

Cluster Housing: What is its likely impact?

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Abstract

The 1970's and 1980's were characterised by a process of de-institutionalisation in many western countries, based on extensive evidence of institutions providing low quality accommodation, poor response to individual need and negative impact on skills and human rights. In the succeeding decades, the movement to group homes and individual accommodation has not kept up with demand, leading to regular calls for greater response to the need for accommodation. Increasingly this call has been linked to calls for the provision of clusters where people with disabilities could live together in a 'community of interest'. In this paper the model is analysed using quality criteria from the PASSING evaluation manual to see if such a model is likely to both meet the needs of people with a disability and provide a positive alternative to other accommodation options. From this analysis it is apparent that the great majority of the problems with institutions are replicated in the cluster model although some advantages over the institution model are apparent. In particular, setting size and location; grouping size, and grouping composition are likely to have negative impacts on competency development and the reputation of residents -- both of which relate to key need areas. On balance, the data from empirical studies and a logical analysis of the model lead to a conclusion that the model is likely to result in more harm than good eventuating for the individuals involved.

INTRODUCTION

Services are established to meet the needs of individuals in particular life areas such as home, vocational, health maintenance or development. There is an assumption that such services will be beneficial, and at the very least will do more good than harm. However reviews of service quality lead to concerns that in many cases, services do more harm than good when systematically evaluated. Flynn 1980; Flynn, LaPointe et al. (1991) reported on the quality of services over the United States and Canada assessed using the PASS or PASSING evaluation instruments (Wolfensberger and Glenn 1969; Wolfensberger and Thomas 1983; Wolfensberger and Thomas 2007). While community based programs were found to score well into the positive ranges, institutions and mini-institutions scored less than 10% of the possible score and were judged as clearly doing more harm than good in these evaluations. Community residential services (that is small individually situated housing) achieved minimal acceptable standards on average and the quality was rated much higher than institutions or mini-institutions that on average scored at totally unacceptable levels of quality. It has also been found that when people are moved out of institutions into community housing their quality of life increases. Residents are more engaged; have greater choice; use more community facilities; increase in their adaptive behaviours; increase contact with family and friends; are more accepted by the community; have a better material quality of living, and service costs were reduced compared to the institutions (Awuonda 1995; Emerson and Hatton 1996; Stancliffe and Abery 1997; Stancliffe, Hayden et al. 2000; Stancliffe, Hayden et al. 2002; Stancliffe and Lakin 2006). These findings need to be qualified in that not all community residences have been found to be better than institutions and even though the move to community improved quality of life, overall the standard of choice and service quality leaves much to be desired in many cases (Emerson and Hatton 1996; Stancliffe and Abery 1997). There is also some concern of problems meeting the medical needs of children with significant intellectual disability in the community (Strauss, Eyman et al. 1996). Nevertheless, the changes in quality as a result of moving in to the community seem to be strong and widespread (Kim, Larson et al. 2001; Young, Ashman et al. 2001).

Factors other than facility size also need to be taken into consideration when looking at service quality. For example quality of staff performance and resident engagement is influenced by the structure and procedures within the setting (Felce 1998). Size itself does seem to be important, and not only between institutions and community housing. Differences in quality have been found when comparing 1-5 persons with quality increasing with lower numbers (Cocks 1996; Stancliffe 1997).

Overall, it is clear from the research that institutions generally provide a poorer quality service than community housing and this has been supported in the courts (Richey 1999). People with a disability themselves have also strongly supported the move to community with those still held in institutions expressing moving out as their greatest wish (Minton, Fullerton et al. 2002).

Much of the evaluation has been on measures such as choice and community involvement using a range of measures that may not be directly comparable and there some inherent methodological problems (Jenssen 1995). The most systematic, broad and repeatable evaluations have been conducted using PASS and PASSING and for this reason the most recent version of PASSING has been used for this theoretical analysis of the disability cluster housing model.

