

**ANGLICARE Sydney's Response to the  
Productivity Commission's Draft Report  
into Disability Care and Support**

**April 2011**

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## 1. INTRODUCTION

The Productivity Commission has released a major draft report into disability care and support in Australia. The report proposes a major overhaul of the current arrangements for disability support and the establishment of a National Disability Insurance Scheme to address chronic underfunding and inequity in the current arrangements. ANGLICARE Sydney welcomes the proposed reforms and wishes to endorse both the breadth and much of the detail of the Commission's approach. ANGLICARE Sydney urges the Government to take a whole-of-sector approach as recommended by the Productivity Commission, rather than an ad-hoc or piecemeal approach. Reform and adequate funding for the whole of the sector are urgently required to provide a proper level of care and support for people with a disability and their carers, so that they may achieve an enhanced quality of life and increase their economic and social participation in Australian society.

In August 2010, ANGLICARE Sydney provided a submission to the initial Inquiry into a disability support scheme for Australia. The current submission is a response to the draft Productivity Commission report and supplements our previous submission.

ANGLICARE Sydney's current submission generally follows the structure of the Productivity Commission's draft report. At the end of this submission, a summary table indicates which of the Commission's draft recommendations are fully endorsed by ANGLICARE Sydney and which recommendations, in our view, require clarification or amendment.

### 1.1 About ANGLICARE Sydney

ANGLICARE Sydney is a Christian community organisation operating a wide range of community services across the Sydney Metropolitan and Illawarra regions of NSW. It embodies the Christian commitment to care for all people in need, as comes from Jesus' command to love your neighbour as yourself.<sup>1</sup> ANGLICARE provides a range of support services for people with a disability and their carers, and is one of the largest providers of such services in Western Sydney, including:

- Commonwealth Carelink and Carer Respite Centres (CCRC's)
- Community Options program for people at risk of premature admission to residential aged care
- Support Co-ordination for Older Parent Carers of people with a disability
- Respite Options for carers of people with a disability
- ComPacks short-term case management and brokerage for people being discharged from hospital with complex needs
- Westlink Host Family Program, offering family-based respite care provided by volunteer families
- Vacation Care: day care during the school holidays for children aged 0-10 years
- Complex Care Support
- Peer Support community-based activities for adolescents aged 14-18 years

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<sup>1</sup> *The Gospel of Matthew*, chapter 22 verse 39

- W.H.I.R.L.S.: out-of-hours respite for people aged 18 years and over with an acquired brain injury and their carers
- Dementia Home Support: in-home respite to people with dementia and/or their carers
- Chesalon Care at Home: Community Aged Care Packages (dementia priority)
- Richmond and Winmalee Day Centres which provide programs for care recipients and respite for carers.

Of relevance to this submission, ANGLICARE Sydney is a provider of both aged care accommodation and aged care services in the community. ANGLICARE Sydney also provides mental health services through the Personal Helpers and Mentors (PHaMS) program, mental health respite programs, the Haven Project and Urban Arts Base.

## **2. WHO IS THE NDIS FOR? (Chapter 3)**

The Productivity Commission's draft report has recognised that the current services and systems to address the needs of people with disabilities and their carers are inadequate and under resourced. The Australian Government is committed to enhancing the quality of life and increasing economic and social participation of people living with disability<sup>2</sup>.

However the Productivity Commission's report goes further by recognising that a cost effective system to benefit all Australians is warranted, not just one to target individuals living with disability. The proposed National Disability Insurance Scheme will cover all Australians who need care and support, providing portable funding and choice for individuals for life-long support and care.

### **2.1 A Tiered Approach to Providing Support**

In order to do this, a comprehensive three tiered system has been proposed which aims to minimise the impacts of disability across Australian society. The report clearly defines the characteristics of the people for each group, how those people will gain benefit from an NDIS and the costs associated with each tier.

