NSW Council for
Intellectual Disability

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Submission

Community Affairs References Committee Inquiry:

Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

May 2010

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28th May 2010

Committee Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Sir/Madam,

The New South Wales Council for Intellectual Disability (NSW CID) is pleased to make this submission for the Inquiry into Planning Options and Services for People Ageing with a Disability.

New South Wales Council for Intellectual Disability is the peak body representing the rights and interests of people with intellectual disability in NSW. Our Board is made up of a majority of people with intellectual disability, and people with intellectual disability are not only consulted on, but drive the work that we do. NSW CID engages in systemic advocacy and policy development, as well as providing a state-wide information service called ASKCID.

NSW CID supports a more cohesive and accessible system that makes it easier for people with intellectual disability to have a good quality of life as they age. In this submission, NSW CID will offer a range of suggestions which we believe would improve the current system and allow for the opportunity of planning for the future with confidence for people with intellectual disability and their carers.

For this submission, NSW CID has chosen to use case studies taken from our ongoing consultation with members and our contact with community members in addition to the available research to form the basis of our recommendations. Whilst these case studies may highlight some of the deficits in the current system, our focus is on offering ways to strengthen the capacity of all stakeholders involved in providing support to better meet the needs of people with intellectual disability as they age.

NSW CID has contributed significantly to the process for two other submissions to this inquiry, being those of the Futures Alliances and Mc Call Gardens Community and strongly endorses the statements and proposals these offer. However, NSW CID regards this issue of such importance for people with intellectual disability that this submission was developed to reflect their specific needs as they age.

NSW CID supports that having access to a more coordinated, flexible and individualised support system is required to ensure that people with intellectual disability are afforded the same opportunities as all citizens. Recognition and response to the key issues raised by this inquiry can begin to address much of the inequity and disadvantage people with intellectual disability have faced throughout their lifetime and avoid it being continued into their old age.

NSW CID strongly recommends that the Inquiry remembers that over 100, 000 individuals with intellectual disability in NSW have hopes, dreams and desires as they age, that are worthy and meaningful. These individuals are entitled to political and systemic action to ensure that their lives are active, purposeful and satisfying as they age.

NSW CID would be pleased to have the opportunity to submit oral evidence if required. Please contact NSW CID on 9211 1611 should you require any additional information or wish to discuss this submission further.

Kind regards,

Carol Berry
Executive Director
NSW Council for Intellectual Disability

What do we know about people with intellectual disability that are ageing?

"Ageing, for older people with lifelong intellectual disability, is a relatively new phenomenon and we are only now seeing the first substantial group of older adults with lifelong intellectual disability reach old age" (Buys et al 2008:67)

Clearly there is an awareness and recognition that people with intellectual disability are living longer and that we need to adequately plan to meet their needs. However it is important to identify who exactly these people are and what their history and current life situations have been.

"In Australia, by far the majority of adults with developmental disabilities live in the family home accounting for around 240,000 people in Australia alone. Of these more than 11,000 currently live with their ageing parents." (Balandin 2008) For many people with intellectual disability that there is a reliance on family to provide for support needs from childhood and into adulthood. There are also people who have been in care for the majority of their lifetime and those who have not been able to access any supports at all.

"Due to their life experiences, people with ID often age from a particularly disadvantageous position." (Bigby 2008:77) This includes for many people that are now aged a lack of access to education, institutionalisation, abuse, segregation in numerous life domains and limited employment opportunities. The longitudinal and multi –dimensional experience of this should not be underestimated and significantly contributes to disempowerment.

With shifts in societal attitudes in the past two decades many people with intellectual disability have been exposed to new opportunities and have become leaders in self advocacy or completed adult education or gained open employment later in life. Many older adult with intellectual disabilities are keen to continue engaging in this new found freedom and explore their potential well into the future.

We also know that while people with intellectual disability are living longer they still have a lower life expectancy than the general population and which is twenty years lower for people with severe disabilities. (Bittles & others 2002) Access to good health care can be impeded by communication difficulties, lack of knowledge about intellectual disability in mainstream health services and lack of information available in formats that people with intellectual disability and their support networks can understand.

What do we know about the planning options for people with intellectual disability that are ageing?

