ANGLICARE
THE CARE THAT CHANGES LIVES

SUBMISSION TO THE INQUIRY INTO DISABILITY CARE AND SUPPORT

Prepared for:
Productivity Commission

Prepared by:
ANGLICARE Sydney

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INTRODUCTION

ANGLICARE Diocese of Sydney (ANGLICARE Sydney) would like to thank the Productivity Commission for the opportunity to make a submission in relation to the Disability Care and Support Inquiry.

This submission from ANGLICARE Sydney responds to the key questions that were outlined in the Productivity Commission's Issues Paper. The submission is supported by references to our research reports and feedback from our frontline service staff.

ANGLICARE Sydney has noted that the Terms of Reference for this Inquiry overlaps with a number of issues covered in the Productivity Commission's Inquiry into the Not-for-Profit Sector. Consequently, ANGLICARE's submission also makes reference, where relevant, to some of the recommendations and findings from that preceding Inquiry.

About ANGLICARE Sydney

ANGLICARE Sydney is one of the largest Christian community organisations in Australia; it embodies the Christian commitment to care for all people in need, as comes from Jesus' command to love your neighbour as yourself.[1] ANGLICARE Sydney has been providing a wide range of professional services to the community since 1856 and serves many thousands of people every year. Its services include: counselling; community education for families; family support services; youth services**;** emergency relief for people in crisis; foster care and adoption for children including those with special needs; migrant services including humanitarian entrants and newly emerging communities; English as a second language classes; aged care both through nursing homes and community services; opportunity shops providing low-cost clothing; emergency management services in times of disaster; disability case management and respite and chaplains in hospitals, prisons, mental health facilities and juvenile justice institutions.

Both historically and to the present day, Christians and Christian organisations have been at the forefront of social justice by caring and advocating for disadvantaged groups in Australia. As a Christian organisation our mission is based on the biblical understanding that God is particularly concerned about issues of justice and oppression and the protection of the poor and the weak. Caring for people with a disability and realising their right to service support has been part of ANGLICARE Sydney's mission for many years.

More specifically, ANGLICARE provides the following services to people with a disability and their carers:

- **Commonwealth Carelink and Carer Respite Centres (CCRC's):** ANGLICARE Sydney has operated both the Commonwealth Carer Respite Centre and the Commonwealth Carelink Centre in the Nepean and South West Sydney regions for nine years.
- **Community Options:** This program offers case management and brokerage for people of all ages with a functional disability who are at risk of premature admission to residential aged care. The program operates in the Blacktown, Hawkesbury, Holroyd and Penrith LGA's.

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[1] The Gospel of Matthew, chapter 22 verse 39

- **Support Co-ordination for Older Parent Carers:** This program provides case management for older carers (65 years+) supporting an adult child with a disability at home.
- **Respite Options:** This program provides flexible respite packages to carers who have a child with a disability.
- **ComPacks**: This program provides short-term case management and brokerage for people being discharged from hospital with complex needs.
- **Westlink Host Family Program:** This program offers family-based respite care which is provided by volunteer families in the community. The program commenced in 1980 and now operates in the LGA's of Auburn, Holroyd, Parramatta, Baulkham Hills, Blacktown, Hawkesbury, Penrith and Blue Mountains.
- **Vacation Care:** This program offers day care during the school holidays for children aged 0-6 years and 7-10 years. Holiday camps are offered to 10-18 year olds, from within the same areas of the Westlink program.
- **Complex Care Support:** This program is funded by the National Respite for Carers Program.
- **Peer Support:** This program provides community-based activities for adolescents aged 14-18 years in the Holroyd, Parramatta, Baulkham Hills and Blacktown LGA's.
- **W.H.I.R.L.S.:** This service provides out-of-hours respite for people aged 18 years and over with an acquired brain injury and their carers / families in the Blacktown LGA.
- **Dementia Home Support:** This program provides in-home respite to people with dementia and/or their carers in the Blacktown LGA and Nepean region.
- **Chesalon Care at Home**: This involves the provision of Community Aged Care Packages (dementia priority) to enable frail aged people and people with early dementia to remain at home for as long as possible.
- **Richmond and Winmalee Day Centres:** These centres provide programs for care recipients and respite for carers.

In seeking to assist people with a disability, ANGLICARE Sydney is informed and motivated by a biblical perspective. The two great commandments for those who would love God and who would follow his Son Jesus, are to 'Love the Lord your God with all your heart and with all your soul and with all your strength and with all your mind'; and to 'Love your neighbour as yourself.' (Luke 10:27).

Our human response often is to seek out the limits of this command, to ask, "Who is my neighbour?" This question can be asked in order to exclude, seeking to treat such people as the 'other', and therefore so different as to fall outside of any call to love. This exclusion can come because of such things as race, religion, social standing, or germane to this submission, disability. However Jesus' response was, in essence, that your neighbour can be any person whom you find (Luke 10.25*ff*.).

Therefore as Christians hearing the call of Jesus to love our neighbours, we aim to:

- walk alongside and assist people with a disability;

- advocate for the removal of social structures and attitudes that burden or demean people with a disability; and
- offer support to the families and carers of people with a disability.

KEY ISSUES IN RELATION TO DISABILITY

There are several issues surrounding disability that need to be taken into account in designing a national disability scheme.

(i) Disability is Complex and Varied

Policy approaches generally do not recognise the diversity in nature and levels of intensity of disability. Nearly all of us can expect to experience some form of disability as we reach old age, if we have not already done so over the course of life. Because of this, some authors have suggested that the able bodied are better thought of as the 'not yet disabled' or the 'temporarily able-bodied' (e.g. Creamer 2009). This is a useful reminder of the fragility of our independence, and adds resonance to the call to love your neighbour as you love yourself, since it may very well be yourself that is experiencing disability.

Disability can be described in three stages (e.g. Creamer 2009; McCloughry and Morris 2002):

1. Impairment — any physical or psychological abnormality or loss of capacity
2. Disability — the consequences of impairment
3. Handicap — disadvantage arising from an impairment or disability

There are different ways of mitigating disability at these different stages, from medical intervention/treatment, to changing social structures and the physical environment to mitigate disadvantage. There is a range of bodily experiences that we can refer to collectively under the terms 'impairment' and 'disability' which can be categorised in a variety of ways. For example, we could think of impairments in the categories: physical disability (such as loss of eyesight, or motor function); mental illness (such as depression, or schizophrenia); cognitive disability or delay (such as Down syndrome); behavioural disorder (such as Tourettes syndrome). Of course the boundaries between these categories are not so easy to draw and often one type of disability can be correlated with another. Alternatively, we could categorise disability as congenital or acquired, permanent or temporary.

Any new national disability strategy needs to be sufficiently flexible and nuanced to cater for this diversity, recognising that a 'one size fits all approach' for disability services and support mechanisms is neither effective or equitable. The nature and level of support and intervention will vary depending on the nature and complexity of the disability.