At the Tier 1 level, the scheme would have a role in minimising the impact of disability by promoting opportunities for people with a disability, creating awareness of the issues that affect them, and use data and research for advocacy purposes.<sup>3</sup> ANGLICARE Sydney sees this as a significant initiative which should result in greater social inclusion for those who have a disability. With the provision of resources at Tier 2 and Tier 3 levels there is an opportunity for outcomes for individuals living with disability will be substantively changed.

### **2.2 Broader Service Delivery Context**

A significant initiative is the proposed interface between the NDIS and systems of service provision in the aged care and mental health sectors, to streamline access to service provision, portability of services and a whole-of-life approach.

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<sup>2</sup> Productivity Commission (2011) *Disability Care and Support. Draft Inquiry Report – Overview and Recommendations*, Canberra, pv

<sup>3</sup> *ibid*, p 11.

Regarding the interface with the *aged care system*, recommendation 3.5 in part reads that “Upon reaching the pension age and at any time thereafter the person with the disability should be given the option of continuing to use NDIS provided and managed supports or moving to the aged care system.” ANGLICARE Sydney believes that people should be able to use the system that best supports them. However will there be a mechanism that would allow people to *return* to the NDIS if they chose to move to Aged Care and then found that it did not best suit their needs? The Disability and Aged Care systems are, in terms of service delivery, conceptually different in their approach to their clients. It is likely then that people who may have spent a lifetime with the disability support system will need the flexibility to be able to return to it if their needs are not met well in the aged care system.

While ANGLICARE Sydney supports a simplified approach to the separate funding responsibilities of the aged care and disability sectors, an issue for aged care service providers is that, in supporting an NDIS client, providers will need to deal with two different service standards, different acquittal processes and two different government departments. The Productivity Commission in its major report on the Not-for-Profit sector made clear the importance of reducing ‘red tape’ for NFPs, particularly in the funding, reporting and acquittals processes.<sup>4</sup> ANGLICARE Sydney believes that the same streamlined approach is needed here to avoid duplication and increasing ‘red tape’.

For instance, ANGLICARE Sydney provides aged care services to people under the age of 65. ANGLICARE has a government funded social support program (HACC) specifically for people with early onset dementia aged less than 65 years. If a person is younger than 65 years with an aged related illness they have access to services within the aged care system. However with the movement of HACC to the Commonwealth, it is understood that this cluster of people will fall under the disability services guidelines. Whilst this shouldn’t impact on the client and/or their family as contractual arrangements will only occur between Commonwealth and State and the service provider, it does mean that the service provider will need to have two funding agreements in place. There is a need then for both Federal and state governments to develop standardised funding contracts, acquittals processes and reporting mechanisms to avoid inconsistencies, complexity, duplication and the use of additional NFP resources.

Regarding the interface with the *mental health system*, the Commission notes that there are similarities in support needs between people with disability, and those with a severe and enduring mental illness. The Commission therefore suggests that people with a severe and chronic condition who require daily support in much the same way as other people with a disability should be eligible for support under the NDIS. ANGLICARE Sydney supports the inclusion of this group of people in the NDIS. But the Commission is also aware that this area is currently under review. It is seeking further feedback on “where the boundaries should be drawn and the implications for the NDIS’s costs, eligibility conditions, service offerings and integration with the mental health system”.

However the treatment cycle of many people with a mental illness can be similar to the example given in the Commission’s report of *severe* bad backs, asthma and migraines, in that these only sometimes affect core self-care activities, although a mental illness can be far more debilitating and

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<sup>4</sup> Productivity Commission (2010) *Contribution of the Not-for-Profit Sector*, Research report, Canberra, pp292, 293.

serious.<sup>5</sup> They could also be equated to the support needs of people with an 'intellectual disability with life-long care and support needs', 40% of whom are not categorised as having a severe or profound disability. It is concerning that some people with a serious mental illness may not be considered likely candidates for individualised supports because of the episodic nature of their condition.