"There is little opportunity for life course planning for individuals" (Disability Investment Group 2009:2)

People with intellectual disability lack choice in most aspects of their lives including accommodation and personal care and are continually denied access to the key opportunities that enable the creation of a good life such as the ability to gain an education, earn money or access comprehensive health care.

With the exception of a number of trials of limited size and scope, NSW does not offer any program that allows for financial self direction for planning support. People want to plan, they are aware that their needs are changing and would like the opportunity to approach the future with certainty. Many younger people contact ASK CID wanting to broach the topic of accommodation and 'moving out', due to significant unmet need in this area there are not options to enable this.

Unfortunately the situation becomes that "*without adequate plans and supports in place, individuals with developmental disabilities can face unfortunate situations of emergency placements in inappropriate settings and inadequate financial and legal safeguards when primary caregivers can no longer provide care."* (Bigby 2008: 156)

"The impact of social exclusion may in fact be more pronounced as people with intellectual disability embark on the ageing process, and the risks of not having any formal advocate to manage relationships with the formal services system become greater." (Bigby 2008:158) People with intellectual disability will often have decisions made for them by family members, parents or service providers. The ability to exercise choice and self determination is stifled, regardless of the legislative systems that are supposed to ensure against this. People with intellectual disability do not have a powerful voice and subsequently their plans for life are largely dependent on policy makers and government.

There are programs such as the Older Parent Carer Program that offers some assistance to carers in the planning process, however there is no similar program for people with intellectual disability who can advocate for themselves. Both families and people with intellectual disability need to have the chance to be proactive when it comes to ageing so that planning well and planning early becomes a reality and a quality of life that is dignifying and meaningful can be sought. This includes notions such as building networks of ongoing support, succession planning, engaging siblings, capacity and strengthening of families and individuals as well as financial and legal arrangements when necessary.

What do we know about services for people with intellectual disabilities who are ageing ?

During consultations regarding human rights in 2009, NSW CID members expressed that the right to have support as the most important human right. Eligibility or pathways to these supports or services however are not clear. The case studies that follow in this submission highlight that this is a significant barrier to accessing services and that this is experienced by not only people with intellectual disability but also the health professionals, support staff and carers that assist these people.

The most common subject of concern that is raised by callers to our information service ASK CID is accommodation issues. Middle-aged and older adults with intellectual disability living at home with elderly parents form a significant proportion of the estimated 23,800 people with disabilities with an unmet need for accommodation and respite services (Australian Bureau of Statistics, 2003; AIHW, 2007). This gross shortfall in availability of accommodation compounds the already emotionally difficult task faced by older families in planning for their family member's future. The Disability Investment Group Report 2009 also found that there is a "*challenge of securing permanent accommodation for people with disability, which reflects their changing needs across the life course*" (2009:71). Rather than exercising choice about the location, type of accommodation, and selection of co-residents, adults with intellectual disability leaving the family home in mid-life may be forced to take the only option available. Some are likely therefore to be ageing not only in a group home, but one which they have not chosen and which is a poor match to their needs. (Bigby)

Boundaries created by the demarcation of funding for ageing being provided by the federal government and disability by the state government restricts and impedes access to many age related services for people with an intellectual disability. People with intellectual disability are often denied an aged service because '*you are a recipient of a disability service'*, regardless of the fact that the disability service may not be funded to meet that particular aged related need. Whilst COAG announcements in May could begin to address these issues, ambiguity and cost shifting is still a possibility as it has not been determined how these changes will be effectively funded. Disability services can be more costly than aged services and how this will be balanced when people shift from one to the other is not apparent. It will be important to ensure that there is not a marked decrease in service provision as people with intellectual disability age.

NSW CID is aware that people with intellectual disability that use support services often have multiple needs for assistance. According to the Australian Institute of Health and Welfare's National Data on disability support services 2007 -2008, "*the most commonly reported disability for the five year collection period has been intellectual disability, with 32% or 77,320 service users in 2007-2008 reporting intellectual disability as their primary disability".* Of this cohort a further 53.6 % of this group had an additional significant disability. (p18) This clearly indicates that services need to be sufficiently resourced and educated to be able to meet complex carer and support needs.