(ii) Alternative Approaches to Disability

There are two key models for understanding and explaining disability.

a) The first, the medical model, defines disability as a loss of bodily function. Within this model, disability is perceived as entirely negative and treatment is directed at restoring function (McCloughry and Morris 2002). Disability, a deviation from what is acceptably ‘normal’, is identified in the body of the person with a disability. This way of thinking about disability can lead to ways of talking about people with a disability as less than whole, where something is missing. Medical practitioners often struggle to balance objectivity and scientific detachment with the empathy and pastoral care required by persons with long-term, persistent illness or disability (*ibid*). The professionalism required of medical staff can also have the negative consequence of shutting out the patient from participating in decision-making. Appropriate medicine should be therapeutic, playing a role in ‘correcting’ the disease or disability, but how much and to what extent? Where do disability and dysfunction stop, and normality begin? In addition given the painfully obvious limits of even remarkably powerful medical intervention, the community’s response must be multifaceted, not simply medical and ‘corrective’ alone but offering care – physical, spiritual and social, showing ‘neighbourliness’ and hospitality. This relates directly to the second prevalent model of disability.

b) The second model is the social or minority model of disability. It shifts the focus of attention from the person with a disability as a patient (to whom things are done) to the person with a disability as a citizen (who does things). Whereas the medical model locates disability in the individual, the social model locates disability in the society that facilitates exclusion. The medical model strives to change the individual with a disability in ways that help them participate in society, while the social model calls for changes in society to allow the full participation of persons who have some form of physical or psychological impairment (*ibid*). The social model of disability is necessarily political, in that it calls for changes in values and attitudes rather than scientific advances.

These models each have helpful and unhelpful elements, and each needs to be taken into account in a national disability scheme. While the medical model can unhelpfully identify disability as personal tragedy, the social model can go too far in disallowing grief and pain (*ibid*). Helpfully, the medical model reveals the embodiment of disability and the very personal experience that can be, while the social model identifies the ways in which disability is so often a result of prejudice and discrimination rather than just the physical or psychological effect of impairment on the individual.

(iii) A Growing Need in Australia

> *“Some form of disability affects about one in five Australians. In the context of health experience, disability may refer to impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors, environmental and personal factors).”*
> Australian Bureau of Statistics 2010

Included in that number are 4% of the Australian population (over 800,000 people) who are considered by the Australian Bureau of Statistics (Ibid) to have a profound or severe disability that limits their independence in three or more core activity areas. Governments around Australia make a major contribution to support for people with disability but there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers.

The National People with Disabilities and Carer Council's 2009 *Shut Out* Report indicated the need for systemic change in relation to people with a disability. Such change revolved around the need for greater economic and social participation, reducing or eradicating discrimination, improving support services which are disability specific and establishing new measures to financially support people with disability over time. While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services. ANGLICARE Sydney supports the concept of a national disability strategy that incorporates all existing government support and compensation schemes, private insurance and the non-government service delivery organizations.

We have comprehensively consulted with our disability support services to provide a service perspective on the nature of such a strategy and how it might be effectively implemented. The remainder of this submission directly addresses those questions outlined in the Productivity Commission's Issues Paper of May 2010.

RESPONSES TO THE INQUIRY'S QUESTIONS

1. Who should be the focus of a new scheme and how may they be practically and reliably identified?

1.1 Key Focus

At present those people who acquire a disability through a workplace or vehicle accident generally receive financial support. However for those who acquire disabilities through other accidents or through a medical condition, or who are born with a permanent disability, there is no automatic support to meet their needs. A national disability support scheme should be wider than acquired disability and should include all who were either born with a disability or acquired such a disability through a medical condition. In Australia, people with a disability and their carers are respectively enshrined in the Disability Discrimination Act 1992 and the National Carer Recognition Bill 2010. These forms of legislation should be regarded as a useful guide in defining the key focus groups for a new scheme.

ANGLICARE argues that the key focus of all disability support should be the person with a disability and their primary carer, who needs assistance and support to play the fullest possible role in their community (including the workplace). It is essential for the scheme to directly cater for the different levels of disability in each area (e.g. intellectual disability) regardless of whether an individual is officially classified as having a 'severe or profound', 'moderate' or 'mild' disability. However, the scheme needs ongoing monitoring and evaluating of an individual's support needs, which may change over time, depending upon their age or circumstances.

Although the Terms of Reference have specifically focused on people aged 65 years and below who have acquired a disability at birth or as a result of an accident or health condition, it is also important that the needs of people over the age of 65 are also addressed, even if it is as part of the aged care system. There should be seamless support and services for such people to ensure there is not a disruptive transition into the mainstream aged care system.

Recommendation 1: The focus of disability support should be the person with disability and their primary carer who need assistance and support to play the fullest possible role in their communities (including the workplace), regardless of the cause of their disability. Support under the disability scheme should continue beyond age 65 years, unless equivalent support can be obtained through the aged care system.

1.2 Assessment Tools

The ideal assessment tool for determining an individual's eligibility for the scheme would involve a practical, individual and targeted assessment for each person, as opposed to simply 'pre-labelling' a person on the basis of their disability. For example, a person with cerebral palsy may have minimal support needs in their daily life, but could require greater support to achieve their longer-term goals. In doing so, the assessment tool needs to recognise the existing capacities of the person with a disability, their primary carer and family members in determining their support needs and preferences in both the short and long term.

Such assessment also needs to identify areas in which further capacities could potentially be built and rehabilitation undertaken, through appropriately directed funding under a National Disability Scheme. Any scheme will have budgetary limitations and it will be important to maximise the utility of the available income for each person. This in part can be achieved by working with people with a disability and their carers to make best use of the resources, funding and abilities they have. It is important, therefore, that a proposed scheme carry with it an emphasis on capacity building rather than just providing funding support.

The implementation of the World Health Organisation's (WHO) International Classification of Disability Functioning Health framework (ICF-10) is a possible alternative to the existing Adult Disability Assessment Tool (ADAT). Feedback from our services indicates that the ADAT has a range of problems, including the inappropriateness of the tool for children and young people, its restrictiveness in identifying maladaptive behaviours and mental issues, and the difficulties in assessing a person with uncommon support needs. On the other hand, the multi-dimensional tool from the WHO is able to determine eligibility and assess the individual, institutional (e.g. education and employment) and social needs of a person with a disability. According to the WHO, the tool is based on the biophysical model of disability, which recognises the value of both the medical and social models of disability. Additionally, the tool also considers an individual's level of advantage or disadvantage, based on their social, economic and environmental context.

Nor should assessment be a one-off occurrence. It needs to be regularly reviewed as the level and nature of disability can change over time leading to different interventions and service support requirements. Such service supports need to individualised and targeted.

Recommendation 2: The proposed scheme carries with it an emphasis on capacity building rather than just funding support. Assessment needs to occur regularly over the life of the person with a disability to ensure changing needs and life circumstances are supported and potential areas for capacity building identified.

Recommendation 3: New assessment tools need to be developed which are age appropriate and capable of dealing with multifaceted disability.

2. Which Groups are most in need of additional support and help?

2.1 Identifying Those Most in Need

ANGLICARE Sydney's wide range of services within NSW addresses the needs of the most vulnerable in our society. We mention them specifically in this section.

We note however that there is a need for more information to identify those areas where the needs are greatest. This seems to require the collection of more data on people with disabilities and their carers, and the burdens they bear and is discussed in question 9 below.

