

Australian Government Productivity Commission

Disability Care and Support - Submission 13 August 2010

Hope Villages Australia

Introduction

Nobody would disagree with the statement by Sherry, Rudd, Macklin and Shorten 2009;

'This inquiry is an opportunity to rethink how we support people with disability so that they engage with the community, get a job where possible and live a happy and meaningful life'

However this statement needs to translate into meaningful action and appropriate services to better meet the changing and different preferences of people with disability in the short and long term.

The NDIS is an ambitious commission, necessary, but ambitious considering the diverse and complex requirements of the disability sector. Lack of factual data about the size and demands of the target group and requirements for providing person centre support within a life course framework will require an enormous and significant shift in government culture that has permeated the corridors of power for decades.

Based on the way the NDIS is being promoted, people who will benefit see the NDIS as the way to obtain all the government funded services and support necessary, based on individual needs excluding housing, over the lifetime of the disabled person. However, you don't have to be Einstein to see this as a big ask, especially in the first decade of the schemes existence. The government is already on the public record stating that 'the NDIS will not be for everyone in the first instance and will be targeted at those most in need and will exclude housing'.

Contrary to the government's desire to share the costs that fall on people with disability and their families among the wider community, it is well documented that informal carers have always provided most of the current support for people with disability with adverse consequences for their long term health and financial wellbeing

Scarcity of funding means government officials and service providers determine what, when and how much will be provided, sometimes with little thought about the specific needs of an individual or capacity to make decisions and how the immediate decisions relate to the life course framework of the individual.

Current government funds are directed at people with complex and challenging behaviour, people at risk of homelessness and young people in nursing homes at the cost of PWD supported and cared for while living in their parents family home regardless of the parents age and wellbeing.

What is the difference between a person with disability living in an aged care /nursing home and a person living with ageing parents?

Greatest Fear of Proposed NDIS

Ageing parents fear the governments focus on the NDIS will over shadow the urgency for supported accommodation and come at their expense. While the NDIS holds out hope for younger parents, 1000's of ageing parents having cared for their child for 25 - 50 years will be forced to go to their grave leaving the future care and accommodation of their disabled adult child in the hands of the government.

The current system and proposed NDIS does not give ageing parents any level of certainty about the immediate or foreseeable future care and housing options for their adult children with a severe/profound disability.

It is vitally important that the protracted timelines associated with the development, introduction and immediate funding ability of a NDIS must not ignore the urgent need to also address the current supported accommodation crisis.

While we endorse the long term benefits of a NDIS we don't accept that its introduction should disadvantage ageing parents who have been waiting decades for an answer to the question

'WHO WILL LOOK AFTER MY CHILD WHEN I AM NO LONGER ABLE TO DO SO OR DIE?'

Immediate Priorities

People with severe/profound disability should be given the same opportunity as all other Australians. That is to become independent of parents as opposed to allowing the dependence to become more consolidated over the years as ageing parents struggle to cope with providing care. It is not the community norm for any person to spend their entire life living with their parents.

Ageing parents are challenged by the responsibility of ensuring their adult child with disability continues to receive suitable accommodation and support after they are no longer able to provide it. National consultations have concluded that when it comes to supported accommodation for people with disabilities 'one size does not fit all'. Parents with adult children want to ensure their child has a home and receives support care based on individual care management needs.

The values of choice and control are central to personalization. We must emphasize that supported accommodation cannot be considered in isolation as health , wellbeing, education, community involvement and ageing in place are intrinsically linked . Ultimately, the failure to link support and housing effectively limits the scope of people with disability to live independently.

Housing is a key issue for all Australians. For people with disability achieving the Australian dream of home ownership , a place to call home, until now has been impossible to achieve, except for those with wealthy parents. Current government policy forces people with disability requiring housing to

accept the existing rental model for accommodation and puts them under pressure to live in situations which are not appropriate to their needs or which they do not choose. For people with disability the rented accommodation model means living in someone else's house as a tenant, facing uncertainty about future tenure and increases in rent. This is discrimination at its worst.

