

Presentation by Krystyna Croft at the Community Housing

Federation of Australia- NDIS Forum on 27 March 2014

Thank you for giving me the opportunity to address this forum.

I am a LEAD Barwon participant, LEAD Barwon is a project funded by the Victorian Government and implemented by the Committee for Geelong. LEAD Barwon is a group of people with a disability, informal carers and family members of people with a disability who are supported to share their personal experiences of the National Disability Insurance Scheme.

I am here to tell my story about housing for our 29 year old son Robert with an intellectual disability. During the last 12 months there have been exciting times, good times, some very bad times and real frustrating times. Ultimately the NDIS has given us hope but we need a lot of assistance to achieve our goals of appropriate housing for our children. I have to advocate for my son as he does not speak and he does not have the cognitive capacity due to his

intellectual disability to articulate his needs. I have a feeling that people like him may miss out on opportunities as the NDIS rolls out. I have the impression that when housing for people with disabilities is talked about generally people think about modification of housing to enable people in wheel chairs to access the housing, it is not about housing options for people like my son. We need both. But my son does not need the sort of modifications that a person with a physical disability needs. My son will always need a person to supervise him overnight in his house and this means that an extra bedroom is needed and may be even a separate bathroom. It possibly means (and I will say more about this later) that he will need a sprinkler/fire system installed.

Housing is and will be such a significant issue as it is my understanding the NDIA has estimated that between 83,000 and 122,000 people with disability across the country will need access to affordable housing options.

So to our story.

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Ever since our son was born in 1984, we have believed that he should be able to live independently but with support. We brought him up to be independent. With the closure of the large institutions everyone thought that people like our son would live in the community. As the years passed we realized that this wasn't going to happen. At the age of 18 I didn't think Robert was ready to leave home, but by the age of 25 he was ready and giving us a lot of curry. It was clear from his actions and behaviour that he wanted to leave home as his sisters had done. I also discovered a parenting truism that children stop listening to their parents. I checked this out with one of my daughters in her mid twenties and she told me in no uncertain terms that she had stopped listening. Robert had stopped listening as well. However, he still had a lot to learn so it was now up to someone else to teach him. Robert has a right to live independently with his peers as do his 2 sisters. He has the same rights as any 29 year old. This is recognized by the NDIS

which funds individualized supports for people to enable them to live and participate in the community.

So I started looking into how I could find accommodation options for Robert. What I found out was that the housing for people who needed support relied on State funding and that basically my husband and I had to be in our graves before our son might be eligible for any accommodation. This was disappointing information as we wanted Robert out of the family home as we believed that he would only reach his full potential if he lived away from home with his peers and with appropriate supports. In May 2013 a provider in Geelong offered Robert a bed in a new facility they had built. It was a 5 bedded respite facility with a 2 bedroom cottage attached. They had decided to provide support and care for 2 people in the cottage with an emphasis on developing individual living skills. The model would be cheaper than providing a stand alone facility as they could leverage some of the support services from the respite facility, especially saving the cost of a sleep over.

So in June 2013 we went to the NDIS and applied for funding based on a quote provided by the provider. On 1 July 2013 it was announced that our son was the first person with an intellectual disability to receive funding for accommodation support and he moved into the accommodation on 21 July. The funding provided by the NDIS covers the cost of personal support only. The participant must pay rent, utilities and food themselves – the same as any other person. Unfortunately after a couple of months it was clear that the placement was breaking down. There was a mismatch with our expectations and the supports which could be provided. So we started looking for other accommodation. It is obviously cheaper if a group of people pool their resources but we didn't know anyone else who was looking for group accommodation options so we obtained a quote from another provider for Robert to live on his own in a unit to be provided by us and that quote came to a rather large sum. This was for 24/7 support. I gave this to our planner at the NDIA and she said that there was a line item in the funding for people to be funded to live