THE QUALITY CRITERIA

The most commonly cited service evaluation tools are PASS and PASSING (Wolfensberger and Glenn 1975; Wolfensberger and Thomas 1983; Flynn, Guirguis et al. 1999). The 1983 PASSING manual has been revised (Wolfensberger and Thomas 2007), bringing the manual into line with the Theory of Social Role Valorization rather than the Theory of Normalisation on which the 1983 edition was initially based.

The conceptualisations of human services by Wolfensberger have had a profound impact on human services around the world and particularly in Australia where much disability and aged care legislation can be traced back to Wolfensberger's writings and presentations. Basically, Wolfensberger points out that various groups in society are

devalued and this devaluation leads them to be subjected to a series of wounding experiences seldom experienced by other community members. For example they commonly experience rejection, branding by stereotypes, segregation, congregation ‘with their own kind’, material poverty and in extreme situations killed. In response to this treatment, Wolfensberger suggests valued social roles as a potent way to reduce and even reverse devaluation. Some of the means to make valued social roles more achievable involve the development of competencies and the enhancement of reputation by avoiding negative stereotyping. The PASS and PASSING evaluations evaluate services on how ‘valorising’ they are in line with the recommendation of the Social Role Valorisation theory.

PASSING consists of 42 ratings of service quality, looking at the impact of the service on recipient’s image and skills (see Figure 1 below).

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The ratings receive different weighting ranges varying from +50 to -50 for the relevance of the service to meet the needs of service users, through to +7 to -7 for some image issues related to the service. The possible total score for PASSING ranges from -1000 to +1000 with a score of 0 indicating that the service does equal amounts of good and harm on balance and so is the minimal acceptable level. The PASSING evaluation is designed as a measure against the ‘ideal service’, which means that to achieve the top rating on any individual item the service quality has to be at the highest reasonably conceivable level and in addition there has to be a high consciousness of the importance of the issue as a safeguard against future quality deterioration. On the other hand, services do not have to be at the lowest conceivable level to receive the lowest rating on individual items. As long as the evaluators rate the service aspect as doing severe damage to the service recipients under set criteria then the lowest score can be given, even though worse services could be envisaged or indeed have been experienced elsewhere by raters.

To rate a service using PASSING, a team of usually 5-10 people led by an experienced team leader visits the service and interviews senior staff to gain an overview of the service and its policies and procedures as well as an indication of how they respond to a range of quality issues such as personal presentation of service users, service user choice and control, privacy and funding. The interviews will last for up to 2 hours initially with opportunities for follow up questions that arise in the course of the evaluation. Access is given to service brochures, staff manuals, policy documents - and in formal evaluations, service user files and data. Team members will individually interview a series of service users (and families where possible), staff and neighbours of the service to gain as deep an understanding as possible of the existential identity of the service users, their past and their current situation – as well as an idea of what the future is likely to bring if the service continues as it is. In formal evaluations these interviews will go over several days as the information from services users is a major source of information for the evaluation as it gives, in particular, knowledge of the people and their likely pressing and urgent needs.

Following the main data collection, the team meets and goes through a process called the ‘foundation discussion’ where the material on the service users is combined and the past, present and their likely future is documented. The team members then look at the likely impact of those life experiences on the service users, which often gives important insight into what are likely to be high priority needs. For example, an almost universal experience of people with an intellectual disability is rejection. When teams reflect on the impact of such a history of rejection, a common analysis is that the impact would be likely to be, for example, low self esteem, loneliness and desire to belong. This then raises likely needs such as belonging, security, acceptance and a positive reputation. The team will go on to make consensus judgements on the most pressing and urgent needs out of those raised; the legitimate scope or purview of the service (i.e. what is the responsibility of the service and what should be more correctly done by others); what would an ideal method be to meet those most pressing and urgent needs; and finally, what the service users receive from the service (positive and negative – for example, by being part of the service an individual may pick up negative images that degrade their

reputation). As the service response to the most urgent and pressing needs is at the base of a large number of PASSING ratings, this foundation analysis is exhaustive and takes several hours to complete.

