Submission to Family and Community Development Committee
regarding the inquiry into Supported Accommodation for
Victorians with a Disability or Mental Illness

Current situation
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Ardyne House is unique - a property with individual units for 6 intellectually disabled young adults, communal facilities and accommodation for full and part-time carers. No Federal or State government financial assistance was sought or received nor any funds made available from any housing organization or philanthropic trust. 100% of the cost of property acquisition, construction of new facilities and necessary improvements to the existing structure was met by the parents of one of the residents.

A basic level of support is provided over the Monday-Friday period by a single service provider, Marillac House, and the cost of this is also met by each set of parents. At present, no government funding for care and support services has been made available to any resident.

Ardyne House does not currently fulfill either the residents or parents' wishes that they live independently, as the house closes at weekends when residents return to their families due to the cost of, and therefore the absence of, staff.

Proposal – outline
The residents at Ardyne House are on the DSR (Disability Support Register) and have various eligibilities for Support and Choice Packages. All have a desire to move out of their family homes and all have been supported by their families to seek different options. All would be eligible for vacancies in shared supported accommodation settings were there any available and if their families were prepared to declare them homeless. However, while they remain at Ardyne House the likelihood of such a crisis occurring is minimal, and therefore they can be considered as effectively being "off" the crisis list. Provided that their parents can continue to meet the cost of private rental, these intellectually disabled adults will continue to live at Ardyne House until the end of their lives. In ideal circumstances therefore, none of them will ever need to be accommodated in a government community residential unit, (CRU). The cost to the State government of providing accommodation in a CRU is above $100,000 per annum for each single resident.
It is a condition of tenancy at Ardyne House that each resident use the services of Marillac House. Potential applicants using other service providers will not be accommodated. The use of a single service provider allows for the most effective delivery of support. For example, were each resident to require help with preparing a cooked meal, Marillac will provide a single care person to supervise this function - were there to be 6 different service providers, in theory there could 6 care persons on the premises at one time, making for a very crowded kitchen! Those wishing to use a different service provider are of course free to find accommodation elsewhere.

In this way, Marillac House provides not only properly targeted support, but does it in a most economic way. With residents absent from the house during thy day either at work or other activity such as ATSS, no staff are required on the premises during this time. In the case of the illness of any resident which requires them to stay at home, then Marillac will organize appropriate care. This very considerably reduces the weekly cost of staff.

It is almost impossible for parents, of whatever financial means, to provide in full for the independent living of their intellectually disabled child. The one-off cost of suitable premises is one thing; but the continuing cost to them of the proper full level of individual support is prohibitive. Almost no one will commit to building or renting a unit or house unless they also know at that time that ongoing funds will be available for care which will allow their child to leave home. As a result, most parents find it quite inconceivable to consider an independent life for their child. Accordingly, unless there is a crisis, the intellectually disabled child becomes an adult and continues to live with their parents until their own death or until their aging parents can no longer cope. These days, advances in medical care now allow many disabled people to outlive their parents, which was not a common event even in the recent past. On the death of their parents, the intellectually disabled suffer two crises - one the loss of family members and two, almost certainly leaving the home in which they have lived their lives. The child has to make adjustments to independent living after a lifetime of living at home, which is extremely stressful.

We believe that it is important that people who are prepared to make a private contribution to the provision of accommodation should be assisted by the accelerated release of appropriate Support and Choice packages. Whilst this may not appear to take those in greatest need into consideration, the delayed release of packages of support has significantly altered the capacity of families to pursue shared equity and shared support arrangements. Ardyne House is a case in point.

The State government wishes to see intellectually disabled people considered as part of the broader community. Those who stay at home often do not enjoy as wide a circle of friends as those who live independently and as their parents become frail there is a growing dependence on each other.
Ardyne House was planned around the joint needs of similarly handicapped people, who would move out from the family home while still in their 20s and 30s and would enjoy a life in the community similar to that of their siblings.

Under the current DHS system, each intellectually disabled person is assessed on the basis of their individual needs and this is expressed as a certain number of hours of support per week. Assessment is not the same as being actually entitled to such assistance, and years may pass before any assistance becomes available. Indeed personal experience of DHS indicates that no promises of help are ever made, no timelines given and no suggestion of what chances there might be of any future development. This would be completely unacceptable were this the way in which the unemployment or medical benefits systems were administered.

The proposal now being put forward is innovative. It would have the effect of moving the provision of care from a most expensive "crisis-driven" system to a broader needs basis. It is not the answer to all accommodation needs for all intellectually disabled people but it does harness the power of private capital to an area where it is currently sadly lacking. The problem of the lack of private accommodation alternatives has arisen as there is no certainty of government individuals support funding and therefore there is no point in private investing their own capital in a property.