2.2 Children and Young People with Severe and Profound Disabilities

ANGLICARE Sydney operates a school for children with a disability, along with a residential facility for the accommodation of students during the week. The school, known as Kingsdene Special School, is accredited to deliver the Years 7 to 10 curriculum required for the NSW School Certificate. The school population of 20 students with severe intellectual disabilities, ranges in age from 10 to 18 years.

Recently ANGLICARE Sydney's Council made the difficult decision to close the school at the end of 2010, after many years of operation. Kingsdene Special School represents the only model of special needs schooling combined with residential accommodation anywhere in Australia for this population. Current students have severe intellectual disabilities with additional disabilities of mobility, speech, communication, visual impairment and autism spectrum disorder. Increasing numbers have severe autism, challenging self stimulatory and aggressive behaviours, obsessiveness and sensitivity to touch, light, sound and social proximity. Some have uncontrolled epilepsy and mental health issues. All students have complex profiles and high support needs in all areas of personal care which affect them in daily life routines. They may suffer the occurrence of frequent attacks of anxiety and distress resulting in a range of injurious behaviours to themselves and others. These children thus are faced with multifaceted disability combined with maladaptive behaviours and require intensive, specialised, life long support. This combination of mental health issues with intellectual disability provides a significant challenge both for accurate assessment and for service support.

Particular supports therefore need to be provided to carers and families of children with severe and profound intellectual disabilities, especially when these are combined with mental health issues and maladaptive behaviours. Families in these situations often face considerable challenges in terms of their family relationships, physical and mental health, employment and social participation, and their capacity to seek respite for themselves and their child with a disability. The level of support required over time will increase as these children grow and become stronger. Similarly, other families may have a child who is classified as having a mild to moderate disability, but with significant behaviourial problems that may increase their exclusion and lead to their inability to attend school. Presently, these families are unable to obtain a further assessment as the needs of their children continue to change.

2.3 CALD and Indigenous Groups

Additional support also needs to be provided to people with a disability and their carers from a Culturally and Linguistically Diverse (CALD) background. This also includes people from small and emerging communities (e.g. Sudanese), as well as migrants and refugees who have recently arrived in Australia. These groups face additional challenges in accessing services and having their voices heard through advocacy efforts as a consequence of the language and cultural barrier.

What does international experience and research reveal of access issues for CALD communities?

- Most people from CALD backgrounds only access services in a crisis.
- Additionally there are issues of the cultural competency of services which acts as a barrier which is reinforced by the lack of information being disseminated to these communities and in their own languages.
- Sometimes the service being provided does not take into account cultural, linguistic and religious factors.
- For some communities there is stigma and shame attached to disability and therefore reluctance to access services which highlight this issue for their family (Roberto, 2000).
- There can also be multiple disadvantage for some CALD families including poverty, the disruption caused by migration and reduced support networks.

The CALD population is seriously underrepresented in HACC funded services. This community accounts for one quarter nationally of all those identified as having a disability but less than 15% access services (Sedger and Boyd, 2007). Research indicates that the CALD community experiences serious systemic disadvantage in accessing appropriate services. There is a stereotype which considers that this lack of access is self imposed as CALD communities are more self reliant on their own family support networks. However, studies indicate that the access issue is related more to a lack of appropriate information and a lack of CALD specific services (EDAC, 2003).

There is a higher incidence of carers among indigenous people in caring for a person with a disability, long-term illness or with age-related problems, in addition to experiencing multiple forms of disadvantage as a result of their caring role. Some of these issues are covered in the report, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2008.* Significantly, when compared to non-Indigenous carers, Indigenous carers are 12 years younger, 1.5 times less likely to be employed, and to live in low resource households with an income of less than $315 per week (36 percent of all Indigenous carers).

Some measures which would assist people with a disability and their carers from a CALD or Indigenous background include:

- The provision of culturally sensitive and responsive respite services which reflect similar values, beliefs and understandings for clients and their carers.

- More specifically, ANGLICARE Sydney recognises the importance of providing support workers who are either from a similar background, speak the relevant language or who have received cultural competency training to ensure that the person with a disability receives a service which is respectful and conforming to their commonly held values and belief system.

- The increased provision of more bilingual counsellors among CALD groups.

2.3 Ageing Parent Carers

In 2003, the Australian Bureau of Statistics estimated that there were 454,000 carers aged over 65 years, accounting for 18% of all carers and more than 24% of all primary carers. More specifically, research undertaken by Carers Australia indicates that many of these older carers are 'hidden from view' and have never engaged with formal support services. For such carers, there may be a strong sense of social isolation, self-reliance, and an inherent reluctance or mistrust of the disability support system.

ANGLICARE Sydney offers both community aged care and disability support services. Some research has been undertaken by ANGLICARE into the care needs of ageing parent carers of children with a disability, who are part of ANGLICARE's Ageing Parent Carer Support Coordination program. ANGLICARE's program is one of the largest in the State for meeting the needs of ageing parent carers.

It is generally recognised that caring activities adversely impact financial well being and the capacity to earn income. In the case of ageing parent carers, all of whom are at least 60 years of age, there is little opportunity to engage in paid work. This issue is compounded by the fact that carers not only have a reduced capacity to earn an income, but are also faced with considerable caring-related expenses, including the cost of therapies and medical costs.

In addition, ANGLICARE's research shows that many ageing parent carers in the community get by without much service support. As part of the research, carers entering ANGLICARE's Support Coordination program were asked about support services they had received in the previous 12 months. A comparison was then drawn between the services they had received and what they considered to be important services to them. In every area of service support there was a significant gap between the perceived need for and the previous receipt of the service. The greatest gaps were in the areas of:

- *Case management* – almost nine out of ten ageing parent carers ranked this as important but only four out of ten had received this service in the 12 months prior to coming to ANGLICARE.

- *The development of a transition plan* – eight out of ten ageing parent carers considered that they did not have a transition plan yet only one in three had received this kind of assistance in the previous 12 months.

- *Social contacts, life goals and life skills* – some of the widest gaps between perceived need and the meeting of need were social: there was a 50% gap in relation to improved social contacts (both for carer and care recipient), in giving assistance for the care recipient to pursue life goals or interests, and in enhancing the life skills of the care recipient.

2.4 Young Carers

Young carers typically receive little mentoring from the parents for whom they care. They can also lack life experience and specific skills needed to provide care. With caring responsibilities, they can grow up too fast, and need to teach themselves to be an adult. The needs of young carers are largely for social time with people of their own age, and the development of helpful mentoring relationships.

Along with the lack of mentors, it is ANGLICARE Sydney's view that more could be done by schools to assist young carers to better manage their situation. A starting point would be the provision of information for local school authorities. There needs to be more understanding from schools about the caring situation of young carers. Young carers need computers with internet connection for their schooling as their families often lack money to purchase one and the young carer does not have the time to use computers in libraries. Some families cannot even afford the heavily discounted computers available through Centrelink.

There is a great need for case management of young carers. Case management over a longer time period could assist carers to participate in their schooling and plan for employment training; the service could also develop an emergency care plan and a future care plan to enable the young person to plan further study or employment.