Following the foundation discussion, the team systematically rates each of the 42 ratings by documenting all of the evidence collected on each rating, characterising it as positive or negative in relation to the rating, determining the balance of the evidence and the impact on the people, and then assigning a rating from 1 to 5. Ratings are by consensus, and where there is an unresolvable difference of opinion in the group, the higher rating is taken.

ANALYSIS

Needs

People with an intellectual disability have the same human needs as all other people. These needs cover the life maintenance needs such as shelter, warmth, food and health maintenance so any service would be expected to cover these as a primary requirement, but much more is expected of residential services if they are to rise above the standard of prisons. Other universal human needs are the need to belong; to love and be loved, to have hope and purpose in life; to have a positive reputation; to have a wide range of valued roles; to have challenge and growth; to have dreams and aspirations. For most people, to have any one of this short list eliminated from their life would mean a life fundamentally deficient. As such it is reasonable to have an expectation that facilitation of meeting these needs would be built into the service, even though it is recognised that many of them are outside of the possibility of services to provide. For example services cannot provide love or dreams, but they can be expected to provide an environment where these essential human aspects are able to flourish. At the very least, services should not make it *less* likely that these needs will be met.

As a result of their common life experiences, people with an intellectual disability have a particular pressing range of needs of such fundamentality that failure to address them will mean that there will be little progress in their lives. For example, a common life

experience of people with an intellectual or physical disability from early years will have been rejection as a regular occurrence. This may have occurred as early as at birth (“Put him/her in an institution and have another child”); from close family members (“Nothing like that in our side of the family”); from neighbours (“Would you mind keeping him inside, I have friends coming around”); from other children (not invited to play, share sleepovers, share sandpits); from education systems (“He really needs to go to the Special School where he can be with other children like him”); and from the community (ignored, avoided, talked over, actively rejected). The impact of such a life experience is likely to be low self esteem, lack of social skills and even challenging behaviour as a result of finding ways to gain attention and recognition. Hence there will be a major need for a positive reputation, community inclusion and belonging, relationships and positive roles.

A second major area of need is skills. A common characteristic of disability, particularly intellectual disability, is below average skills over a wide range of areas.

While there will be a range of additional needs, many quite individualised, the need for belonging, community relationships, positive reputation, positive roles and accelerated skill development will be fundamental for a large majority of this group of people under consideration for system residential support. If these needs are not addressed as a priority, then other needs will be particularly hard to meet. For example, if a person has low self esteem, poor volition and a poor reputation, it is unlikely that teaching programs will be effective until these more fundamental esteem and image needs are addressed.

This consideration of needs leads to a conclusion that at the very least any approach to meet people’s residential needs will have to avoid making the situation worse, and preferably would make it more likely that these fundamental needs will be met.

Optimum

If we are looking to evaluate a service option, we have to compare it to the optimum means to meet the fundamental needs of the people under consideration. Any other

criterion is likely to lead to solutions that are less than optimal. In our society, the fundamental needs for a positive reputation, belonging, skills etc are residentially met in a home, which is much more than a building. This is acknowledged by services as is shown by the terminology ‘group home’ and the use of the word ‘home’ in the brochures and publications of most organisations. As the community analogy attempting to be replicated is a home, some consideration of what that means is necessary if we are to see the possibility of cluster housing being an appropriate response to that need. Clearly a home is much more than a house and for adults will include aspects such as:

- ✚ Choice of location.
- ✚ Choice of co-residents.
- ✚ Considerable power within the home environment to ‘do your own thing’.
- ✚ Relationships, including intimate relationships.
- ✚ Projection of positive images and reputation.
- ✚ Positive social roles.
- ✚ Expectations and responsibilities.
- ✚ Opportunity to build social and other skills.
- ✚ Well positioned in relation to work and recreation.
- ✚ A place to express your individuality.
- ✚ Etc.