### ***Recommendations***

***1. The Productivity Commission's report include provision for clients to be able to return to the NDIS system from the aged care system, if they find that the NDIS better suits their needs.***

***2. An additional recommendation be added to the Productivity Commission's report regarding the need for governments to avoid duplication and to streamline the funding, acquittal and reporting requirements where an aged care provider is providing support to NDIS clients.***

***3. In determining the boundaries for inclusion of people with a mental illness within the NDIS, the Productivity Commission have regard to other aspects, such as the impact and severity of the mental illness, apart from whether it would require daily support.***

## **3. INDIVIDUALISED SUPPORTS (Chapter 4)**

ANGLICARE Sydney is supportive of the broad range of individually tailored supports to be funded by the NDIS including physical aides and appliances, personal care, domestic assistance, respite, home and vehicle modifications, community access, transport assistance, specialist employment services, specialist accommodation support, therapies, case management, crisis/emergency support and guide dogs and assistance dogs. It is important that this list of supports be seen as non-negotiable and protected from redefinition by future Governments, in order to provide the minimum level of Government-funded care and support into the future. This list should rather be seen as a starting point to which further supports will be added, as the NDIS matures as a scheme.

The report states that it is a policy goal to move away from primary reliance on specialist disability services to the use of mainstream services or a mix of the two.<sup>6</sup> However ANGLICARE Sydney is pleased to see that it is acknowledged that not all needs can be met by mainstream services and that specialist knowledge and service delivery will continue to be required for many people.

ANGLICARE Sydney welcomes more flexible funding arrangements including the option for self directed funding, which will allow NDIS provided supports to be better tailored to meet individuals' needs. The specialist disability services provided will be on a 'reasonable and necessary' basis and will not be subject to means testing - although an annual front-end deductible payment will generally be required.<sup>7</sup> While there is provision for this payment to be waived where families make a significant contribution towards the cost of their support through unpaid care, more clarity is needed around the family needs assessment in relation to this payment.

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<sup>5</sup> Productivity Commission (2011) *Disability Care and Support. Draft Inquiry Report, Volume 1*, Canberra, p3.11.

<sup>6</sup> *ibid*, p4.11

<sup>7</sup> *ibid*, p4.33

ANGLICARE particularly applauds the focus on innovative supports which are determined by the requirements of people with a disability. With individualised funding a wider range of services will be enabled and service providers will need to tailor their services to meet the need. There is the recognition that 'one size does not fit all'.

### **3.1 The Role of Mainstream Services**

ANGLICARE supports the continued reliance upon mainstream services in principle, as outlined in the Commission's report. In relation to education, the Commission notes that there has been a large increase in enrolments by children with disabilities at state schools. However the Commission's report also notes that there continues to be significant inadequacies in state education systems for children with disabilities and special needs. In NSW the Independent Schools sector provides 'specialist' educational services for children and young people who currently are not well served by the State system.

The Commission's report states that, "the education sector should not have to meet all of the needs of students with a disability. At the same time, shared responsibilities needs to work effectively and not result in unreasonable loads on the individual or their carers".<sup>8</sup>

ANGLICARE Sydney believes that there are some children with severe and profound intellectual disabilities and significant levels of challenging behaviour, whose needs cannot be readily met within mainstream schools and whose care does create an unreasonable load upon their families. Our view is that some of these children would be better situated in special schools which also address their accommodation needs and the respite needs of parents. For thirty-five years ANGLICARE Sydney ran an independent boarding school (weekdays in school term time only) for children with intellectual disabilities and complex special needs often including challenging behaviour, which provided a vital service where the family unit was at risk of breaking down. This shared care model was not seen as 'philosophically correct' in service provision for children with disabilities and required significant levels of funding to run. However it was a model with demonstrated educational and social outcomes for the children themselves and their families. It kept families intact, enabled siblings to have their own needs met and the children and young people were able to be maintained in the family unit rather than being surrendered to state care. ANGLICARE Sydney was forced to close the school at the end of 2010 due to funding difficulties. Portable individual funding combined with NDIS funding may well result in such a model being financially viable.