People Centered Decisions

We are assured that the government wants to put the person with disability at the centre of all service delivery planning.

However in services that are crucial to lifestyle, learning and care, people with intellectual disability are treated as passive recipients rather than consumers with their own views and needs. Disability should not be a bar to choice and control of one's own life. Ensuring people with disability have the best possible quality of life and equality in choosing their own accommodation is fundamental to a socially just society.

Lessons Learned

Understanding the specific needs of the care receiver is essential to an inclusive and person centred service response. However, too often we see policies that bear little resemblance to what is needed.

The Special Disability Trust is a prime example of the government not understanding the needs of the people it purports to support. Promoted as the tool that would ***'help parents make provision for the child's future care and accommodation needs'***. It was launched with much fan fare and claims of costing the government \$200 million and expectations 5000 SDT's would be set up. The Senate Standing Committee on Community Affairs- Building Trust: Supporting families through Disability Trusts-October 2008 reported that only 22 SDT's were established in the first 2 years following its introduction.

Equal Rights

As parents of adult children with severe/profound disability we demand equality of citizenship in every aspect of our adult children's lives including where they will live and that they have the best possible quality of life irrespective of their disability.

There is NOW an urgent need to develop new supported accommodation options which deliver personalized care, home ownership and addresses the challenges of aging in place.

Currently the overarching goal of the Australian governments disability policies is to enhance the quality of life and increase the economic and social participation of people with disability and their families, including enhancing and protecting their rights. (Disability Care and support - Productivity Commission Issues Paper May 2010)

People with disability and carers have a fundamental right to shape and commission their own care services. The right to self determination must be at the heart of the governments philosophy.

Priorities should ensure that people with disability have a choice of where they live including ownership or rental, who they live with and that they are supported at every level to achieve the best possible outcomes.

Restrictive Housing Options

There has been a revolution in home ownership for the general community, with private sector developers improving choice by providing new tenure options that help people achieve home ownership. Many people with disability would also like a wider choice of tenure in housing.

However housing currently provided through Government /church /charity service providers is only provide as part of the supported accommodation package on a 'rental only basis'.

A person with disability loses control over their own life when accommodation and support services are provided by the same organisation. That arrangement occurs without any security of tenure or contractual arrangements to ensure the person's rights are protected at all times and standard of care is maintained at an agreed level.

Driven by necessity, parents have accepted placement of their adult child in the current accommodation services through desperation, lack of choice and scarcity of available accommodation options.

Who will look after our severe/profound disabled adult children, who are totally dependent on their parents for day to day living, when parents are not able to care for them or die? There is no evidence to suggest that the government even understands how many ageing parents urgently need supported accommodation for the adult child or how to partner with parents to bring forward private funding and new accommodation options.

Funding and Inaction Discrimination

People with severe/profound disability who live in the family home and are cared for by their parents have no chance of receiving money allocated on the basis of need, until parents become totally spent and their adult child becomes homeless.

While government tries to come to terms with the challenges of the disability sector, parents are left to carry on regardless. Parents must cope with each day regardless of government policy, while waiting on government-initiated reports to be produced, evaluated, discussed in committees, taken to public consultation, findings tabulated, reports written, more discussion, more committees, more public consultation on the findings, another report on consultations of the findings and so on, before

they take any action - **IF AT ALL**. Then the minister or the government changes and the cycle begins again. End result -parents cope, not by choice but through necessity. Parental responsibility does not end with some government decree.

AGEING PARENTS COPE, BUT FOR HOW LONG? TIME IS ALL WE HAVE AND IT IS RUNNING OUT.

Home Ownership

Increasingly there has been a shift to provide PWD and carers/families more control to better meet the changing and different preferences of people tailored support. People with long term, permanent, severe/profound disability and their families who can partner with government by providing capital for infrastructure should be encouraged to do so.

