

Submission to the Productivity Commission on the Disability Care and Support Scheme

“ At present:

- there are many Queenslanders with disability who don't get the support they need to live decent lives in the communities of their choice; and
- there is a high level of reliance on a funding and service delivery system that is predominately crisis driven.

The potential population of people with disability requiring services is projected to increase markedly in the next ten years. Our disability service system is not well placed to respond to current levels of need, much less projected levels of need, under the current arrangements.

The solution required is much broader than how government chooses to respond to disability as a resourcing issue. The solution at this point is likely to lie in how community chooses to respond to disability as a social issue. It will require change borne of an expansive vision for an inclusive community — changes driven and owned by people with disability, their families, carers, service providers, public servants and the broader community”.

Blue Skies Scenario: An alternate future for people with disability and their families — version 1 — June 2009...(1)

Kyabra Community Association welcomes this opportunity to provide input to the discussion on the need for a National Disability Care and Support Scheme. As highlighted in the above extract from the Blue Skies Scenario, current arrangements for supporting community members who have disabilities are inadequate and require substantial change. This submission supports many points raised in the Productivity Commission's Issues Paper, highlights some of our key experiences of working inclusively with people with disabilities and their families and discusses some key areas where we believe change can be enacted to enable significant outcomes for the lives of people with disabilities.

Kyabra Community Association acknowledges the fundamental importance of some of the key points raised in the Issues Paper, including:

- *Need for flexibility of funding:* Funding provided to people with disability needs to be portable to support flexible lifestyle choices. Funding should be attached to the individual and should be allowed to be used in a flexible way in order to ensure that the individual needs of each person with a disability remains at the centre of the support. People

with a disability should be supported and encouraged to design and direct their service to ensure the service is relevant, timely, and flexible and enables the person to maintain control and direction over their lives.

- *Importance of access to early intervention services:* Intervention that is timely, seamless and offers practical advice and support is fundamental to anyone in the early stages of having a disability. This applies to parents of young children with disabilities, or to people who acquire disabilities later in life.
- *Importance of supporting people's participation within the community:* people with disabilities should be supported to take their rightful place as active, participating members of society. This means they are supported to participate in all social, political, spiritual and cultural aspects of society.
- *That the funding under such a scheme should be seen as an entitlement:* It is important that access to appropriate and relevant supports and equipment is seen as an entitlement rather than something that families and individuals are constantly having to struggle to obtain.
- *The need for a sustainable model of funding:* People should have an opportunity to purchase generic services or specialist services depending on their individual need. People should have a right to a funding model that will be able to assist them in acquiring support and services throughout their life.
- *Importance of appropriate supports during transition periods:* Kyabra supports the idea of lump sum payments being made available to people in periods of transition so they can buy the goods and services they need or make investments around particular life stages. An example of this would be a lump sum payment being made to a young person about to move out of the family home so they can pay for any home modifications necessary, or buy in the support they need to live independently.

Current Barriers

A number of key obstacles that families experience include:

- *Lack of access to appropriate informal and formal supports* - due to the current funding system, many people do not have access to appropriate levels of support and sometimes informal support networks

are pushed to the absolute limit, with many people with disabilities ending up in crisis situations.

- *Lack of access to affordable and accessible housing.* Kyabra has identified a number of barriers that may arise even if a person has secured funding for accommodation/ lifestyle support. These include issues such as:
 - People not already having a house to live in - with appropriate, affordable housing being in such short supply, finding a place to live can be an enormous struggle and creates a very real barrier to people's future plans.
 - Public housing not being readily available to people – for example, in recent years the Queensland Department of Housing, now known as Housing and Homelessness Services has moved to the One Social Housing System. A major implication of this new system is that the housing waitlist has gone from a wait-turn system (ie it will eventually be your turn) to a segmented waitlist (ie only housing those in highest need). This means that many adults with disabilities who still live with their parents will potentially not receive housing assistance as they are not homeless or at risk of being homeless.
 - Barriers to accessing the private rental market – there are many barriers to people with disability accessing the private rental market, including: physical access issues, affordability, supply of universally designed housing and discrimination.
- *Connection, belonging and active citizenship in community* requires flexibility of funds as an individual's entitlement.

Kyabra's Work: BTT & LivingIn

With regard to working with families who have a member with disabilities, Kyabra's recent focus has been on working with families whose son/daughter is planning to move out of the family home and into the community. The Building Tomorrows Together Project at Kyabra (currently funded by the Charles and Sylvia Viertel Foundation) has a focus on providing support to families who have an adult son or daughter. The project works in partnership with families around futures planning and support. Kyabra's LivingIn Project coordinates with the BTT Project to involve individuals and their families in the design process of their new homes. This level of participation is not typical for many people with disabilities and their families and provides an example of the type of developmental partnership that can exist when flexible, appropriate and relevant services are in place and each aspect is funded accordingly.

This LivingIn Independent Living Project is a collaboration between Queensland University of Technology, The Design Institute of Australia and Kyabra Community Association Inc. The Project brings the combined resources of these partners to the challenge of designing and delivering accommodation that is universal and inclusive.

The Project works with families who have an adult son or daughter with a disability to design and construct housing that enables a move to independent living in accommodation that caters for their particular physical or cognitive restrictions.