NSW CID realises that this inquiry allows for the opportunity to examine the possibility of individualised, self directed funding for all community members ageing not just those with intellectual disability. NSW CID is of the view that opportunities to choose individualised or self-directed funds management (also known as flexible packages) should be more widely available as an option for families in New South Wales. This option is available in some jurisdictions around Australia, and is considered to provide good value for money and excellent individual outcomes. Internationally, there is a shift from the block funding of disability support services, to a direct funding approach. In other words, individuals who have a disability are funded directly by the Government. This approach focuses more on the support needs of individuals in the allocation of funding resources, and allows for greater empowerment of individuals with disability within the system. In the United Kingdom, there is a system called the *Direct Payments* system, where the funds are handed over directly to the individual. This system allows for the greatest amount of control and freedom to the individual. From NSWCID's perspective, the key benefit of the provision of individualised funding options in NSW would be that some consumers may substantially benefit from being able to access this choice in regard to their funding for supported accommodation options. On this point, it is our belief that individualised funding will offer a greater degree of control for individuals as they age which will allow for an increase in provision of high quality services and providers.

NSW CID is unsure as to why the mainstream population does not have a stronger agenda opposing the institutionalisation of elderly community members. There has not been widespread advocacy against this possibility and the introduction of more innovative community living responses to the aged care dilemma. Disability movements have been strongly opposed to institutionalisation for decades. The importance of creating opportunities for people with intellectual disability to partake in community life across the lifespan has been emphasised. NSW CID believes that the NSW Government approach to redeveloping current institutions for people with intellectual disability into village style accommodation or cluster housing is not the answer. We believe that with the correct planning a range of other models of supported living with the necessary safeguards and appropriate supports can be developed.

Finally it is also important to note that for many people living with intellectual disability that they do not necessarily identify as having a disability at all. This is especially true for people from Aboriginal and Torres Strait Islander backgrounds, and older people that have not had continued access to appropriate health care or relevant supports throughout their lifetime. The complex needs of these people will need to be accounted for and solutions that are sensitive sought.

Recommendations

Choice

Introduction of self directed, individualised funding packages that are lifelong and assessed on the support needs of the individual, rather than on disability or age.

Support for consumer lead initiatives and initiatives planned in collaboration with families and friends where this is not possible.

Accommodation

Access to a full range of accommodation options and supports that are similarly available to anyone else in the community who are ageing.

Allowing people to age in place, living where they want to live with the supports they need to do so.

Supporting community living based options for all people with intellectual disability including those with high or complex support needs, to avoid inappropriate or premature admission to aged care facilities.

Prioritising the devolution of large residential centres and institutions so that people with intellectual disabilities can have the opportunity to live in the community in their lifetime.

Unmet Need

Create the flexibility in Commonwealth and State funding agreements and eligibility so that those who could use an aged care support, such as in home care, due to premature ageing can access it easily and maintain independence.

For the purpose of gaining more equitable access to support, recognition as a 'Special Needs' group within the Aged Care funding and legislative framework, such as is offered to other groups of disadvantaged people such as Aboriginal and Torres Strait Islander peoples.

Recognition of the complexity of having more than one disability and the significant impact that this can have on receiving the right support.

Addressing unmet need in the context that it is a human rights issue, not as an ageing or disability issue.

Health

The development of specialised services to enhance the capacity of the mainstream health system to provide equitable and cost effective health care to people with intellectual disabilities throughout the lifespan, but especially as they become older.

Continued development of assessments that accurately identify ageing and health issues for people with intellectual disabilities, such as recognising the signs of early onset dementia.

Recognition of and response to the grief people with intellectual disabilities encounter in their life, with regard to not only death of significant people, but of lost life opportunities and potential.

Communication

Legislative change that requires government material, both ageing and disability related, to be produced in a range of accessible formats, enabling people to partake in everyday activities independently e.g. being able to understand meals on wheels brochures, thus reducing the cost for unnecessary support.

Advocacy

Adequate funding to meet the increased need for independent advocacy, thus ensuring advocacy is available for people who are unable to and/or have no support from families or carers to manage.

Funding initiatives that promote the continued involvement of older people with intellectual disabilities in self advocacy and systemic advocacy, so that they can actively partake in influencing policy for new issues that emerge as they enter a new life stage.

Research

Funding to conduct ongoing research into quality of life measures that are important for people with intellectual disability and using this developing evidence base to direct future policy direction.