Nett savings from partnership arrangements which bring forward capital and transfers long term risk and responsibility to the private sector should be encouraged.

The key test for the Hope Villages Australia scheme is to address existing deficiencies in an equitable, efficient , cost effective, accountable, sustainable and practical way while addressing the pitfalls and inadequacies of the current system

Many families have an ability to bear and finance some risks themselves including housing infrastructure.

In return they would trade off access to respite services, carers allowance and carer payment etc for care funding for their adult child to live in a home of their own. This would entail significant benefits and cost savings for the government by realizing funding consolidation across all jurisdictions and allocation of capital risk and responsibility to the private sector.

By utilizing capital funding from parents and reallocating government funds already paid to keep the person with the disability living in their parent's home, ageing parents would at long last, see a way of providing supported accommodation.

Housing in the Hope Villages Australia model will belong to the residents providing security of tenure for the whole of their lives.

Capital Raising

Funding the purchase of a home for our adult child is generally a major stumbling block for most parents. However the large majority of ageing parents will be asset rich and income poor. The proposed method of funding the property purchase has been specifically designed to accommodate this situation

Hope Villages Australia proposes that parents could fund the purchase of a home for their adult child using a special shared ownership arrangement. In effect it is a part sale of the parents property. The parents keep the remaining share and continue living securely in your home for as long as they require. When the property is sold the parents or their estate will receive their share of the sale proceeds, including capital gains, based on the percentage of the property that was originally sold. This method of funding is modelled on State Government schemes already operating in many states of Australia.

A shared ownership arrangement as proposed by Hope Villages Australia will provide parents with:

- The ability to plan for the future using funds they did not know they had.
- A financially viable funding mechanism without the need for monthly repayments.
- The opportunity to accommodate other siblings through estate planning while providing home ownership for the disabled person as the first priority.
- Guaranteed tenure through home ownership.
- Separation of home ownership from the provision of care.
- Control over where the person lives and who they live with.

Lifestyle

Hope Villages Australia will create villages that will ensure residents feel they belong and empowered to participate in community life. We aim to provide a quality of life through good design which leads to people-orientated surroundings which will have a significant impact on residents feeling of safety and comfort living in their own homes. The Village will be a place in which people want to live and which they can be proud of.

Each Village will consist of normal residential dwellings (similar to the modern Retirement Resort) specifically designed to meet the needs of people with disabilities. One bedroom, two bedroom and four bedroom homes set in fully landscaped gardens will create a vibrant environment for residents with a community centre, swimming pool and BBQ area.

Village communities are about more than the built environment and infrastructure. The way that services are located, organized and delivered is also important to making a community work for the residents who live in it. High quality support care services should compliment social activity, mutual support and opportunities for active participation in the community. Hope will create communities of choice which address the needs of its residents now and in the future.

Support Care Funding

The model proposes that support care services for village residents be funded through the reallocation of the existing benefits received by the parent/carer, e.g. Carer Payment, Carer

Allowance and associated respite program funding. It would also draw on "entitlements" to other government funded support services.

Further details of the proposed model are available on request.

Action Priorities

The impetus for a new scheme stems from the flaws in current policies and excessively rationed and limited housing options and support services.

Hope Villages Australia will not be just providing people with a roof over their head, instead it will be about providing people with a 'life course framework' embracing quality lifestyle and care options tailored to the individual, security of tenure, community access and a whole lot more. Hope Villages Australia will operate as a private not-for-profit company dedicated to the provision of home ownership, lifestyle, learning and care for adults with severe/profound disability.

- Groups which can partner with government to provide increased services within current expenditure and attract private capital investment should receive immediate attention for development and implementation.
- People with disability or families have insufficient capacity to exercise choice about services they use and control over the financial resources directed to them. The application of equal opportunity regulations must be consistent with upholding people's rights and for social justice which are not recognized in current arrangements

Change will not come if we wait for some other person or some other time.

We are the ones we've been waiting for. We are the change that we seek.

Barack Obama

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