2.5 Carers with Low Incomes

There is a critical need to provide better financial support to carers and families who are on low incomes, especially for those who are heavily reliant on government benefits, so as to ensure an adequate standard of living. Although there are few Australian studies examining the link between poverty and disability, research by the UNSW Social Policy Research Centre has found that where there is a person in the household with a disability, poverty rates are higher and hardship is more prevalent. In terms of income, the cost of a disability is estimated at an average of 29 percent of household income (adjusted for equivalised household income size), and rising to 40 – 49 percent of income for those with a severe or profound form of disability (Saunders, 2007).

Recommendation 4: *Any new national disability support scheme needs to especially consider young people with profound and complex needs, people with disabilities from a CALD or indigenous background, ageing parent carers, young carers and carers on low incomes.*

3. The kinds of services that particularly need to be increased or created?

3.1 Case Management

Case management is a valuable service in assisting people with a disability and their carers. ANGLICARE Sydney operates its current services in adherence with the principles of best practice, being well resourced and having a client-centred focus that recognises the needs of both the carer and the care recipient. Critically, there is a long waiting list for services that consider the needs of both parties.

Case management needs to be supported by access to substantial care packages, information and education, accessible respite and accommodation, and emotional and financial support options. What is required is an integrated, coordinated model that is flexible, genuinely inclusive and equitably maximises the effective options for both parties of a culturally appropriate service. Additionally this should be a model that has a family focus, single entry point, and be responsive to need. Significantly, the provision of case management should enable families to work with a single caseworker, thereby increasing their access to appropriate services, accurate information, and a relationship that provides support and trust. Caseworkers too need to have a role in developing the capacity of their clients, not just providing care for people.

In ANGLICARE Sydney's experience, case management also needs to recognise the importance of family members in planning for the family, in order to build the resilience of each person. However, case management plans also need to account for the age and physical capacity of the carer and person/s for whom they are caring, the ability of the family to solve problems and the relationship context within the household and local community in terms of other formal and informal support networks. In addition, case management also needs to recognise a range of diverse factors, including religion, language and culture.

Recommendation 5: *In order to be effectively applied, new resources have to be accompanied by adequately funded case management supported by access to appropriate care packages, information and education, accessible respite and accommodation, and emotional and financial support options*

3.2 Supported Accommodation

It is generally acknowledged that there is a chronic shortage of supported accommodation for people with a disability. While transition planning is a critical component of ANGLICARE's Ageing Parent Carer Support Coordination program, a key element in the success of such planning is the availability of suitable and sustainable supported accommodation options for people with a disability. Currently there is a significant gap in the provision of such accommodation which would allow both ageing parent carers and their adult children with a disability to be co-located in the same or adjoining facilities.

There is a view that the shortage has been exacerbated by budget constraints arising from an unsustainably expensive model (group housing) that has not delivered the quality improvements expected. The consequence is expensive care for some and nothing for others. This issue does appear to need investigation.

Recommendation 6: A significant and sustained increase in supported accommodation options.

3.3 Respite Services

A major need for carers is the availability of respite services. This applies across the spectrum of carers taking care of people with disabilities, chronic illness and at the end of life. In ANGLICARE Sydney's view, there is still a shortage of both emergency and planned respite beds. There is limited subsidised respite for people with disabilities such as vacation respite care, overnight respite or weekend day programs and respite options for children under 16 years with disabilities. At present, planned respite cannot be guaranteed in those subsidised respite houses that are managed by government departments (ADHC or FaHCSIA).

Recommendation 7: A significant increase in the availability of flexible subsidised respite options particularly for children under 16 years of age.

3.4 Out-of-Home Respite for People with Challenging Behaviours

There is a lack of residential respite for people with disabilities who also have behavioural problems. There is a waiting list for an ADHC-funded behaviour intervention service for a young person with a disability. This waiting list for ADHC funded services can be as long as one year. But respite is difficult to find until the behaviour can be managed. Subsequently, there is a need to reduce this waiting list through the provision of extra funding.

Recommendation 8: Increased provision of out of home respite for people with challenging behaviours.

3.5 Respite Beds in Nursing Homes and Hospitals

At present, emergency respite for older clients can be obtained through nursing homes. However many of these beds are disappearing. Nursing homes should have dedicated respite beds if they have respite funding – not only when a bed is available on their terms. In ANGLICARE Sydney's experience, some nursing homes manage their respite beds well but others do not.

Recommendation 9: Tighter regulations need to be introduced to ensure that respite beds in nursing homes are planned and managed as exclusive respite beds.

3.6 In-home Respite for Ageing Carers

Many carers are uncomfortable with out-of-home respite. In an in-home respite situation, staff become familiar with the client receiving care, whom the client learns to trust. The care giver too becomes more confident in the respite care as they observe the staff person giving care such as personal care/ showering, activities around the house, going for drives etc. It is then more likely that they will be willing to leave their loved ones in respite situations.

Recommendation 10: There is a need for increased funding for in-home respite care.

4. Ways of achieving early intervention?

4.1 Person Centred-planning and Case Management

The current early intervention system is affected by a lack of coordination and long waiting lists, which is particularly problematic for children with an intellectual disability and their families. Families with children experiencing multiple issues may need to access five or six separate services and have to navigate the system without support or coordination. In many instances they find the service system is fragmented. There is also the issue of accessibility. Following diagnosis, some families are left waiting for several years to access appropriate services, and even then, they may only receive some of the supports they require. However, the provision of early intervention services at the appropriate life stage will often result in improved behavioural patterns for some children with intellectual disabilities, thereby reducing their need for intensive support services in later life.

Therefore, the early intervention process needs to be supported with a comprehensive suite of services, such as person-centred planning and case management, which would be implemented once a person has been identified as being eligible for the scheme. It is essential that early intervention services are available to support people over the 'life cycle' of their disability, including childhood, adolescence and later adult life. Person-centred planning and case management services should provide people with a disability and their families with sufficient opportunities to address major and unanticipated life events, changes in medical or support needs, and transition planning for ageing carers.

Ultimately, there is a significant need for consistent practices from disability services, as this will enable families to navigate the system with greater ease, and for service providers to retain their focus on person-centred planning, in terms of staff training and ongoing best practice service delivery.

Recommendation 11: Early intervention requires investment in case management to ensure a more streamlined access to services, particularly for families with children experiencing multiple issues. This needs to be supported by long term person centred planning – not just in the early years but over the full life cycle of the individual.

5. How a new scheme could encourage the full participation by people with a disability and their carers in the community and work?

5.1 Social Inclusion

Social inclusion has become the foundational principle for the construction of social policy and a clear point of reference for our progress as a nation. Undoubtedly, social inclusion as a principle cannot, by definition, be well thought out if it is isolated from the various contexts and relational dynamics of the wider community. Social inclusion as a policy platform needs these social contexts in order to be practicable. An outcome of allowing the concept of social inclusion to sit in its natural context of the wider community is having initiatives that encourage its members to become aware of their profound roles in making social inclusion a reality. Within the complexity of social exclusion lies the simple fact that communities around Australia engage in everyday relationships and social activities while people with disabilities and their carers live in their midst but remain socially excluded (ANGLICARE Sydney, 2010).

A National Disability Long Term Care and Support Scheme sees the wider community engage with disability initially by means of pooling individual risk. This has the indisputable outcome of widening the scope of community responsibility for people with disabilities. Community responsibility for disability will additionally require inclusive attitudes and conduct towards people with disabilities to become a permanent feature of our social and civic landscape.