### **3.2 Specialised housing**

The draft report outlines that the NDIS will fund the provision of specialised accommodation, including group homes. However, as the Commission notes, group homes are currently in short supply. Consequently, the Commission proposes innovative funding models to increase housing choice, such as individuals being able to 'cash out' the cost of their specialist accommodation support in order to rent or purchase alternative housing.<sup>9</sup>

ANGLICARE Sydney's view is that a much more comprehensive approach is needed to this important issue and that the report is far too light on detail as to how the shortfalls in the supply of such

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<sup>8</sup> *ibid*, p4.17

<sup>9</sup> *ibid*, p4.5

housing will be addressed. It is known that group homes account for only a fraction of the accommodation supply of people with a disability, since most continue to live at home with family members. Reliable estimations of the likely demand for such housing are needed and how the NDIS will fund the large capital works that would be needed. Estimating demand will be difficult in a situation where parents have provided long-term care for a son or daughter with a disability – often for many decades. It may take a long cultural change before such carers and their care recipients take full advantage of such accommodation resources and become fully aware of the options available to them.

In addition it should be noted that the group home model does not meet the needs of many people with disabilities and ANGLICARE Sydney is pleased that the Commission has recognised the need for more creative and innovative models required to provide supported accommodation for the range of people with disabilities.

ANGLICARE Sydney notes that the NDIS would not necessarily ‘own the bricks and mortar’ but the funding it provides would cover the cost of capital works.<sup>10</sup> Further detail is needed regarding the funding of support services which accompany models of supported accommodation, such as the employment of a support worker and other operational costs.

Many people will be identified as requiring specially designed accommodation suited to their particular physical or behavioural needs. They will also require models which respond to the particular needs for support which are identified in NDIA’s ongoing assessment process. This may range from the person living in their own studio apartment to a cluster housing model, with many options in between. Such options should reflect models of accommodation currently used by the wider community. The difference will be that people with a disability will require different levels of support to make such accommodation options viable. These additional needs will require adequate funding.

While the Commission’s report makes clear the goal to provide greater housing choice for people with a disability, there appears to be no detail regarding the situation where a son or daughter with a disability wishes to remain with an ageing parent who themselves have high care needs. As an aged care provider, ANGLICARE Sydney has come across many examples of people with a disability and ageing parent carers wishing to co-locate once the carer needs to move into an aged care facility. However the accommodation of the son or daughter with a disability in an aged care facility is not seen as desirable. ANGLICARE Sydney’s view is that the issue of providing more choice for people with a disability is constrained by an almost complete lack of acceptable solutions to this co-location issue. To address this issue requires not only funding and a greater ability to choose, but also systemic changes in the provision of accommodation.

People who are in their 40’s and 50’s are being admitted to aged care accommodation due to significant health and disability issues. Such people would be assessed by an ACAT team for a specific residential facility. This might be a person with early onset dementia, a person with Down syndrome (who has aged early), early stroke, or people with an acquired brain injury. Residential aged care is generally not a socially appropriate option for this age group. In addition, residential aged care services do not provide for people with significant intellectual disability and/or challenging

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<sup>10</sup> *ibid*, p 4.6



behaviour outside the area of dementia. What kind of accommodation alternatives will exist for these people under an NDIS?

A parallel may be drawn with the issue of young people whose needs can currently only be met in nursing home care. These categories of young people include ABI, physical disability, neurological and intellectual/psychiatric. The innovative accommodation options being suggested and/or trialled in rural areas for these people include:

- Specialist units attached to nursing homes
- Small residential homes providing accommodation for people of all ages with complex chronic disabilities and conditions, with staff trained and sensitive to the needs of young people and people with disabilities. The main aim is to provide the choice of living in a small home environment, which enables them to remain in the local community.

### ***Recommendations***

***4. More clarity be provided in the report around the family needs assessment for the deductible payment for specialist disability services.***

***5. The need for special boarding schools in meeting the educational and respite needs of children with severe and profound intellectual disabilities be included in the Productivity Commission's report as a complimentary approach to the role of the mainstream education system.***

***6. A comprehensive approach be taken by the Productivity Commission to the overall demand and supply of specialised housing, with a view to arriving at an adequate funding and delivery model to address the chronic undersupply of such housing.***

***7. Special accommodation issues, such as for people with a disability wishing to co-locate with an ageing parent carer who themselves need to move into an aged care facility, be specifically addressed in the Productivity Commission's report.***

## **4. ASSESSING CARE NEEDS AND SUPPORTS (Chapter 5)**

ANGLICARE Sydney's view is that a valid and reliable assessment process is absolutely critical to the success of the NDIS. We recognise the need for the development of a suite of tools that will be used to assess the nature, frequency and intensity of an individual's support needs across the life span.