on their own but this was only if they could not live with any one else and our son was capable of sharing. The planner said that she had assessed the reasonable and necessary costs for our son's accommodation support and the amount was not going to cover the cost of living on his own. It would be necessary for us to pool our resources with others. But how did we find "the others". The NDIA knew who they were but because of privacy laws they could not tell us. Then the NDIA decided that it would be a good idea if those of us who wanted funding for accommodation completed a Profile form for shared supported accommodation. So we did that but nothing has eventuated from those forms as yet. In the meantime I had found a couple of parents with adult children with intellectual disabilities who were looking for accommodation. We thought a good short term solution was to rent an ordinary 4 bedroom house in the community and to pool our resources and find an organization who could support our children.

However, there was one bit of folklore holding us back in seeing this accommodation option come to fruition and that is the requirement that where 3 or more people with disabilities live together the house needs to have a sprinkler system installed. So I set about making enquiries and having a really good relationship with my iPad. What I found was that everyone with a connection to the State Government told me this was so but no one could give me the authority for the proposition. Ultimately I found the fire safety guidelines for houses built, owned or managed by the State Government. But if there is no State Government involvement due to the funding coming from the Federal NDIS do these guidelines apply? I also discovered the Building Code of Australia but as a non professional I cannot gain access to this. There is something about purpose built houses in this code but as I understand it would only apply to new housing. And then someone told me about the bilateral agreement between the Victorian and the Commonwealth Governments in relation to the launch of the NDIS in the Barwon region. One of the Launch Site aims is that “there will be no

diminution of Victoria's quality assurance system and safeguards".

So what does this mean and can it be enforced?

This issue is such a significant barrier to the accommodation issues because the cost of putting a sprinkler system into a house can be approximately \$50,000 so not only does it increase the cost of building accommodation but more importantly it means that we cannot rent a house for our adult children and all our plans are dashed. It is very necessary to resolve this issue.

Robert's placement did finally break down but I was very fortunate to find someone who cares for Robert in their own home but I only have funding for this until July this year by which time I have to have found another placement.

I have some suggestions which may help resolve the predicament I am in, as follows :

1. We need to identify groups of people with like needs and supports and match them to enable the most appropriate

outcomes. The NDIA holds most of this information so how do we get around the Privacy Laws.

2. The rules and legislation regulating housing must be transparent and flexible to ensure all people in our community are assisted to live independently.
3. To enable appropriate accommodation to be built we need some creative financing solutions and this will require participation of both Federal and State governments as well as charities and/or philanthropists.
4. Technology for electronic surveillance sensor systems should be encouraged to be developed so that in time we can do away with the need for sleep over supports.
5. Several options and arrangements may need to be trialed before we work out what will work best for individuals and that may change a number of times. This is the same for all young people leaving home.

Where I am up to now;

I am now working with 2 other parents to create an independent living arrangement for our 3 adult children. We have come up with a model whereby a Housing Association will be the lead tenant of a property and our children will sub-lease from the Association. This takes the lease risk out of our hands. We will then have to agree on the same disability service provider and pool our resources.

Conclusion

The NDIS is providing my son with the opportunity to live the independent life we have always dreamed he would have, we now need the service providers to think creatively about the community based housing options they can make available to make that dream come true.

Like many ageing parents of an adult child with a disability, we want to see Robert transition to an independent, but supported living environment while we are still around. I don't want my daughters to be responsible for Robert for the rest of their lives; I want them to be able to have a supervisory role but not to have to take control of his life.

So what have I learned from my journey. I have learned that the scheme is not the same system we had previously in Victoria, with some more money. It truly is an insurance driven scheme but with more funding opportunities to think creatively. This means that the more supports that are put in earlier the more likely people with disabilities will be able to live more independently. We need good future planning with clear outcomes. It is very clearly an outcome based scheme. The supports need to be reasonable and necessary which is not always compatible with wants and desires.

The NDIS provides the once in a generation environment for creative and flexible housing options to be developed; so let us all get on with the task in hand.