Inclusive conduct has to be seen in the context of a particular community. These communities include workplaces, local neighbourhoods, educational institutions and religious and social organizations.

Care for the poor and disabled has always played an important role in the life of the Christian church – of which ANGLICARE is an example. We believe that the development of an inclusive culture needs to be integrated closely with the churches as well as other faith based organizations.

5.2 Community Education

Whether or not there is a National Disability Strategy, there is a need for an educational initiative for a wide range of community participants to become more informed and concerned about people who have disabilities in their communities. Government should devise an educational initiative as community attitudes will be an essential component in generating community support for people with disabilities.

If a new disability strategy is based on the principle of a community-wide approach to risk and claims management, then a community-wide educational initiative aimed at raising awareness complements this principle. Such a community education program should be developed from a social inclusion framework and provide a clear understanding of the diversity of disability and the individual needs of people with disabilities.

This initiative should go hand in hand with the development of more effective case management that would include the brief of promoting social inclusion. This would also assist government and community organisations with early intervention service provision by furnishing the wider community with the sensitivity and appropriate responsiveness to the needs of people who have disabilities – and indeed by challenging unfair discrimination where it takes place.

The content of educational programs on disability awareness should be sourced from people who have disabilities as well as carers and organisations with experience working with people who have disabilities. These educational programs would aim to engage participants on how individual and community attitudes towards people who have disabilities can mean the difference between social inclusion and social exclusion. Government should support such initiatives as it would build community involvement and community support for people with disabilities and their carers.

The starting point for education about disability begins with an acknowledgement of disabilities. A history of disability is characterised by stories of deliberate ignorance and in many cultures (including our own) a desire to *not* acknowledge a person's disability. Acknowledgement of a particular disability underscores recognition of the people who have disabilities and assists in establishing that a *person comes before the disability.* This in turn brings people to a better understanding their role in shaping socially inclusive interactions and procedures for people who have disabilities. Individuals can better understand the profundity of their role in determining the extent of a person's disability and in doing so make a positive difference in the lives of people who have disabilities and their carers. Such a program would seek to shift attitudes away from thinking of disability as simply a deficit or a problem, towards understanding that disability is largely defined by relationships with other people and interactions with the varied interactions of life, such as built environments and social procedures.

Thomas Reynolds argues that disability is, “a range of physiologically rooted social performances, a series of moments defined by relationships between human beings (Reynolds, 2008, p173).” For example, a person who is a wheelchair user experiences social exclusion when they are physically unable to enter a building or told they are unable to be seated in a theatre. A person with a disability involving speech is disabled not solely by their own physiological variation but also by a person’s unwillingness to take the time to listen carefully in order to understand what is being communicated. In fact, with the second example it could be argued that the person’s speech variance is not a problem at all if what is communicated in a speech act is properly understood by the recipient of that speech act. Reynolds continues: “In a basic sense, the distinction between ability and disability is built into the fabric of communal life.” (ibid). This is a profound insight and brings a perspective on how attitudes determine disability. In a sense, individual and communal interactions have the power to give a person a disability by allowing their differences to impede their communal participation.

Recommendation 12: Government should support and fund educational programs designed to change community attitudes. The content of the program should be provided by people with disabilities, carers and organisations with experience in disabilities services. It should hand in hand with better funded case management that actively addresses issues of social inclusion “on the ground”.

5.3 Employment and Educational Supports for Carers

Additionally adults who are caring for their parent or child with a disability need long term regular respite to enable them to work or study. In the case of children with disabilities their parent carers have great difficulty in accessing before and after school care. The ANGLICARE Kingsdene program is supported by a Monday to Friday residential facility. This enables parents to work during the week and care for their child on the weekend. However, once their child leaves Kingsdene then one parent will generally have to forfeit full time work to ensure full time care for their child. If this is a single parent family then the parent is forced onto welfare. There is a need for after school care programs for such children until the age of 18 as well as 9am-5pm vacation care.

For both adults with disabilities and older frail people, activity centres often only operate from 9am – 3pm, and there is a lack of funding for extended operating hours. People with disabilities may only be able to attend a day centre 2-3 days per week. This reduces the opportunities for their carer to find adequate employment.

Carers of people with challenging behaviour have even fewer opportunities as their care recipients may not be eligible for day programs. There is some funding for long day centres for older people with dementia, enabling their carers to work office hours, however this is not available for younger people with disabilities.

Carers also have specific concerns when looking for work. Whilst carers may only be available to work limited hours a week, or need work that is flexible to their caring responsibilities, employers sometimes have the attitude that carers won’t be reliable as they will have to field phone calls or leave early to support their care recipient. Carers should not have to advocate their needs to employment agencies with little understanding of their situation. They need assistance from a service which already understands their needs and not only helps them re-enter the workforce but also advocates their needs to employers.

For carers seeking part time or flexible work arrangements there is often a need to undergo retraining. However carers are often time limited in terms of the commitment they can make for such training and need to be able to access it in a way which is flexible and takes into account their caring responsibilities.

For some carers, particularly those who are ageing and post retirement age, there is little possibility of a return to the workforce – either because of age, their own infirmity or the 24 hour role of the carer. However, this does not mean that they should not have the opportunity for further study – to enhance their connectedness to the community and their own intellectual stimulation and well being. This can only be achieved with the provision of regular respite.

For many carers who have not had access to superannuation in their working life or who have not been able to work because of their caring responsibilities, there is heavy reliance on government benefits as the main source of income. Additionally the cost of medications, multiple services, physical aids, mobility aids, household renovations for disability access and continence products, impacts significantly on income. Carers require greater income support to meet the costs of caring and to recognise the valuable role they play in reducing the costs on the health system if caring was no longer done in the home.

Recommendation 13: Provide for long day care and vacation care to enable carers of children and adults with disabilities to work office hours.

Recommendation 14: Establish employment services specifically for carers, or provide for positions within employment centres for employment consultants who work specifically with carers. The service would provide upskilling programs and liaise with and educate employers, advocating for the needs of carers, especially the need for flexibility.

5.4 Creating More Employment for People with a Disability

Employment, if possible, is one of the most effective ways of creating social inclusion. It not only provides additional dignity, social interaction and purpose but it is also cost effective. The *Disability Discrimination Act 1992* prevents unfair discrimination against people with disabilities, but we suggest there is a need to promote discrimination in their favour. For adults with a disability there needs to be targeted and flexible employment options which provide suitable training and opportunity that enables appropriate levels of workforce participation. This might be achieved by providing informed case workers with flexibility to use their budgets to promote employment.

We also suggest that pilot programs should be run in government departments to set a quota of employees with disabilities. If successful, this could in due course be extended to all employers.

Recommendation 15: Provision of appropriate funding for the development of targeted and flexible employment options for people with a disability.

6. How to give people with their disabilities or their carers more power to make their own decisions (and how they could appeal against decisions by others that they think are wrong?