ANGLICARE Sydney supports the recognition that the assessment process needs to continue over the life span of the person and that the resources allocated to the individualised package may need to be changed and other service areas (aged care, mental health and health) involved at different stages. The assessment process needs to provide for a comprehensive analysis of individual situations with an emphasis that is person-centred and forward looking, allowing them to achieve their potential. While focusing on needs it is important not to neglect aspirations and the building of individual capacity.

It is positive to see that the role and contribution of unpaid informal caring will be recognised and assessed as part of this process. ANGLICARE Sydney provides a range of programs for carers and young carers and recognises the immense contribution they make to meet the unmet service needs for their person. The assessment will also provide a way to identify the support needs of the carer to ensure that the caring role is not 'unreasonable' in its demands.

In this respect, the term 'reasonable' that is used in relation to individual care and support needs is problematic, particularly in the absence of valid and reliable assessment tools.<sup>11</sup> Such a term is open to interpretation and assumption in the absence of such assessment tools.

#### **4.1 Assessment tools**

It is recognised that no ideal tool or set of tools is available at this time and that any tools designed by the NDIS should be reliable and valid and subject to monitoring, evaluation, and adjustment. Individuals lead multi-faceted lives so the tools will need to be comprehensive enough to include the nine 'activities and participation' domains from the ICF. However ANGLICARE Sydney agrees that it is necessary to commence with the tools that are available rather than wait for the 'perfect' tool to be designed.

ANGLICARE Sydney urges that the development of new tools be given priority so that the complex and diverse support needs of young people and adults living with a disability are able to be assessed more accurately and the support package associated with this assessment will be sufficient to meet the needs of the individual. To date, tools that have been in use such as SNAP and ICAP have not been able to sufficiently address issues such as challenging behaviours, to the detriment of people with disability and their families. Often the views of the family and carers who know the person the best have been used where necessary in the assessment process. However an NDIS will require national standards to ensure fairness so that people with similar levels of need get similar support.

ANGLICARE Sydney welcomes the toolbox approach. People with disabilities are a diverse group, including within sub-groups of disability. One tool will never address all people's support needs even within the one sub-group. A toolbox approach would allow an assessor to access a range of profiles/questions that suit the person being assessed. ANGLICARE Sydney's experience in our Brokerage Option Program has shown us that one tool does not fit all. This program supports people with a disability 18-64 years living in the community. We have one assessment tool that has a number of profiles however they don't always address the support needs of the client. These needs are usually drawn out in conversation and rapport building by the case-manager.

#### **4.2 Capacity building**

ANGLICARE Sydney's previous submission recommended that the NDIS carry with it an emphasis on capacity building where possible rather than just funding support for individuals. Assessment therefore will need to occur regularly over the life of the individual, to ensure that changing needs and life circumstances are supported and potential areas for capacity building identified, such as in relation to life skills, education and employment.

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<sup>11</sup> *ibid*, p5.8

Supporting people with a disability to develop capacity to reach their potential would contribute to both the social and economic capital of Australian society. The value of making a contribution to others through paid or voluntary work is well recognised in programs designed to support unemployed people to re-enter the work force. It must, however, be recognised that for some people the process may not lead to 'work' as such but to greater inclusion in the community. For all groups, ongoing assessment and effective program design and delivery will be required over the life span of the person. Costs associated with this process need to be factored into the individual package. However greater capacity for the person may also result long term in reduced costs related to that person for the NDIS.