There are a number of unique features that place this Project at the forefront of innovative action research.

1. Universal Design has tended to focus on physical access and the Project broadens this focus to the application of universal design principles to a range of physical and cognitive impairments. The application is relevant to an ageing population.
2. Individuals and families are involved in all aspects of design and construction. This ensures that their hopes for independent accommodation of their choosing can be realised.
3. The Business model developed to deliver an affordable housing outcome is financially sustainable and not dependent on ongoing financial support from external sources.
4. The rights of people with a disability to participate fully in society are enhanced through the development of inclusive and affordable accommodation.
5. Environmental sustainability is central to design.
6. The housing outcome is functional, inclusive and visually beautiful.

The LivingIn Independent Living Project provides a template for government, community and business to dramatically enhance the lives of people with a disability and their families both within Australia and internationally. It represents a unique and innovative model of design and construction that enshrines concepts of participation, sustainability and positive social outcomes.

The Mission and Vision of the Project is as follows:

The Collective will provide a world's best practice model of Universal Design for government and community to enact their hopes for an inclusive society enshrined in human rights worldwide. The Collective will achieve this through the development of a process and model of

research, design and development that is collaborative, innovative, affordable and sustainable. Our Vision is of fair, thriving, sustainable communities that instill hope, embrace diversity, promote safety, and in which all people feel a sense of belonging.

This model together with Kyabra's Building Tomorrows Together Project works with the families in order to plan for the housing needs of the person and also to plan for the support requirements of the person, once they have moved from the family home into a home of their own. The planning takes into account the range of informal and formal supports that a person might require in order to live in their own home and participate in the community. The cost of this model will be different for every individual with whom we work; however it will be significantly less expensive than some of the alternative models such as group homes or residentials.

A property being developed in Allingham St, Kuraby (in Brisbane) is one example of this collaborative work. While the LivingIn Project has worked on creating a functional, universally designed dwelling, the BTT project has been thinking about who might like to live in that property. We identified one man who is ready to 'make the move' and have been doing some developmental work with him and his family around how this might operate. He identified another man (in this case, also with a disability) that he might like to share the house with and we have been working on a developmental plan with both families as to how this might work. This plan has included providing assistance to apply for Community Living Initiative (CLI) funding (through Qld's Department of Communities, Disability Services), thinking about appropriate informal live in support and other informal support that will need to be provided by both families.

We have also supported both men to trial living together in accessible holiday units on the Gold Coast. In this scenario we were able to help both men explore issues around compatibility, sharing a living space, socialising together, food preparation, bill paying, living independently on a pension and house rules.

This scenario is dependent on these men receiving some formal supports. The families should hear the outcome of their funding applications shortly. Allingham Street will be ready to live in by the beginning of the 2010/2011 financial year.

In the above example, both men have applied for \$20 000 per year in CLI funding. This would fund their formal supports. The model is also dependant on access to informal supports and generic services in the community. Thus, the total costs for the two men to live in their home in the community would be \$40 000 plus usual living costs (including rent, transport etc).

If these two men were unable to access this type of model and were forced to live in a group home or residential, the costs may exceed \$260 000 plus living expenses...

“A single group home place costs taxpayers up to \$130 000 a year. If round-the-clock care is needed, as it often is, three shifts of care workers are employed every day, seven days a week”. (2)

If a national disability insurance scheme is to be brought in to place, it needs to provide some security for people with disabilities and their families in order for people to be able to plan for a future in the community without having to resort to a group home or residential arrangement. Apart from the financial aspects and the fact that living in the community in a home of one’s own is a far less expensive option, the positive social outcomes of living in the community far outweigh the negatives.

The Kyabra model enables the person to have access to affordable housing and involves them in the individual design process. This will be made possible in the long-term by the LivingIn project partnering with other stakeholders and enhancing affordability by accessing the National Rental Affordability Scheme.

Under a new national disability insurance scheme, access to a lump sum payment at critical transition times (such as moving into one’s own accommodation) would allow a person to participate in such a model. At the same time, access to appropriate funding to purchase support with futures planning and to purchase direct “lifestyle” support will ensure seamless and positive experiences for the person and for their family.

Conclusion

Experience from both the BTT and LivingIn Projects indicates that, under a national insurance-type scheme, individuals would require access to additional resources, including lump sum payments at particular transition periods, particularly during the transition to living in their own accommodation. Such a lump sum payment could be used for capital costs such as housing modifications that would allow for universal design principles to be applied. Kyabra’s model would allow for the person to be at the centre of this process, with regard to input and decision-making and for the design process to cater for their current and future needs.

Community-based models, such as the LivingIn and BTT projects have a range of benefits, including improved social outcomes and enhanced opportunities for participation in community life, increased capacities for informal supports and community-linking, and a significantly reduced economic cost to the community as a whole.

With regard to sustainability of a funding model, it will be important to ensure that individuals and their families can experience the security of knowing that funding will be available and that they can put plans in place for the future.

(1) www.blue-skies.info

(2) "The struggle for care" by Sue Corrigan, The Weekend Australian Magazine, March 28-29 2009

See also:

- Kyabra Community Association's website: www.kyabra.org
- LivingIn Project: attached information and website: www.livingin.org.au