Rating of service aspects

It is clear that a service can range from good to poor depending on how it is organised. Thus one can have ‘good’ group homes and ‘poor’ group homes as has been shown in service evaluations over time (Emerson and Hatton 1996; Stancliffe 1997). However, when we look at the data on institutions, there is overwhelming evidence over many decades that their quality of service and appropriateness to meeting needs is poor and that overall, institutions do more harm than good when systematically analysed (Flynn 1980; Flynn 1999). That is, it is clear that the institutional model itself is fundamentally flawed and even in the best-run institutions, the chance of doing good overall seems to be minimal or non-existent. When they were first designed this was definitely not the expectation – they were to provide an asylum from a rejecting society. There is a danger

that the ‘disability cluster housing’ concept also could have a negative impact so it is important to look at the model in detail to see if it has inherent strengths or weaknesses that support or undermine its usefulness as a model to meet people’s needs.

Physical aspects of the service: Location.

If one is to arrange for a disability cluster home, it almost certainly going to be built from scratch. While it might be possible to buy an existing block of units or buy out a local street, in reality the Australian experience is that they have been constructed by government or agencies. However the experience also has been that building such a complex is actively resisted by the local community so they are normally built on isolated land to minimise criticism, or on already institutionalised land such as on the grounds of a hospital or other institution (as is happening in Kalamunda WA for people with a chronic mental illness). The very fact that community hostility is generated for such arrangements indicates that just their presence *exacerbates* the rejection of the community and adds another level of rejection to that already experienced. In comparison, the alternative of one or even two people with a disability moving into a local street is unlikely to be even noticed and may in fact bring out positive inclusive responses from others.

Other impacts of the location are on skills. As the clusters are almost certainly going to be built on isolated land as that is the only place where such sized blocks are normally available, then it is almost certainly going to be isolated from opportunities for social inclusion and social skill building by such activities as going to the local shops, getting a local job; joining local clubs or societies, or even meeting neighbours. In new or isolated areas public transport is likely to be poor, meaning that ‘cluster buses’ are more likely to be employed in taking people to local shops or facilities. Hence it is probable that social skills are likely to reduce through lack of practice or at best remain less developed as a result of the location.

Physical aspects of the service: Setting neighbourhood harmony.

In designing cluster housing, architects are constrained by a large number of practical aspects. The facility will have to cater for a range of residents over time, some of whom are likely to be difficult to deal with. This is because more competent and less difficult to manage people will already be living independently in the community or in lightly managed accommodation due to choice as well as system needs to minimise support costs. This need to design for a wide range of people is likely to lead to the need for external fencing for security and building in staff facilities such as accommodation and offices. These necessary adjustments will almost certainly lead to a group of buildings that 'stand out' and do not harmonise with the existing neighbourhood. Other houses in the neighbourhood tend to be individual with individual fencing and the architectural clash exacerbates the 'different' and 'not belonging' image of the residents. This is damaging to their reputation. This may be made worse by poor aesthetics in the design that characterises many of the disability clusters in operation, although it is conceivable that this could be overcome by better architecture in future so less damage is done to reputation.

Physical aspects of the service: congruity with culture

The reality in our society is that people do not live in segregated clusters within the wider society. While there is a trend to build walled communities in new subdivisions, this is different to building a cluster for only one group of people. An example would be to build a cluster for Buddhists or a cluster for Italians. It is clear that any such arrangement would *decrease* the likelihood of inclusion of such groups into the wider society and damage their reputation. The same applies to a disability cluster.

Grouping Implications: Image – group composition

How people are grouped has implications for both their reputation and potential to develop skills (Wolfensberger and Thomas 2007). For image or reputation, every grouping has an image impact, positive or negative. Hence we see politicians trying desperately to be grouped with sports stars or other valued people, and avoiding any grouping with people who are devalued unless in some 'charity role'. That is, they would

be quite likely to visit nursing homes, but unlikely to live in a 'lifestyle village' whilst serving as an MP.

Any grouping has the effect of highlighting the characteristic shared by the group. Hence a group of athletes highlights health and capacity whereas a nursing home grouping highlights extreme age and incapacity. The dominant characteristic of the group can then improve or degrade the image of an individual in the group. A less capable person grouped with athletes is likely to be seen as more capable than he or she may in fact be. Similarly, in the nursing home example a young person with a disability living there is at risk of being seen as older and less capable than they actually are. The basic rule is that the image transmitted will be of the group majority. Therefore, to enhance image the group should consist of a large majority of people with a valued image and a small minority of people with a less valued image (Wolfensberger and Thomas 2007). The reverse balance is likely to degrade image of the more capable.