In order that capacity building may occur it will be necessary that paid and informal carers be assessed and trained in identifying how this can be achieved for the person. The distinction between caring for a person in the sense of supporting their daily needs and caring for them in terms of developing their capacity needs to be stressed and taken into account when recruiting and training workers.

Increased capacity for the person may also create opportunities for the family member who is currently the carer to be assisted to re-enter the paid or volunteer work force, thus improving both their economic and social outcomes. In ANGLICARE Sydney's previous submission, we recommended the establishment of specific employment services for carers or the provision of specialised employment consultants within existing employment centres to work specifically with carers<sup>12</sup>. This service would provide up skilling programmes and liaise with and educate employers advocating for the needs for carers, especially the need for flexibility.

#### **4.3 Assessors within the NDIA**

It will be absolutely critical that assessors acquire specialised training and be able to use highly sophisticated tools. The report suggests that assessors should be drawn from a pool of allied health professionals.<sup>13</sup> However allied health professionals take a clinical approach which is too narrow for the broad assessment that is required. A better approach would be that a generalist case-manager undertake an holistic assessment and draw upon allied health professionals as required. People with disabilities are not necessarily sick and do not always require a clinical approach. Clinical assessments will be needed if they have complex needs including mental health issues and will be a critical element that may affect funding package. It is this clinical strand that needs to be included in a more sophisticated tool box, in the same way that challenging behaviour needs a more sophisticated assessment.

The draft recommendation (5.4) that assessors should not have any longstanding connections to the care recipient person is understandable at one level but absurd at another level. It is noted that assessors will need to be trained, objective professionals. Long standing relationships are beneficial in that the client doesn't have to retell their whole life story upon initial assessment, upon transition or if their needs rapidly change. The initial assessment will form part of the person's electronic data base which will be available to all relevant people and services, thus removing the need for a person

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<sup>12</sup> ANGLICARE Sydney (2010) *Submission to the Inquiry into Disability Care and Support*, Submission prepared for the Productivity Commission, August 2010, p17

<sup>13</sup> *ibid*, p5.21

to retell their story over and over. We suggest that independent assessors should be required to consult with those people who do have long-standing relationships with the client, including support workers.

Given that assessment may lead to referral to other systems, consideration should be given as to how NDIS clients can avoid having to retell their stories to professionals in other systems. The current service system is fragmented, resulting in duplication of assessments and a retelling of the clients' story. If the NDIS acted as the sole assessment point, and all information required is entered on the national data base which is available to other systems, this would stop the need for re-telling of client stories and duplication.

### *Recommendations*

*7. The development of new tools be given urgent priority, so that the complex and diverse support needs of people living with a disability are able to be assessed more accurately, the support package associated with this assessment will be sufficient to meet the needs of the individual and any potential areas for capacity building identified.*

*8. The NDIS carry with it an emphasis on capacity building where possible rather than just funding support for individuals. In this respect assessments need to take capacity building potential into account and sufficient funding needs to be provided for support services (eg. employment services for people with a disability and their carers).*

*9. The requirement for independent assessors be retained (Recommendation 5.4) but that the assessor be required to gather information about the person from those who know them best, including other support workers.*

*10. The NDIS assessment be available to other systems to avoid duplication of assessment and the need for clients to retell their story.*

## **5. WHO HAS THE DECISIONMAKING POWER? (Chapter 6)**

The Productivity Commission acknowledges the need for people to have greater power and choice over their lives which will be provided through individual choice of services and supports. The Commission proposes that this occur in two broad ways:

- People with disabilities always have power to choose their service providers (SPs), with the support of intermediaries if they wish
- People with disabilities have the choice, subject to some conditions, to cash out their individualised package of supports and manage their own budget, allocating it to specific supports they assemble themselves (ie self directed funding).<sup>14</sup>

It is noted that overseas experience shows a low level of uptake for self directed funding. This may reflect the responsibility required in managing their own care and support funds. It may also reflect

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<sup>14</sup> ibid, p6.4

high levels of satisfaction with the current service delivery already being received from service providers.