Inclusive research, lead or achieved collaboratively by people with intellectual disability that reflects their lived experience, which may of course include a life time of care.

Relationships and Social Inclusion

Support available to assist people with intellectual disability to cope with grief, change and transitions that occur as they and their families' age.

Opportunities for people with intellectual disabilities and their advocates, be it families or otherwise, to plan together for the future, avoiding crisis and emergency situations.

Understanding that some ageing parents and carers may no longer, despite good intentions, be able to act in the best interests of their children due to their own ageing experiences and the provision for independent advocacy in such situations.

Recognition that not all older people with intellectual disability have families or social networks to support them as they age.

Community development initiatives at all government levels to promote the social inclusion of older people with intellectual disabilities in all aspects of civic life, especially in relation to seniors programs, activities and groups.

Education

The introduction of planning mechanisms for people with intellectual disabilities so that they can as much as possible direct their own futures. This could include workshops, access to case workers, material in easy to understand formats and independent advocacy and information.

Pre and post graduate training and curriculums to to include disability studies for health, allied health and community services professions.

Cross Sector Initiatives

Elimination of demarcation of funding and eligibility criteria between age and disability sector providers so that services are person centred, focused on individual need and coordinated in their response.

Development and funding of formalized programs, training and resource sharing networks that allow for knowledge and skills to be shared between disability and aged care staff.

The recommendations are founded on the numerous case studies that NSW CID has gathered through our consultations and ASK CID information service (examples of which are included in this submission), as well as evidence from research and importantly from what people with intellectual disability have indicated that they need in order to have a good life as they get older – or as one NSW CID member said "become an old duck".

NSW CID realises that the implementation of these recommendations does not solely rest on the government rather it is shared with people with intellectual disability, families and carers, disability and aged care providers, the community, mainstream services and advocates. However the government is encouraged to take a decisive leadership role to ensure that these are prioritised and that widespread systemic change can begin to happen.

Case Study 1: Wanting to plan

Alyssa contacted NSW CID through the information service. She has two cousins, who are aged in their 40’s, who currently live with their parents. Alyssa explained that she was enquiring as to what will happen when the parents could no longer care for them at home. She wanted to start planning but did not know where to start.

- “What are the options other than group homes – we don’t want them to live there”
- “Our family has some money, who could help us set up a place for them to live? They, (the parents) are old now and could not do this by themselves.”
- “Does the government offer any assistance or money to people who can contribute towards accommodation?”

What could we tell her?

- Due to the limitations of the eligibility criteria hers cousins were not able to benefit from the Special Disability Trusts initiative
- Even if they desired to live in a group home, there is currently an enormous shortage of places available
- There is currently no formal mechanism in NSW to guide people with disabilities and their support networks who wish to set up a supported living arrangement
- The NSW Government does not offer any financial support to those who are able to contribute towards the cost of a supported living arrangement

We were able to link her to the Older Parent Carer Support Scheme, which is useful in assisting parents to plan for the future – however, the planning process highlights that there is actually little choices or options for people when it comes to accommodation.

Case Study 2: Healthier Lives

Emily rang ASK CID to enquire where she could get some advice about her sisters Rebecca's health. Her mother had passed away recently and she was now caring full time for her sister who was 47. Her sister had been visiting the same family GP for over twenty years and she felt that the GP was not adequately addressing her sister's needs. She expressed concern she felt her sister was depressed and perhaps grieving due to both the death of her mother and moving to live with her sister.

Whilst NSW CID was able to refer her to a clinic which would potentially meet her sister's needs, this did involve a waiting list due the demand of the service. There is also a shortage of psychology and counselling services that have experience of working with people with intellectual disabilities that ASK CID can refer such people too.

Further to this the GP consequently contacted NSW CID and advised that whilst he knew Rebecca well he did not have a large amount of information available about intellectual disability and what would be the appropriate course of action.

Please see the attached *NSW CID Position Statement on Health*, which proposes for the development of specialised services to enhance the capacity of the mainstream health system to provide equitable and cost effective health care to people with intellectual disabilities.