If we look at the cluster home example, the whole group or at least the strong majority will be made up of devalued people, so the impact on their image will be negative. An alternative, where one or perhaps two people with a disability live in a regular house in a regular neighbourhood street carries an image of normality, belonging and personal capacity.

Grouping Implications: Image – group size

The size of a group also carries an image. Large groups of people sharing some characteristic are commonly somewhat frightening, even if valued people. For example, sharing a plane with a highly valued football team can be a discomfoting experience. The pure size of the group makes it much harder for people outside the group to approach individuals within the group to make personal contact, so the probability of connections occurring are low – the size of the group is just too overwhelming. When the large group is composed of people already devalued by society, the negative impact of a large group size is exacerbated. For a disability cluster, the pure size of the group will make it likely that the residents will be seen by group image (e.g. the 'disabled village people') rather

than as 'Harry' or 'Helen', which is likely to be possible if they live next door in an individual house.

Grouping Implications: Competency – Group composition

For the building of skills, the presence of competent models is a well-established pedagogy. The basic principle is that in any grouping to maximise skill development, the large majority of the group should be more capable with a small minority less capable (Wolfensberger and Thomas 2007). We can see this when we play sport with people more competent – our skills tend to improve, whereas playing with a group of less competent people tends to have the opposite effect. To group a whole lot of less capable people together in a cluster where all the models are poor is clearly breaching this pedagogical principle. As an alternative, one person sharing a house with 3 competent models would be much more likely to have a beneficial effect.

The grouping of a large number of less competent people together has an even more negative impact as well. If one person is likely to wander into danger, doors will be locked for others who might well be able to handle considerable freedom. That is, there is an inbuilt tendency to cater for the lowest common denominator. In this aspect, it is hard to see why a disability cluster would be superior to institutions which are renowned for unnecessary restrictions and the lack of individual freedoms.

Grouping Implications: Competency – Group size

The larger the group, the less likely it is that community members will interact. It is almost inconceivable that neighbours would approach a cluster to initiate contact, whereas one or two people in a house or unit could easily allow neighbourly contact and real relationships to develop with valued people from the community. From the community response to the building of such clusters, the reaction of most community members is one of fear and avoidance, meaning that there is *reduced* likelihood of relationships developing with a cluster than in smaller groupings of 1 or 2 (or even 4) people with a disability.

The other likely outcome of larger group size is group activities. If one is in a cluster of 50-60 people, it is not feasible to have cars for every 2-3 people as would be the case in a suburban situation. Cluster buses are much more likely, again producing groups of such size that the public are likely to be made more fearful or at least unlikely to interact.

There is also the consideration of the capacity of the local community to absorb the numbers. Sixty people descending on a local shopping centre would be overwhelming and highly likely to increase fear and rejection. The likelihood of being able to absorb such a number into local clubs and societies would be minimal, effectively forcing the provision of segregated and congregated recreational activities. It is going to almost guarantee that unemployment will be the norm for the same reason, again forcing segregated and congregated options. These are all going to *decrease the inclusion* and belonging of the residents and so make worse one of their most fundamental areas of need. In comparison, one or two people living in a house with these houses scattered around different neighbourhoods overcomes all of these problems and makes it much more feasible to build community links through club membership, community involvement and real jobs, paid or voluntary.

Grouping Implications: Competency and image – Support personnel

One of the groupings involved is the people doing the support, given that the people living in such accommodation are normally defined as requiring support in order to gain a place. In a disability cluster, the supports will effectively all be paid staff or organised volunteers as it is not really conceivable that members of the public will provide natural support in such an environment. In fact most members of the public will almost certainly be put off from entering the site by its size and grouping characteristics. This means that one of the major means that individuals can make community contacts, through their home, is cut off from them due to the size and nature of the environment. As community belonging and inclusion is a major need of this group, the size of the service in fact mitigates against this need being met and makes it more likely that the residents will endure continuing community isolation. There are also image implications in that the residents are always seen as needing paid support, which is a devalued role in our society.