The draft report observes that the implementation of self-directed funding will provide significant challenges.<sup>15</sup> The international experience suggests that it takes time to adapt processes for consumer-directed payments and to build up the capabilities in government, service providers and service users for their adoption. It is unlikely that take-up will be very high initially because:

- people with disabilities and their families will need to become aware that they have scope to be in control of their funding and to understand how the system works. Many families will never want to undertake these tasks, given their existing workloads
- the NDIA overseeing the system would need to develop accounting systems and other approaches to manage the new system, as would providers service providers who will have to adapt to a system that reduces their certainty of funding
- service coordinators and case managers will need to take different approaches to decision-making about services for their clients.<sup>16</sup>

ANGLICARE Sydney further notes that with the considerable shift in the way services will be delivered to people with a disability under individual choice of services and supports and self-directed funding, there needs to be a period of training and information delivery for service providers to prepare for the change in their role.

### **5.1 Employing People Directly**

Despite the likely benefits of self-directed funding, ANGLICARE Sydney has some reservations about this option as it is proposed in the Commission's draft report, which would allow care recipients and/or their carers to employ support workers or other roles. The Commission has produced evidence based on both overseas and Australian jurisdictions that the risk of abuse or criminality in such arrangements appears to be low.<sup>17</sup> However the Commission's report is not fully clear on what safeguards will exist to prevent or to detect abusive or fraudulent behaviour when it does occur and what procedures will be followed in the event that such behaviours are detected. Furthermore, the Commission acknowledges that there is a higher risk of misadventure on the part of carers and care recipients under the self-directed funding option.<sup>18</sup> Where funds are misspent by a carer, what procedures will be available to ensure that the proper needs of the care recipient are still met?

Another issue is ensuring the highest quality of care in situations where people with a disability directly employ support workers. Ongoing monitoring of such arrangements by the NDIA will be needed to ensure that the needs of people with a disability are being met and best practice approaches are being used.

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<sup>15</sup> *ibid*, p6.46

<sup>16</sup> *ibid*, p6.47

<sup>17</sup> *ibid*, p6.41

<sup>18</sup> *ibid*, pp 6.19-6.20, 6.38-6.40

The Commission notes that there can also be risks for support workers, such as low pay, failure to meet statutory employment standards and abuse.<sup>19</sup> However, the report states that there is little consistent evidence of low wages, but reasonably reliable evidence that wellbeing of employees is typically better, or at least no worse.<sup>20</sup> Whilst there are no strong grounds for restricting people with disabilities from employing support workers, there are grounds for some protections.

ANGLICARE Sydney believes that recruitment and employment processes and guidelines will need to be carefully detailed to assist people to ensure that all legal requirements are covered and appropriate checks carried out. Care recipients and their carers need to be made fully aware of their obligations. In this respect, draft recommendation 6.6 should be amended to include information for people on the responsibilities of employing people, industrial relation issues, workers compensation, how to do a position description etc.

ANGLICARE Sydney considers that the capacity of people to enter into the self-directed funding option must form part of the assessment process outlined in Chapter 5 of the Productivity Commission's report. Recruitment, employment and ongoing monitoring of workplace issues require a level of skills which needs to be identified in the assessment process. In addition, many people with a disability are in a vulnerable position and this needs to be taken into account in the assessment process.

The Commission's report notes that some people with disabilities are not able to make all of their own decisions (as is the case with profound intellectual disability). In that case, decisions about their well-being will often be made jointly with or by their primary carers, who are usually familiar with the strengths, goals and other preferences of the person with a disability. However, while such carers will usually have the best interests of the person with a disability at heart, the Commission recognises the vulnerability of both the care recipient and the carer in this situation<sup>21</sup>. The assessment process needs to include a determination as to whether the self-directed funding option is in fact suitable in each case.

## **5.2 Employing Family Members**

Special consideration and assistance needs to be given to those people with disability and their families who live in country areas where services and supports are not viable due to the low numbers of people who require them. In these cases families need to rely on their own informal support mechanisms, including family members. In such situations, family members being paid to provide care may be the only real option under the NDIS.

