Why are institutions and disability villages a bad idea?

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In considering the place of institutions, large or small, it needs to be understood that their historical roots over the last century are firmly rooted in eugenics (Black, 2003). That is, they were not established to provide an appropriate life and service for people with impairments. Their aim was openly to protect the rest of society from the 'breeding of defectives'. Community leaders such as Churchill, Huxley, Keynes and many others openly supported the segregation and sterilisation of people with intellectual impairments. Many writers contend that some current practices in society are a form of 'neo-eugenics' and re-institutionalisation would fit into such a doctrine (Hubbard, 1987; MacLeod & Fraser, 1998; Sayce & Perkins, 2002; Stehlik, 2001). To revisit such a discredited doctrine would be astonishing in a modern pluralistic society, particularly as it appears that the work done on including people with a disability in society has produced positive changes in attitudes in the younger generation (Yazbeck, McVilly, & Parmenter, 2004).

Why are institutions a bad idea?

The fundamental reasons why institutions are a bad idea go to moral objections based around eugenics and the human rights objections to a policy of life incarceration for the crime of impairment (Jackson, 2005b). In addition, several decades of research indicates that they are a poor quality alternative to community-based alternatives. The most widely used service evaluation scales in the literature are PASS and PASSING (Wolfensberger & Glenn, 1975; Wolfensberger & Thomas, 1983). These scales are scored from -1000 to +1000, with scores below zero indicating that the service is overall doing more harm than good, and scores over zero indicating the service is overall positive. A sample of 213 programs in the USA, Canada and the United Kingdom showed that residential institutions on average scored at 21% of the ideal and were on balance doing more harm than good. This was far worse than community residences (group homes) where the mean score was 37% of the ideal (Flynn, LaPointe, Wolfensberger, & Thomas, 1991). Similar results have been found in a wide range of similar studies in many countries

(Flynn, 1999). Felce, Thomas, De Rock, & Saxby (1985) investigated the differences between people who had moved from the institution into community housing to a control group of people who remained in the institutions. They found an increased level of opportunity in the small homes due to the considerably greater range of things to do and extent of usage of the physical setting. Similar results were found by Malara (1994). Young, Ashman, Sigafoos, & Grevell (2000) reported that reviews of the research literature on people moving from institutions into group homes shows development of a more normalised lifestyle and an increased quality of life. Increases in adaptive skills were also common but dependent on the quality of service provided in the group homes. They also reported initial results on the closure of a Queensland institution, the Challinor Centre. They found significant increases in life circumstances and enhanced choice making when people moved from the institution to group homes. From direct observations, more appropriate behaviour was observed and less challenging behaviour. This does not establish that a move to an institution would produce the opposite results although the research on service quality in institutions would imply that such an outcome could be considered likely (Flynn, 1999).

There is also considerable research on the impact of size of institution on service quality and quality of life of the residents. Conroy (1992) analysed national information in the USA on 13,000 people with an intellectual disability, a 5-year longitudinal data base on an additional 1300 people from Connecticut, and a further 1300 from a 13 year data base in Pennsylvania. National data showed higher integration and satisfaction in institutions below 10 people to those over 10 people. Analysis of the longitudinal data showed better skills development, higher integration and more individualised treatment in the smaller homes. Emerson, Robertson, Gregory, Kessissoglou, & et al. (2000), in a study involving people with severe and complex disabilities, found that people living in dispersed housing schemes had significantly greater quality of life and care than those in institutions. Similar results were found by Malara, (1994) but in addition this study found those in the community spent more time in mainstream community environments and participated in more activities that they liked.

There are also data indicating differences in quality in different sized group homes. In Perth Western Australia, Cocks (1996) reported on the formal evaluation of service quality in 13 group homes using the evaluation instrument PASSING. The group homes varied in size from 2 to 5 persons, with the size inversely related to PASSING scores. Houses with 2 people scored highest, with houses of 4 or more scoring below 50% of the possible score. Similar results on the relationship between homes of 1-3, 4-9 and 9 plus residents were found by Mathison (1997). It needs to be noted that other factors than size can interact with service quality. Quality and numbers of staff, skill level of residents and level of maladaptive behaviour may also differ in different residential environments and so could impact on quality. However, given that skills have been found to increase and behaviour to improve in smaller community environments, the argument that the differences are due to such factors rather than facility size is hard to sustain Persinger (2000). Families also report a higher level of satisfaction with smaller facilities and believed that they provided a higher quality of life for their son or daughter than large facilities (Chaya, 2005). In addition, facilitating family support is related to quality of life (Harris, 1999), and family involvement is much easier to achieve in small community homes.

The idea of looking for a compromise in 'cluster housing' or 'disability villages' is also not supported. Emerson, (2004) compared 169 adults with an intellectual disability in cluster housing to 741 adults in dispersed housing. Those in the cluster experienced worse staff ratios; endured greater changes and inconsistencies; tended to live in larger settings; to have less freedom and endure more restrictive practices such as restraint and sedation; spend more time doing little; be underweight and have a more restricted range of leisure, friendships and social activities. Few potential benefits were found for cluster housing and the authors concluded that cluster housing offers a poorer quality of life and quality of care than dispersed housing.