6.1 Individualised Funding Arrangements

ANGLICARE Sydney is aware that the Federal Government is currently exploring individualised funding arrangements for people with a disability. In 2006, Stainton observed that the vast majority of literature in relation to these funding schemes has demonstrated a strong increase in positive outcomes for service users, including an improved quality of life, satisfaction and independence (Stainton, 2006). Other benefits that have been reported by Carers UK include: improvements in meeting the needs of care recipients, greater flexibility and choice, and an increased ability for carers to participate in paid employment (Carers UK,2008).

However, as the Allen Consulting Group has recognised (2007) these arrangements may not necessarily be “appropriate for, or desired by many consumers.” In particular, there is limited evidence indicating the benefits of these arrangements for people from a CALD and ATSI background, older people and people with severe and profound disabilities.

ANGLICARE Sydney is aware of different models of client-directed service delivery and the advantages and benefits that can come with these. However ANGLICARE is also concerned that, as recommended by the Productivity Commission in its inquiry into the Not-for-Profit Sector, there be appropriate safeguards in place to protect and empower vulnerable clients (or their carers) in exercising choice and ensure an acceptable minimum level of service quality and provision.

In this respect, a system of client-directed care or individualised funding would need to be designed to account for the following issues:

- A system of client-directed care must be designed to avoid burdening recipients who are lacking in the appropriate skills or finances to manage their own care. Such programs require much input from these individuals and their families, especially where it involves having to negotiate an individual workplace agreement with paid care staff. While many people will be willing to assume responsibility to find, hire and manage a service which suits them, there are other clients who will not want this responsibility and will be burdened by choice. There is a danger that by cutting out service providers, Governments will shift the administrative cost and responsibilities to clients.
- Not all people have the literacy, experience and help needed to assume full autonomy – some groups such as CALD groups may be further disadvantaged by a client-directed care system. Client-directed care is less likely to be taken up by older people.
- Successful client-directed programs are dependent on the provision of support for service users, such as case management, brokerage services, financial agents, advocacy and counselling. This will result in increased costs for Government to put a proper system into place
- Clients may not receive sufficient funds to account for the real costs of their care under ‘cash for care’ models
- The potential impact on salary and benefits for disability and/or aged care sector staff, including differences between those employed by traditional service providers and those employed directly by care recipients

- Potential to alter the relationship between the primary carer and care recipient. For instance, 'who is the client?' becomes an issue where there is both a carer and an adult with a disability. Where there is conflict between the two, who will hold the funds and make decisions for adults with a disability?
- Maintaining the strength of traditional service providers, to continue to cater for service users (especially older people) who would prefer to use a service agency as a source of receiving care, as opposed to using family, friends or other private carers.

Recommendation 16: With respect to systems of individualised funding packages, that appropriate safeguards be put in place to protect and empower vulnerable clients (or their carers) in exercising choice and ensure an acceptable minimum level of service quality and provision.

6.2 Complaints or Grievance Handling

ANGLICARE is satisfied with the role, of the NSW Ombudsman as the arbiter of complaints and grievances – the process is transparent, fair and simple.

6.3 Advocacy

Apart from having a decision making role in the type and nature of services to be accessed the person with a disability and their carers could also have greater access to opportunities for advocacy. ANGLICARE Sydney applauds the provision of funds to people with disabilities and their carers to participate in this Inquiry and recommends that such funding be made available to other Inquiries where appropriate to enable their concerns and issues to be heard and addressed

Recommendation 17: People with disabilities and their carers be provided with funding to ensure adequate participation in community consultation and government inquiries.

7. How to improve service delivery – including coordination, costs, timeliness and innovation?

ANGLICARE Sydney has noted the NSW Government's commitment to work with the sector to reduce the amount of 'red tape' for Non-Government organisations, as outlined in the report *Non-Government Organisation Red Tape Reduction*. Similarly, the National Compact with the Third Sector also contains a welcome commitment to improve funding and procurement arrangements, reduce red tape and streamline reporting, and the implementation of consistent, simple financial arrangements across government. ANGLICARE Sydney considers that these arrangements would be further supported by the introduction of an Office for the Not-for-Profit Sector, and the implementation of reforms addressed by the Productivity Commission's Review into the Not-for-Profit sector. These reforms were proposed by the Labor Party in August 2010.

In relation to the current compliance arrangements, ANGLICARE Sydney contends that the following improvements are now needed:

a) **Streamlining funding applications and tenders, including across different Departments and levels of Government:** Most of the State and Federal Government funding available to the Not-for-Profit sector is accessed via a tender process. Each tender is specific and different from every other tender – with different criteria and demands. The process of tender application is unnecessarily costly and time consuming. Even where a relationship already exists with a department such as ADHC, not for profits are required to pour the same extensive resources into fresh tender processes. Streamlining the process, such as through reliance on information established through previous tenders and through referees, would reduce the administrative and resource burden on agencies and also provide a more equitable tender environment. The NSW State Government's commitment to reduce the information required from not for profits in the tendering process by July 2010 should be noted in this regard. Another potential innovation in this area relates to the introduction of long-term contracts, so as to enhance continuity and stability for people with a disability and their families.

Recommendation 18: Government streamline funding applications and tenders, across different Departments and levels of Government.

b) **Removal of multiple contractual and reporting arrangements across departments:** Every Government department, including ADHC, has a different funding agreement or contract with different accountability requirements. This creates issues in terms of multiple reporting and is extremely resource intensive, requiring considerable commitment of staff time by Not-for-Profits. In general, having one simplified contract with any government department with one end date and simplified reporting requirements would be helpful. This would also reduce auditing requirements. The NSW State Government's commitment to develop a small suite of contracts is noted.

Recommendation 19: Government remove multiple contractual and reporting arrangements across departments.

c) **A common acquittals process, with acquittals limited to the end of the contract term:** The acquittals process is complex and inconsistent across programs. Regardless of the length of the contract (1-3 years) acquittals have to occur annually. If there is a surplus, which is usual in the first year with set up etc, the Not-for-Profit has to apply to retain the surplus. It usually takes 6 months or more before the result of the application is known, which then puts pressure on the Not-for-Profit to spend any surplus before the end of the next financial year. It would be administratively easier if acquittals were not required until the end of the contract period. The Not-for-Profit could still supply an annual statement for accountability purposes.

Recommendation 20: Government develop a common acquittals process, with acquittals limited to the end of the contract term.

d) **Standardising the reporting requirements for State and Federal Government departments:** With different funding types there is no consistent approach between State and Federal Governments in relation to reporting service delivery outputs – the State Home and Community Care (HACC) programs are reported quarterly and the Commonwealth National Respite Carer Program (NRCP) programs are reported half yearly. HACC goes through an integrated monitoring process and the Commonwealth goes through a quality reporting process. The two processes are different in that one requires the preparation of a self assessment desktop audit and the other conducts workplace assessment. Some service providers are responsible for several programs which each include the two types of funding streams. It would be helpful, therefore, if all governments adopted a more co-ordinated approach using one monitoring process.

Recommendation 21*: There be a standardising of the reporting requirements for State and Federal Government departments.*

e) **Research, development and innovation:** ANGLICARE Sydney is in the process of researching and developing an integrated service delivery model, as part of its commitment to best practice in disability services. This model would enable families to enter the service system at a single entry point and to undertake a single assessment, thereby assisting service providers to collaborate and share information. Significantly, this would mean that clients and their families would not be required to constantly share their story when seeking services from a new service provider or in the event of staff turnover at an existing service provider. Additionally, the model would be supported by the aforementioned case management approach, as well as a comprehensive assessment tool which would improve the timeliness of assessments and the provision of services to clients and their families.

