is the support of older people. The work of Joyleen Thomas has been the most systematic of implementation efforts in Australia (Better Practices Project, Aged Care & Housing Group, 2000).

Challenges for the future

Is the potential "crisis" of ageing" what is required to prompt us to think differently about the way in which our societies treat older people and the way in which we organise supports? Or will the economic pressures associated with this crisis lead to older people who are frail being even more devalued and at risk in our community? Is the potential decline in informal supports a consequence of our modernistic thinking and is this open to influence?

There is a need to not only engage those who provide services for older people in SRV training and implementation efforts, but also to engage the families of those people in a broader family and community movement to raises consciousness about the issues.

While there is a growing literature on "positive ageing", this is slow to infiltrate service practices and is not generally seen as relevant to those who are frail or cognitively impaired. The service culture is increasingly dominating people's older years, and those who resist services are seen as "uncooperative" and "cantankerous". There is little clarity around appropriate personal and family domains and the relevant areas for service intervention. The service culture also stresses the need for dependence and incapacity to be maximised in order to gain funding resources. Approaches to strengths-based assessment of older people (such as those developed by Helen Kivnick (1998) are not widely used.

Where small pockets of innovation have occurred, there is little awareness of the origins of these and the insights derived from SRV that may have led to these new service models being developed. There is a need to safeguard these innovations as well as developing many more demonstration projects that focus on supporting and maintaining valued roles for older people.
The teaching of SRV needs to incorporate more examples relating to older people and would also benefit from more theoretical developments, for examples in relation to role theory and older people.

There a number of people internationally who teach SRV as part of academic courses relating to the areas of disability or mental health, but there appear to be few courses on Gerontology that cover SRV theory. There is also little in the way of published material that addresses SRV in relation to ageing.

There is much that can be learned from Social Role Valorisation Theory that could be utilised to improve the life conditions and experiences of people who are ageing. It is a challenge for the SRV movement to encourage the application of SRV theory to the support of older people, and a equal challenge for those who provide support to older people to examine what can be learned and applied from SRV theory.

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