In looking for the 'ideal' service, it appears that the closer a service is to 'an ordinary life' the more likely it is to approach the ideal. Broughton, (1987) surveyed people with a physical disability and found that participants grouped heterogeneously (that is, with non-

disabled people) were generally more satisfied with their leisure activities than those congregated with other people with disabilities. Similarly, people with an intellectual disability who are socially involved in the regular community have a higher level of life satisfaction (Carey, 1997). Firth (1997) found that the variables considered important to a person's life quality are similar for all disabled groups and are clearly concordant with life aspects valued by the general community. The factors considered important (in order of strength) were Security, Freedom, Relationships, Safety, Achievement, Health, Lack of resources/privacy and Rights. Lunsky (1999) interviewed 84 adults with a mild intellectual impairment on factors affecting their well-being. Aspects such as social support, reciprocity in relationships and health predicted their mood and quality of life six months later, with the factors affecting their mood similar to people without cognitive impairments. Similarly, in a study of 220 participants with an intellectual impairment it was found that people who lived in the community and made more choices scored higher on quality of life indicators (Neely-Barnes, 2005). Indeed it seems that in a supportive community the impact is particularly profound. Comparing adolescents with an intellectual impairment in a rural town who had always lived in the ordinary community to those without an intellectual impairment, no significant differences were noted on any measure. Measures included awareness and usage of community facilities, subjective quality of life, shopping, leisure, and sports participation (Petty, Rapley, & Bramston, 2002).

Sometimes the argument is advanced that aged people are increasingly choosing congregated accommodation such as 'lifestyle villages' so it would be prejudicial to not make such alternatives available for people with a disability. This research on the similarity to other members of the community is of critical importance. It demonstrates that there is in fact no difference and that the quality of life of all humans is fundamentally affected by similar things, and the needs of all people are remarkably consistent. That is, people need to belong, to be valued, to contribute, to have friends, to be supported, to be free, to make their own choices and to be healthy. We know for ourselves that these human needs would be met more poorly in institutions and even in small community housing, and in fact can only be achieved by access to an ordinary life.

For a group to ask for this one simple thing, access to an ordinary life, cannot be beyond our capacity to deliver.

In Tables attached to this document, Table 1 analyses likely effects on competency and image of living in an institution, Table 2 explores the likely effects in small community housing, and Table 3 repeats the analysis for people living independently or with valued community members. While individual ratings can vary in any of the scenarios outlined, the overall impact proposed as likely is consistent with the research evidence.

In summary, on the basis of historical, moral and human rights concerns, institutions cannot be supported. In addition the research on de-institutionalisation and community living indicates that quality is not only poorer in institutions, it is most likely to do more harm than good under systematic investigation. For community housing, cluster housing and large community housing cannot be recommended even though their negative impact has been found to be less than institutions. The best alternatives focus on attempts to achieve an ordinary life in the community for individuals with as many natural supports as possible. By building natural supports including family and local community, costs have been shown to be comparable, although it is not suggested that cost should ever be used as an argument involving human rights and dignity. Modern approaches indicate the selection and training of staff with the 'right relationship' is critical, and the focus needs to be on an ordinary life, which will automatically involve the family and community as well as the individual in all major life decisions.

The initial focus of this paper on the need for flexibility and individuality is to be commended. In a review of the models that were shown to be effective in disability research, Sloper (1999) noted that services needed to work directly with the family's assessment of a situation and the resources available to the family, but to do it in a way that enhanced the family's ability to mobilise resources themselves and build on their strengths. For models that work, Sloper (1999) identified a 'key worker' or 'link person' as a common characteristic of highly rated services. This key worker needed to have wide knowledge and ability to 'work the system', accessing service from a range of agencies. As an example of the impact, Sloper (1999) reported a controlled study where a key person model was found to produce higher family morale, greater satisfaction with services and less isolation. It was seen as particularly valuable to have someone to talk to who could be approached for help when needed. Other services rated positively were family to family interactions (and getaways together); befriending schemes; family based care schemes; and schemes that are particularly beneficial and developmental for the person while also offering some form of a break for the carers. In summary, Sloper (1999) indicated that the characteristics of the staff are fundamental. They need to be long term; have regular contact; trust and be trusted; able to work with families to determine needs; acknowledge the expertise and relationship of the carers to the individual cared for; have good knowledge to assist the families or help them to gain the assistance required; and work in partnership rather than an 'expert' role. Similar results of the effects of a key person as a cost effective means of meeting need in the community have been found in two reviews I have completed for agencies in Victoria and South Australia (Jackson, 2004, 2005a). Note that in all of the leading approaches to this problem world wide, solutions are being found in the community rather than in institutions.

The intention to move back to 'larger institutions' is one that cannot be recommended on the basis of history, research, human rights or moral grounds. Such a move would subject the State to wide derision for moving backward at a time when others are achieving full individualised community inclusion for large numbers of people (see

http://www.jaynolan.org for one example of such a move). That is, there is a move worldwide at the cutting edge for a re-communalisation of people who are trapped in the mini-institutions of group homes. Schools are finally starting to become fully inclusive with the eventual recognition of the Disability Discrimination Act (1992) and the Educational Standards (2005). To be re-institutionalising people at the same time as other sections of the same government are going the opposite direction would be to open the government up to ridicule.