Specifically related to ageing, the main stream health services which would benefit from the knowledge of intellectual disability experts include:

- Geriatricians
- Psychologists
- Social and Caseworkers
- Speech Therapists
- Occupational Therapists

Case Study 3: “Something to Do”

Patsy who is 63, recently retired from employment due to the onset of health needs. She had worked for over 20 years in a supported workplace environment. Patsy had been paid on a subsidised wage system and does not have a superannuation package which allows her retire with sufficient funds to pursue many leisure or recreational interests.

Patsy contacts ASK CID as she “wants to do something, I’d like to get out of the house.” She has become increasingly anxious and is losing confidence to independently travel as she rarely utilises these skills. She has no contact with her family and is very socially isolated. She is ineligible for aged care services recreational services as she does not meet the eligibility criteria of being 65 nor is she eligible for the *Active Ageing Program Disability Program* in NSW as her disability is not classified to meet their criteria of moderate to severe.

NSW CID has tried to link her with an individual advocacy service in her area in the hope they can assist her to navigate a pathway to some supports and recreation programs. Patsy is currently on the waiting list for this, whilst sympathetic of her situation her issue in not prioritised due to many competing people needing advocacy support.

Evidence suggests that “positive effects of physical activity on mental health and psychological well-being (including various outcome measures such as mood, life satisfaction and self efficacy or confidence) has been reported for adults aged 60 years and older (Boutcher, 2000; Callaghan, 2004; Atlantis et al, 2004), but very little attention has been paid to the well-being of adults with intellectual disability” (Carmeli et al 2005:300).

For people with intellectual disability, as with the rest of the population group, often many social and emotional needs are met at work, contributing greatly to having a sense of purpose and good quality of life. Post retirement can have an enormous impact, especially so if you are unable to facilitate or negotiate access to other meaningful activities. Consultations with NSW CID Members have indicated that in almost every aspect of daily life there was not enough information in easy to understand formats.

Case Study 4: Inappropriate Institutionalisation

Eloise contacted NSW CID to find out what she could "do" with two of the people she supports in a nursing home. One person was aged in their late 30's another person was aged in their 40's, both had intellectual disabilities and some health care needs.

As an activities officer she was at a loss as to how to communicate with them, they were unresponsive to the usual activities she organised and she felt that they were sitting around all day doing nothing.

She expressed that she only recently discovered that "just because you have an intellectual disability does not necessarily mean you have dementia". Eloise said no one in the nursing home had any training in disabilities. Eloise had contacted numerous services before ours and was desperately seeking information on why these people were not living in the community.

"Older people with and without an intellectual disability living in older people's homes experienced poor quality of life outcomes in terms of participation in meaningful activity and community involvement compared with older people with an intellectual disability who lived in intellectual disability homes" (Higgins et al 2009:211)

Little is known about their quality of life in these homes, they do not have access to skills based programs that promote lifelong learning and enhancement of skills – aged care facilities are not equipped, educated or to provide the right support for people with intellectual disability – they have a fundamental difference in thier purpose. "People who live in intellectual disability accommodation require support to carry out activities of daily living and to promote independence, whereas people who live in older people's homes (without an intellectual disability) mainly have needs related to the ageing process and as a result may have associated high health needs" (Higgins et al 2009:208).

"As clinical psychology services receive more referrals for suspected dementia (Wade et al., 2003), the present challenge is to devise effective methods to assess, accurately diagnose and meet the needs of this client group. (Kirk 2006 et al:358)"

Case Study 5: Exerting Control

Peony is 35, she lives in a flat by herself and she works part time. She travels independently on public transport and belongs to a self advocacy group where is actively involved in promoting the rights of people with intellectual disability. She has completed two TAFE courses and is a valued member of her work organisation.

Peony's mother has been unwell in recent months. She has no social networks and relies heavily on assistance from Peony to manage her health and some of her living needs. Peony is an only child and often finds that her mother requests are not reasonable. At times her mother hides information from Peony, has begun to make arrangements for Peony without her consent and has threatened that if Peony does not do as she requests will not talk to her anymore. Peony's mother has also stated that despite Peony's demonstration otherwise that she is not competent in managing her life.

This situation causes much anxiety for Peony, she is torn between wanting to control her own life – yet realises that her mother is her only family and the impact of losing this connection and relationship could be devastating personally. Peony is not sure who can help her to 'sort through' these issues.