Recommendation 22: Government fund research into best practice within the sector as well as fund pilot projects which are innovative and which provide evaluation and feedback to the sector.

8. The factors that decide how much support people get and who decides this?

8.1 The Need for an Holistic Approach

Currently the factors that may determine the nature and level of support provided to people with a disability and their carers includes:

- The capacity to advocate
- Information and service support knowledge
- Ability to successfully navigate the complex service system
- Previous service support experience
- Family relationships and levels of carer stress
- The nature and level of the disability
- The current gaps in service delivery
- The adequacy and availability of such services

Assessment is also a critical factor. This may be focused on particular disability issues and lead to service provision by five or six different and uncoordinated services. What is needed is an holistic approach which examines the needs of the entire family. We believe that this in turn requires a single case manager with access to information from all service providers, and with an appropriate and flexible budget.

8.2 Better Case Data

Accurate data is essential in determining how much support people need and get. Rather than embark on the extremely expensive and risky task of developing a national database, we believe that steps should be taken to allow for a more systematic approach to the collection of the data necessary for appropriate case management. This involves:

- Addressing the privacy issues that will otherwise prevent the collation of data
- Creating a standardised approach to the classification of disabilities and the measurement of quality of life
- Developing standardised case reports that can eventually be incorporated into national system

Recommendation 23: Government needs to provide a more systematic approach to the collection of case data to ensure adequate and equitable support is provided to those who need it.

9. How to ensure that any good aspects of current approaches are preserved?

9.1 Governance

The governance and administration structure of a new scheme should incorporate a range of experts from across the disability spectrum, including people with a disability, their carers, and representatives who are involved in both service delivery and/or disability advocacy from the not for profit sector. This could be established as a type of National Advisory Council that receives, considers and re-releases information about best practice initiatives from each state and territory. Where possible, the government would allocate funding for the piloting or continuation of these innovative and best practice programs that seek to address considerable gaps in service provision (such as supported accommodation or respite services). However, the provision of additional funding must also be matched with a commitment to increase staffing levels in an already overburdened disability support system.

9.2 Data collection and research

The preservation of best practice models is contingent upon the rigorous and transparent use of research, data collection and evaluation by each level of government and across the not for profit sector. At present, there are notable gaps in the areas of data collection (focusing on client wellbeing), evaluations of best practice service delivery models, and in emphasising person-centred outcomes. This information would greatly assist not for profits in terms of bringing about program improvements and enabling comparison between providers, in order to identify best practice models and to further improve services for clients and to identify areas of particularly pressing need.

Indeed, the recent Productivity Commission Inquiry into the Not-for-Profit sector has highlighted the necessity of evaluation for productivity improvements and has strongly recommended the funding and implementation of evaluation practices in the not for profit sector. Additionally, the Productivity Commission is also recommending the use of evaluations to help identify the contributions of Not-for-Profits on individuals and the community, and to help shape data collections. While these are all worthwhile objectives, ANGLICARE Sydney's experience is that:

- there are many kinds of evaluations and there is no agreed best practice in the area

- evaluation is costly and can be resource intensive
- larger organisations would be in a better position to carry out robust evaluation than smaller organisations
- funding should not be made contingent upon evaluation being carried out; evaluation should have the goal of improving Not-for-Profits' service delivery and enriching the whole sector
- there is a lack of expertise in most organisations to carry out robust evaluation.

Recommendation 24*: Government should fund program evaluation within program budgets, and that evaluation should only be mandatory for programs above a certain dollar value. More specifically, there is a need for regard to the size and nature of programs in arriving at the scale of evaluation that may be required.*

10. What to do in rural and remote areas where it is harder to get services?

While ANGLICARE Sydney programs do not traverse remote communities, the wider Anglicare networks suggest that for rural and remote communities:

1. There is a lack of qualified and accessible professional staff in key areas of disability – particularly mental health. Suggestions to modify or mitigate this shortage include the development of circuits of therapies or the equivalent of a flying doctor service for specialist intervention and support services.

2. Geographic isolation also increases the cost of service provision which reduces accessibility and feasibility of service provision and not accounted for in many current funding arrangements.

3. The Local Area Coordination Project has been providing services, brokerage and support for people with an intellectual disability and their families in rural Western Australia since 1988. It has been suggested by Dr Jane Tilly that the introduction of similar self-directed care or consumer-directed care arrangements in rural and remote Australia would lead to an increase in the supply of carers as they "responded to the availability of payment", and the "payment for family member carers." While these arrangements could ease the burden in the provision of personal care services (such as showering and grooming), it should not be regarded as a long-term substitute for qualified disability support workers.

Recommendation 25: *Provision of appropriate disability support services via a circuit to rural and remote communities.*

Recommendation 26*: Provide travelling contingencies in current funding arrangements for disability specific support services.*

11. Reducing unfairness, so that people with similar levels of need get similar support?

Issues of equity of access are of particular significance for people with a disability and their carers. Inequity often reflects lack of knowledge of the service system and to be mitigated requires more effective information and communication strategies by both governments and service providers.

However complexity, the type, nature and intensity of the disability also plays a role in the adequate meeting of need and the effectiveness of outcomes. An excellent example is that of children with profound and complex needs. Children with physical disabilities fare better in terms of social inclusion and educational outcomes than those who experience intellectual disability, mental health issues and behavioural disorders. The nature and type of interventions for the two sets of disabilities can be very different. Studies have examined differences in a child's disability in relation to their successful integration academically, socially and physically and have reported a high degree of success for children with physical and sensory disabilities and language disorders compared to children with emotional, behavioural and multiple disabilities. Unfortunately students with emotional and behavioural disabilities are still the least likely to go on to further education and employment.

Equity is not about all people with a disability gaining equal access to services. It is about adequately meeting the needs of all people with a disability – regardless of the level, intensity and nature of that disability. It is also about building capacity in different ways to enable greater independence, acquisition of skills and social participation to the fullest possible extent Fairness for those experiencing complex and multiples issues requires coordinated and multiple service entry points with intensive support and often case management. In turn, services need to be client centred, innovative and flexible in approach.

Recommendation 27: A new disability support strategy needs to ensure that a 'one size fits all approach' is not adopted but that the nature, level, complexity and intensity of disabilities are considered in service, education and employment support options.

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12. Getting rid of wasteful paper burdens, overlapping assessments (the 'run around') and reducing duplications in the system?

These issues have been addressed in question 7.

13. How to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

While it can be described as fragmented, the current system provides people with disabilities with significant resources through existing government and private support, compensation and insurance schemes. There is much that can be done to ensure that the benefits are integrated with each other.

For congenital conditions, ANGLICARE supports incorporating a scheme as part of the Medicare levy so that it is equitably shared across the community. Those with acquired disabilities that are not covered by an employment based insurance would also fall under this insurance scheme.

While the revenue from such a scheme is likely to replace some current funding, care should be taken that it does not in any way compromise current systems and levels of care.