Table 1: Institution – Likely impact of some service characteristics

Service Aspect	Likely Competency Impact	Reason	Likely Image Impact	Reason
Meeting Needs	Negative	Less likely to belong in valued community, hold valued roles.	Negative	'Institution inmate' role highly devalued.
Skill development	Negative	Less opportunities to develop skills in natural community, lack of competent models.	Negative	More likely to develop devalued behaviours.
Behaviour	Negative	Poor models, low staff ratios, restrictive and unstimulating environment.	Negative	Lack of positive models, probability of enhancing prevailing stereotypes.
Location	Negative	More likely to be isolated from local community and family.	Negative	Location (e.g isolated, in service ghetto, near devalued sites such as prisons) likely to enhance existing stereotypes of 'not belonging'.
Building Size	Negative	Less likely to develop normal skills related to homes and community due to inherent limitations due to size.	Negative	Enhances stereotype of 'different and not belonging'
Grouping size	Negative	Less individualised, more likely to be limited by 'lowest common denominator'.	Negative	Large number of devalued people together increases likely rejection.
Grouping composition	Negative	Lack of more competent and social models, greater difficulties for staff to individualise.	Negative	Grouping devalued people together enhances the focus on negative characteristics.
Activities	Negative	Routinised, limited by facility size and isolation and grouping impact (lowest common denominator).	Negative	Unlikely to be natural, valued activities common to valued people of similar age.
Cost	Likely to be higher in the long run due to ancillary services required such as gardeners, cooks, domestics, medical staff as well as basic care and teaching staff.			

Table 2: Small (<4) , dispersed group home – Likely impact of some service characteristics

Service Aspect	Likely Competency Impact	Reason	Likely Image Impact	Reason
Meeting Needs	Positive	With appropriate support, likely to belong in valued community, hold at least some valued roles.	Neutral/ Positive	Have home and security needs met in more 'normal fashion. More likely to contribute to community
Skill development	Positive	Opportunities to develop skills in natural community, with competent models.	Positive	More chance to develop positive relationships with valued community.
Behaviour	Positive	Small, natural environment more likely to produce 'normal' skills and behaviour. Staff find it easier to individualise in a familiar 'normal' environment.	Positive	Normal, community behaviour much more likely to be elicited.
Location	Positive	Much more likely to be close to local community and family.	Positive	Sends message of 'belonging' in the general community.
Building Size	Positive	Normal, expectable size found in regular community. More likely to be easily learned.	Positive	Sends message of 'belonging' and 'like the rest of us, living a regular house'.
Grouping size	Neutral	Number is still difficult for others to easily relate to. May be viewed as a group rather than individuals.	Neutral	Atypical grouping to have this number of unrelated adults living together, but small enough to be tolerated.
Grouping composition	Negative	Lack of good models, grouping is by devalued characteristic rather than choice or talent.	Negative	Grouping devalued people together enhances the focus on negative characteristics.
Activities	Neutral/ Positive	Potential to be positive if maximum use made of interactions with community and use of community facilities. Grouping may make this difficult for staff.	Neutral/positive	Bizarre activities unlikely. Can be positive if maximum use made of community in image enhancing ways.
Cost	Likely to be lower than institutions in the long run due to minimal need for ancillary services required such as gardeners, cooks, domestics.			

Table 3: Individualised community settlement – Likely impact of some service characteristics

Service Aspect	Likely Competency Impact	Reason	Likely Image Impact	Reason
Meeting Needs	Highly Positive	With appropriate support, likely to belong in valued community, hold at least some valued roles.	Positive	Normal, expectable, natural way to meet needs.
Skill development	Highly Positive	Opportunities to develop skills in natural community with competent models as community more likely to be involved.	Positive	High probability of positive relationships with valued community.
Behaviour	Positive	Under the influence of 'normal' community expectations and supports.	Highly Positive	Normal, community behaviour much more likely to be elicited.
Location	Highly Positive	Much more likely to be close to local community and family.	Highly Positive	Sends message of 'belonging' in the general community.
Building Size	Highly Positive	Normal, expectable size found in regular community. More likely to be easily learned.	Highly Positive	Sends message of 'belonging' and 'like the rest of us, living a regular house'.
Grouping size	Highly Positive	Number is easy for others to easily relate to. Likely be viewed as an individual and given opportunities. Individual planning likely.	Highly Positive	Typical to have one or two unrelated adults living together.
Grouping composition	Highly Positive	Normal grouping found in community. Much more likely to find community models and meet community expectations.	Neutral/Positive	Typical to have one or two unrelated adults living together. If both devalued, positive impact reduced.
Activities	Highly Positive	Much more likely to be normal community activities common for people of same age.	Highly Positive	Much more likely to be normal community activities common for people of same age.
Cost	Likely to be lower in the long run than institutions due to no need for ancillary services required such as gardeners, cooks, domestics. Can be lower than group home with good planning and building in unpaid community and family support.			

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