Dependence on family members can work both ways. NSW CID is aware of numerous cases where people with intellectual disability are out-living their parents and due to their competence and good health are becoming carers for their parents. Often this isolates people with intellectual disability from the wider community and age related peers. They are unable to pursue their own life goals as parents still exert control over financial decisions and they remain living in the family home. Bigby suggests that sometimes emancipation only comes for these people when a parent's death occurs and a new found freedom is tasted.

As people with intellectual disabilities, families, advocates and supports are facing these challenges for the first time as this group ages, there needs to be an increased awareness and learning developed regarding this. Ongoing reflection and reviews of ways to manage this will be essential so that best practice will evolve for these sensitive issues.

Case Study 6: “It is a catch 22 whichever way we go”

Betty contacted NSW CID for legal advice. The service which supported her adult daughter was being amalgamated with another one and they were not being included in this process adequately. Betty said that she was very concerned that the new service would not support as much family involvement. They had no choice in this process happening, were told the old service was no longer viable and that if the merger did not go ahead there would be no place for Mary to go.

Betty said that there was no one else to look out for Mary, her other child had mental health issues and he would not be able take on such a responsibility. She told ASK CID she was scared to die, the worry never goes away about who would make sure that Mary was ok – “Mary can’t speak up for herself – who will? The old staff are nice, but they have lives they move on and Mary has to start over again”. She felt that she “can’t really complain because we have no other choice and we don’t want them to treat Mary unfairly”. Thus the statement “it is a catch 22 whichever way we go”.

This highlights not only the challenges for families but also those of service providers who often would like to be able to sustain continued care as people age but cannot attract the amount of funding needed to do this. Disability service providers have indicated that having the resources to more comprehensively meet the health care needs of these people would ensure that they could continue to live in their current community living arrangements for longer.

NSW CID supports the notion of Ageing in place which “prioritises the choice that the support and care of older people can take place in their home and community” (Hambleton et al, 2009).

There is promise - things can be better!

These snippets demonstrate ***possibility*** - of what people are able to do when they have the support to follow their own dreams and desires, regardless of what they may be.

It shows not only the capacity of people with intellectual disability, but also of those who provide support and how they too can be motivated to operate in a person centred manner – no matter where they work or who funds their program.

NSW CID advocates for the creation of environments that can foster lifelong learning, opportunity, inclusion and empowerment for people with intellectual disabilities.

Eric, at the age of 52 being able to say “it is nice to try new things – my parents never used to take me to Chinese restaurants”; after moving to a community based living program.

Betty a 63 year old lady with intellectual disability and early onset dementia, being able to continue to access her day program when she moved into an aged care service; due to a ‘flexible’ arrangement between the two service providers. This allowed her to maintain friendships, continue her role looking after the program’s pet and regularly going to the club for a middy of beer. The nursing unit manager commented that she wished all the residents in her care, disability or otherwise, had as much access to the community and activities that Betty did.

Sean, at the age of 56, surprising his older and technically inept sister, by asking for her email address after he completed a WEA computer course on how to use a computer. Sean had only attended school till the age of 13 in the institution he had been placed in due to his intellectual disability. This had remained his only formal education until he had support as an adult to attend an adult education course. Indeed “studies indicate that assistive technology can support people with intellectual disabilities in community participation but remains an untapped resource for this population” (Mirza and Hammel 2009: 447).

Grace demonstrating that it was perhaps the food and the environment at her nursing home, rather than her behaviour and health needs that had led her to pursue a hunger strike. Grace had shown pictures from her weekly outing to staff, who were shocked to see her eating a sausage roll and ice-cream in a cafe. The community access worker noted that Grace had never displayed ‘challenging behaviour’ except when surrounded by peers and a choice of what to eat in the community. The community access worker had been enabled by Grace’s inheritance allowing her to pay for a service otherwise not available to her. She had been placed in a nursing home at the age of 45 when her mother died.

Staff that participated in the Disability Aged Care Interface Pilot (DACIP), as established under the Aged Care Innovative Pool (IP), creating ongoing networks and partnerships with aged care providers, HACC and ACAT teams. This has allowed for ageing in place strategies to be implemented – such as installing grab rails and having home support for cooking, instead of premature relocation to a 24 hour support facility for some people in the program.

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Please contact NSW CID should you require copies of any of the reference material.