The separate funding and administration of the scheme will serve to offer people with a disability and their carers some 'protection' from future policy changes to the scheme, through the calculation and provision of funding on an individualised basis. It is also ANGLICARE's view that such a levy should be in addition to the current funding of disability services, and that it should not in any way compromise current spending commitments by the state or federal governments, especially in the onset of an ageing population, higher incidences of disability in very old age, and an increasing number of claimants for disability services.

Nevertheless, it is also acknowledged that other countries (such as Germany) have faced considerable pressures in the financing and administration of their long-term care insurance schemes. The German insurance scheme was introduced in 1995, but has been adversely affected by a shrinking revenue base. In 2007, the Institute for the Study of Labour canvassed a range of alternative options for the future funding of the German scheme, in a paper entitled *The German Social Long-Term Care Insurance: Structure and Reform Options* (Amtz et al, 2007). The current funding model includes all employees who are earning less than the social security earnings ceiling (3,937.50 euros per month in 2006). Equal contributions are made by employees and employers, which are calculated from gross income up to a social security contribution ceiling.

The proposed replacement funding options include:

- *Fixed premiums*: These premiums would be completely independent of wages and the tax system would be responsible for redistribution. Under this system, premiums would be calculated on “entrance age” – for example, a fixed contribution of 52 euros for a 20 year old, to 66 euros for a person aged 45 years and above. It has been proposed that if these rates exceed a certain percentage of household income, the state will “assist with subsidies paid from taxes.” However, critics of this model have opposed the idea of higher income earners paying more money than lower income earners to finance the insurance scheme.

- *Fully-funded system*: This system would involve the building of capital stock from each individual’s lifetime paid contributions. However, it appears that this system would require a fairly lengthy transition period – specifically, for older people to be entitled to payments, in spite of not having accumulated enough capital, and for younger people to build a capital stock to finance their future care needs. Several variations have been proposed relating to the contributions of older people and younger people – both in terms of a fixed cost (e.g. 50 euros) or contribution rate (ranging from 0.5 percent to 3 percent).

- *Pay-as-you-go system linked to a fully-funded system*: This approach combines aspects of the existing scheme with the system described above. It has been suggested that the system would be funded with an increased proportion of the pension rate and a general wage-related contribution, with a percentage of the latter contribution to be deposited in a personal financial security account.

- *Private Insurance*: The shift from a social long-term care insurance scheme to a private long-term care insurance scheme would be achieved through compulsory membership for all citizens. One of the proposed schemes would be based on a ‘risk’ system, where people with a higher potential need of care would be required to pay higher premiums.

- *Citizens’ Insurance*: As per the private insurance scheme, all citizens would be insured under this scheme – including civil servants and the self-employed.

While ANGLICARE Sydney is not advocating for the introduction of a *particular* funding model, the experiences (and funding solutions) of other countries should be taken into account, in conjunction with rigorous economic modelling.

Recommendation 28: The development of a new funding model should take into account international experience and be based on rigorous economic modelling.

14. The practical aspects of a scheme that will make it work, such as how existing arrangements would fit into a new scheme, how to manage risks and costs, and ideas for attracting people to work in disability services?

14.1 Staff Recruitment and Retention

In ANGLICARE Sydney's experience, it is becoming increasingly difficult to find appropriately skilled and qualified staff for disability support programs and to properly remunerate such staff. Increased funding is required to raise the base wage rate, in order to attract the appropriate people with skills into the sector. Attracting qualified personnel is reflected in the remuneration offered and as such Government must increase funding accordingly. To operate to best practice standards, not for profits must seek to be Employers of Choice and to do this must be able to offer better conditions, opportunities for career advancement and education and reasonable, comparable pay rates. Subsequently, this will provide a stronger incentive and encouragement for younger qualified people to regard employment in disability support services as a real and long-term career option.

Possible issues to be considered include:

- Providing defined career pathways, particularly for young workers entering the sector. This cohort could be attracted by training opportunities (e.g. scholarships) that would provide a career pathway.
- Many people coming into disability support workforce are mature staff and perhaps entering a second or third career
- Recognition of overseas qualifications – can support be offered until they are accredited and giving opportunities to work their way through the care system?
- Tapping cohorts of potential employees, such as women with young children
- Providing more flexible working hours and child care support

Recommendation 29: Intentional policy to recruit and retain staff in the disability sector needs to be developed which considers pay rates, defined career pathways, improved training opportunities, recognition of overseas qualifications and provision of more flexible working hours and child care support.

15. How long would be needed to start a new scheme and what should happen in the interim?

Implementation of such a scheme would take time dependent on the nature of the scheme, the level of community consultation required and the degree of advocacy required to effect the changes – including support infrastructures, resourcing, staffing, management and administration. A transition plan would need to be established with evaluation and monitoring built into every new service model developed.

SUMMARY OF RECOMMENDATIONS

Recommendation 1: The focus of disability support should be the person with disability and their primary carer who need assistance and support to play the fullest possible role in their communities (including the workplace), regardless of the cause of their disability. Support under the disability scheme should continue beyond age 65 years, unless equivalent support can be obtained through the aged care system.

Recommendation 2: The proposed scheme carries with it an emphasis on capacity building rather than just funding support. ***.*** *Assessment needs to occur regularly over the life of the person with a disability to ensure changing needs and life circumstances are supported and potential areas for capacity building identified.*

Recommendation 3: New assessment tools need to be developed which are age appropriate and capable of dealing with multifaceted disability.

Recommendation 4: Any new national disability support scheme needs to especially consider young people with profound and complex needs, people with disabilities from a CALD or indigenous background, ageing parent carers, young carers and carers on low incomes.

Recommendation 5: In order to be effectively applied, new resources have to be accompanied by adequately funded case management supported by access to appropriate care packages, information and education, accessible respite and accommodation, and emotional and financial support options.

Recommendation 6: A significant and sustained increase in supported accommodation options.

Recommendation 7: A significant increase in the availability of flexible subsidised respite options particularly for children under 16 years of age.

Recommendation 8: Increased provision of out of home respite for people with challenging behaviours.

Recommendation 9: Tighter regulations need to be introduced to ensure that respite beds in nursing homes are planned and managed as exclusive respite beds.

Recommendation 10: There is a need for increased funding for in-home respite care.

Recommendation 11: Early intervention requires investment in case management to ensure a more streamlined access to services, particularly for families with children experiencing multiple issues. This needs to be supported by long term person centred planning – not just in the early years but over the full life cycle of the individual.

Recommendation 12: Government should support and fund educational programs designed to change community attitudes. The content of the program should be provided by people with disabilities, carers and organisations with experience in disabilities services. It should hand in hand with better funded case management that actively addresses issues of social inclusion “on the ground”.

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Recommendation 26: Provide travelling contingencies in current funding arrangements for disability specific support services.

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Recommendation 29*: Intentional policy to recruit and retain staff in the disability sector needs to be developed which considers pay rates, defined career pathways, improved training opportunities, recognition of overseas qualifications and provision of more flexible working hours and child care support.*

CONCLUDING REMARKS

ANGLICARE Sydney appreciates the opportunity to provide input into this Inquiry and we greatly look forward to positive outcomes from such consultation.

Peter Kell

Peter Kell
Chief Executive Officer

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