Proposal - in detail
Encouragement will be given by State government agencies to groups of parents or individual support providers to establish suitable accommodation.
This encouragement is to be by way of a guaranteed support package, defined as a certain number of support hours per week per person. The State government would not supply the premises - this would be the sole responsibility of the parents' group or other association. The parents or guardians of the residents will engage a support provider of their choice to administer this "block" of hours in the way most effective for the group. The residents would remain on the DSR list, since over time, residents may leave and there could be other changes to personal or family circumstances. This "block" of hours would not be equivalent to the total number of hours as assessed for the total of all individual residents.

Example: 6 potential residents are assessed through DHS as needing an average of 20 hours per week each. If each person were accommodated separately, DHS would fund 120 hours of support per week. Instead, the parents of this group of 6 purchase a suitable property, which DHS is prepared to individually fund at 60 hours per week. This funding is administered through a single service provider chosen by the parents. While the number of hours may well not be sufficient to cover every assessed need of all residents when calculated individually, it should be sufficient to ensure that the
project is appropriate for residents' needs and is, most importantly, made on a permanent basis. Those parents who wish for further support can make their own private arrangements with the service provider, but this proposal is not designed for those intellectually disabled adults with very high needs. Indeed such people are probably not capable of truly independent living in a facility of this nature. A major benefit to the State government is that the annual cost of 60 hours per week for 6 residents is broadly equivalent to the cost of a single resident in a CRU. In addition, it is the responsibility of the parents to supply the accommodation and neither the cost of this nor the running expenses are borne by the State government either.

Conclusion

Clearly this proposal does not meet the needs of all, particularly parents with no or very limited means, nor for those with particularly high needs. However this proposal will reduce the numbers on the DHS waiting list and it will certainly reintroduce private funding into the disability field; an area which now sees very little of this. Most importantly, it introduces certainty into the lives of the intellectually disabled and their parents', something that is sadly lacking today.

Tony and Judy Baird

Addendum: Genevieve Morgan and Johanna Snelleman (Marillac House)

- Within the DHS-funded Shared Supported Accommodation/Community Residential Units system there are very limited opportunities for individuals with low to moderately-low support needs to be offered a place. These individuals may be unable to live independently (without a reasonable-sized package of support), but their support needs are not necessarily high enough to warrant placement in a sleepover-model CRU that has am and pm support.

- Such individuals would certainly not be seen as a priority for sleepover-model Community Residential Units unless their parents/caregivers passed away or became significantly incapacitated;

- We are aware of the existence of a very small number of DHS-funded Community Residential Units that only have peak hour support i.e. staff are rostered only for a couple (2-3) of hours in the evening, and there is no morning support or sleepover staff. Whilst these Community Residential Units might be appropriate for the individuals we are talking about, there are some issues with this:

  1. The very small number of such CRUs again limits opportunities for access/number of vacancies declared.
2. Peak support CRUs have no capacity/flexibility to provide additional support at times of resident illness, holidays, etc. In particular, when a resident's support needs increase beyond that already provided, and the higher support needs are deemed to likely to be long-term or ongoing, the resident will be forced to move to alternative accommodation (be it another CRU, SRS or hostel/nursing home). Thus, the permanency of the person's accommodation for the term of their life is far from guaranteed (in fact, is highly unlikely). Ardyne House in comparison, has the capacity to increase the support provided to meet the residents' needs (up to a point obviously), and is intended as a long-term accommodation option with flexible support provision. There is a greater capacity for "ageing in place".

3. Ardyne House gives residents choice (and thus control) of the residents with whom they reside - this is not an option for any resident in a Community Residential Units or Supported Residential Services.

4. An Ardyne House model of accommodation gives residents the opportunity to develop their independent living skills on an individualised basis, with no expectations of a minimum or maximum attainment of skill level or speed at which such skills are attained.

5. One of the issues faced by people with a disability (especially those with Autism Spectrum Disorder) is that living independently in the community can become social isolation and result in difficulty linking in with local community networks (recreation/leisure, friendship/social, supports etc). As with Neighbourhood Connections (KeyRing), Ardyne House-style accommodation gives residents a starting point for a "ready-made" social network (should resident wish to take part). Residents can also support one another with activities of daily living and community access by providing opportunities for skill-sharing and role-modelling.

It has been evident that there is not sufficient support for families of people with disabilities who wish to pursue private equity accommodation options to gain funding for flexible and recurrent support for their sons and daughters. Very few families can afford recurrent life-time staffing support for sons and daughters with disabilities.

Genevieve Morgan
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Note: Tony and Judy Baird, Genevieve Morgan and Johanna Snelleman would be glad to make verbal presentations to the Family and Community Development Committee regarding this submission.