



Submission to the Productivity Commission Inquiry into Disability Care and Support

Who we are

The ACT Community Living Project Inc (CLP) is a not-for-profit community organisation representing over 250 families in the Canberra region, most of whom are caring in their home for a family member with an intellectual disability.

In common with many thousands of families across Australia, CLP families are deeply concerned about how to ensure there is a safe, supportive and home-like living environment available for their much loved family member when ageing parents and other family members can no longer provide the care and support they need.

CLP was established in early 2009 and is working actively to secure community and government support for the development of an 'urban village' to provide supported accommodation for people with significant intellectual and other disabilities.

Our core principle

CLP believes that people with a disability should have the same opportunities as the rest of the community – in particular the opportunity to exercise choices – in key areas such as:

- being able to choose from a range of accommodation options that suit their needs;
- being able to access lifelong education and training;
- having meaningful things to do every day – including employment (paid or voluntary), hobbies, leisure activities and exercise;
- having access to adequate, appropriate and timely medical and dental care;
- being able to have meaningful social interaction with their peers; and
- engaging positively with the wider community.

The urban village concept

The CLP 'urban village' concept envisages an holistic model of accommodation, care, lifestyle supports, and meaningful activity, operating within a small community setting (of between 50 and 150 people) with close links to the wider community.

It is envisaged that the village would include supported accommodation places for both long-term residents and respite visitors with an intellectual disability, including those with significant disabilities or complex needs. For many such people, there is currently no alternative other than to be cared for at home.

The village is seen as providing a range of accommodation options to suit individual care needs, including:

- hostel type units for people with high needs and for respite care;
- independent living dwellings supported by appropriate levels of care and supervision; and
- smaller units for more independent residents, including people without a disability who may choose to live as part of the village community.

The health and care needs of residents are envisaged as being coordinated by the village in an holistic person-centred approach that will include a focus on participation in preventative health screening, supervised treatment of ongoing conditions, ready access to acute care when necessary, and promotion of healthy lifestyles and exercise programs. A closely coordinated approach to care will help reduce health care costs and social costs in the longer term.

Health and care services could be provided through a variety of approaches including:

- employment of resident health care staff by the village;
- partnerships with specialist health providers to supervise the complex needs of residents and to work with GPs, visiting consultants and nursing staff to provide quality and timely care;
- a medical centre to be located at the village, which could be accessible to village residents and others not living in the village; and
- engagement of dieticians and nutritionists (coupled with supply of nutritious food) to help residents regulate the quantity and quality of their diet from day to day.

A key priority within the 'urban village' concept is to maximise the independence of people with disabilities through providing them with opportunities to learn skills and to work, recognising that work delivers major benefits through being a source of fulfilment, companionship and income for people with disabilities.

This will be addressed through :

- placing a strong focus on identifying the abilities and interests of residents, and their individual training and skill development needs;

- identifying work opportunities for residents associated with the running of the village, including in areas such as meal preparation, cleaning, gardening and laundry; and
- encouraging residents to pursue paid employment, training or volunteer activities within the wider Canberra community.

Furthermore, jobs within the village could be made available to non-residents, which would maximise social interaction opportunities for all and expand work force options for people with a disability. The village could also become a centre for high quality training of care staff, and partnerships could be established with educational and training bodies to utilise the village for supervised student placements.

The element of social inclusion is integral to the urban village concept. This will be achieved through providing residents with regular contacts with a variety of people including:

- those involved with their personal care planning and in helping them with daily tasks;
- those who organise and participate in work, leisure and exercise programs;
- family members and friends who would be encouraged to visit regularly;
- neighbours and local community groups who would be encouraged to establish a partnership relationship with the village; and
- staff engaged in providing appropriate ‘commercial’ and other services in the village, such as a café, pool, gym, and medical centre.

Social support is important to the health and happiness of any individual. For people with disabilities, social contacts are also an important way of monitoring whether the individual is receiving adequate care and is not subject to abuse.