In an ideal service model, the person with a disability would be living with valued members of the community as happens in many examples around the world including in Australia. This provides opportunities for considerable skill gain through mentoring and direct community experience, as well as a positive image of belonging with valued people who have chosen to live with individuals with an impairment. The comparison of image impact is also very strong. Compare the image of living with valued community members against being supported and supervised by large numbers of paid specialist staff. The image of one is belonging, capable and valued and of the other, different, incompetent and not belonging in mainstream society.

Activities: Image considerations

The size of the facility means that the probability of community inclusive activities with valued people, a key need, will be almost impossible for any individual and out of the question for all of the residents as a regular occurrence. The logistics of organising the activities for such a large number will force them into congregated and segregated activities, which will further diminish their reputation for being equal citizens. The types of external activities will be similar for those historically provided under 'Post School Options', sheltered work, 'Activities other than Employment' or similar manifestations. All of these activities will be almost certainly degrading of image due to their segregated and congregated nature.

Activities: Competency considerations

Due to the nature of the activities being segregated and congregated with large numbers of low skilled people, the probability of them having high expectations on performance and powerful developmental components is likely to be low due to the need to cater for the lowest performers and maintain control of a diverse and unmotivated group. On the other hand, there is potential for the activities within each house to have more normative expectations in a similar way to a group home and so be better than a full institution. Again, in comparison to an ideal with a person with a disability living independently or with valued community members, the differences would be stark. In such situations expectations would be high for normative levels of behaviour, the competent models

would make individualised skill building more likely and motivation for skill development and community belonging would be likely to be high.

Neutral or uncertain areas for image and competency impact

IN PASS and PASSING ratings of residential services, some common characteristics of larger facilities are rated negatively. For example, distinguishing signs on buildings; play equipment in adult facilities; unbreakable furniture; unpleasant smell; poor food; deficient staff attitudes; age degrading groupings and poor community access are just some examples. In many cases these types of ratings score better in small group home facilities, leading to the overall result that community residences (group homes) score significantly higher than institutions and often meet minimal acceptable standards, whereas institutions on average achieve less than 10% of the possible score (Flynn 1980). Arguably, disability clusters could achieve the same level as group homes on many of these miscellaneous items if there was a high awareness of the importance of image and competency development, so no attempt has been made to argue that these types of ratings would inevitably be lower. The experience of larger size leading to a lower overall score (Cocks 1996) however lead to a concern that lower scores than group homes would be likely even on these miscellaneous ratings.

Conclusions

If we start with some basic assumptions such as people with an intellectual disability have the same human needs as other human beings then the impact of their life experience can give us insights into what are likely to be their most pressing and fundamental needs. It is responsibility of a service to respond to those needs within its purview in the best manner possible, and at the very least to not exacerbate those needs. An analysis of the characteristics of the disability cluster model shows that many fundamental human needs are less likely to be met than in individualised housing, and in many cases the needs are likely to be increased. In addition many of the inherent characteristics will lead to harm of individuals in the service, both in their reputation and limitations on their gaining of skills. This damage is similar to the damage demonstrated in evaluations of institutions over several decades. On the other hand, the small

individual units and more 'home like' surroundings mean that they share some of the characteristics of group homes that have been found to rate more positively on service evaluations than institutions. Overall though, the negative characteristics outweigh the mitigating factors, leading to a conclusion that cluster housing is likely to do more harm than good to individuals in the service. As such it should be avoided as a service alternative.

	Program elements primarily related to recipient social Image enhancement	Program elements primarily related to recipient competency enhancement
Physical Setting of Service	11 ratings	6 ratings
Service Structured Groupings, Relationships and Social Juxtapositions	7 ratings	6 ratings
Service Structured Activities and other uses of Time	3 ratings	3 ratings
Miscellaneous Other Service Practices	6 ratings	--

Figure 1: Service quality rating from PASSING (Wolfensberger and Thomas 2007)

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