A significant ancillary benefit of the ‘urban village’ concept is in the real potential to reduce the burden on carers, thereby improving their physical and mental health, enabling them to maintain regular employment and income, and to contribute to the community in other ways according to their skills and aspirations.

The research behind the concept – a synopsis

Following deinstitutionalisation, the predominant model for providing supported accommodation for people with a disability has been group housing dispersed within the community, guided by the principles of normalisation and inclusion.

Research indicates that dispersed housing achieves best results for those at the more able end of the spectrum of people with disabilities, particularly in terms of increasing choice, skills development and participation in community activities. However, people with more severe disabilities are more likely to experience inferior outcomes in the same areas.

Evidence suggests that the most important factors in determining quality of life for people with disabilities are not the exact features of the accommodation, but the maintenance of quality management, family values and person-centred practices. Hatton (2003) found that “out of all the factors associated with high quality care, the capacity, motivation and support of staff/carers ... and positive practices of active support” are the most critical.

Cummins and Lau (2003) argue that “as integration [within the community] is being pursued to benefit the individual, the essential goal should be to achieve a sense of community connectedness, rather than being concerned with physical integration within the general community”. They conclude that “such connectedness [for people with an intellectual disability] is more likely to be achieved within the community of people with an intellectual disability”.

While the evidence on the benefits of dispersed housing compared with cluster housing and intentional village models is contested, CLP supports the findings of Cummins and Lau noted above, and suggests that the urban village concept is more likely to achieve positive community connectedness outcomes than other accommodation and support models.

Impediments in the current policy environment

The Inquiry will be well aware of the separation of policy and funding responsibilities between the Commonwealth and state and territory governments in relation to accommodation, support services and employment for people with a disability.

The absence of an holistic person-centred approach to policy and service delivery presents major difficulties for parents and carers seeking a service response to meet the full needs of their person with a disability. Typically, services need to be negotiated in a piece-by-piece manner with separate providers, having regard to varying eligibility criteria, and brought together by the client’s representatives to try to make a coherent package. To achieve an effective integrated outcome demands considerable time, energy and persistence as well as a sound understanding of how the system works and of the full range of options available.

Compare this with the aged care system, where the full package of services likely to be needed by a client is accessible in a ‘one stop shop’ service model through individual accredited aged care providers. It is basically a matter of choosing between providers on the basis of the package of services they offer, and other factors such as personal preference and availability of places.

The ‘urban village’ concept supported by CLP is much closer to the aged care model than the current framework around the provision of disability services. As an organisation seeking to engage with government to secure support for the village concept, CLP finds that neither the Commonwealth nor the ACT Government is able to provide a direct response because the concept does not fit within existing policy parameters.

Although the responsibility for funding of disability accommodation services rests with state and territory governments, it is unlikely that the ACT Government would have the capacity to fund the CLP urban village, and therefore Commonwealth financial support would be necessary. This is unlikely while the current demarcation of policy and funding responsibilities continues to prevail.

Conclusion

While the primary focus of the Inquiry may be on a national disability insurance scheme, it is clear that people who may accrue an entitlement under the scheme will nevertheless need to be able to access appropriate services to meet their needs from providers within the community.

CLP believes strongly that the urban village concept represents the most effective model for meeting the long-term needs of people with an intellectual disability by combining accommodation with medical and related supports, family integration, work and lifestyle opportunities on a single site with close connections to the local community.

CLP therefore encourages the Inquiry to carefully address the overall framework of responsibilities for policy development, funding and service provision across the range of services for people with a disability, with a view to recommending the adoption of a much more coherent, integrated and cost effective approach that is focused on achieving person-centred outcomes.

References

Cummins, R A, and Lau, A L D (2003); Community integration or community exposure? A review and discussion in relation to people with an intellectual disability; *Journal of Applied Research in Intellectual Disabilities*, Vol 16, 145-157.

Hatton C, (2003); Strategies for change: Implementing valuing people at the local level – Developing housing and support options: Lessons from research; UK Institute of Health Research, Lancaster University.