However ANGLICARE Sydney supports the cautious approach adopted by the Commission in proposing a trial scheme of allowing family members to provide paid care. A rigorous assessment of family members must be required, as would occur for non-family support staff. The process should include an assessment of the competence of the carer, checks to identify any evidence of abuse or neglect in the past, training, education about the possible pitfalls of paid family care, a mandatory schedule of respite if caring is intense, and assessment of any economic stresses that may indicate the potential for financial abuse. There are also complex interpersonal issues which may be difficult

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<sup>19</sup> *ibid*, p6.30

<sup>20</sup> *ibid*, p6.43

<sup>21</sup> *ibid*, p6.11

to resolve but would need to be part of such a trial, such as when does the care recipient know when the carer (eg a brother) is in the role of 'carer' and when is he a 'brother'? How does a person who may have complex needs or a severe and profound intellectual disability indicate if they do not want to have a family member or non resident relative as their carer?

While ANGLICARE Sydney understands the reasons for a proposed discounting by 20% of the individual budget where family members are employed, we would argue that this not be included as part of the proposed trial (draft Recommendation 6.5). In principle, employing family members, if it is to be permissible, should not be subject to penalty or inequitable treatment in the longer term.

### 5.3 Impacts upon Service Delivery

The report notes that block funding, despite the efforts and goodwill of both service providers and funding agencies, by its nature shifts the decision making away from service users and in so doing limits their choices and opportunities.<sup>22</sup> ANGLICARE Sydney is concerned about how individual choice of services and supports and self-directed funding will impact service delivery for organisations that are currently financed through a tender process and block funding and what this will mean for the health and viability of some organisations in the sector.

ANGLICARE Sydney also believes that a market driven service delivery without any block funding may not deliver the full range of services that are needed when responding to complex support needs. This possibility is also acknowledged in the report, especially in relation to services in rural areas and for addressing very complex needs or very challenging behaviours.<sup>23</sup> We are particularly concerned for those people with a disability who also show challenging behaviours. This group of people often have difficulty maintaining family connectedness; have difficulty in accessing available services; find that services are often not set up to meet their needs and may be unable to sustain the required support. Providing services for people with challenging behaviours is often costly requiring specialised support.

ANGLICARE Sydney is also concerned about people with disabilities where clinical considerations are critical in the delivery of service, including mental health issues. We are very concerned that this group may be neglected in the development of a suite of services more driven by market forces. There are very few services now for these groups of people and unless there are incentives within a market driven sector, once again this would become a neglected area. Therefore, we urge the Productivity Commission to recognise the important role of block funding and continue to apply block funding as a tool to address areas that will not be adequately addressed by a market driven approach in the long-term.

#### ***Recommendations***

***11. The Commission identify what safeguards and accountability will be put into place in the situation where people 'cash out' (draft Recommendation 6.1).***

***12. The capacity of both people with a disability and their carers to enter into the self-directed funding option must form part of the assessment process outlined in Chapter 5 of the Productivity Commission's report, in view of the greater level of responsibility and vulnerability associated with direct employment of support workers.***

***13. Clear guidelines and assessment procedures be put into place in relation to the employment of family members as carers. The proposed trial of family members as paid carers take into account not only the suitability of carers for the role, but also the effect of the confusion of roles that will occur.***

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<sup>22</sup> *ibid*, pp 8.40-8.48

<sup>23</sup> *ibid*, pp 8.47-8.48



*14. The proposed discounting by 20% of the individual budget where family members are employed not be included as part of the proposed trial (draft Recommendation 6.5). In principle, employing family members, if it is to be permissible, should not be subject to penalty or inequitable treatment.*

*15. Draft recommendation 6.6 should be amended to include information for people on the responsibilities of employing people, industrial relation issues, workers compensation, how to do a position description etc.*

*16. Draft recommendation 6.6 should be amended to encourage existing disability support organisations to have these roles; the formation of further organisations does not appear necessary.*

*17. Draft recommendation 6.7 should include an appeal mechanism for families if there is an issue with the assessment process.*

*18. The Productivity Commission more extensively address the benefits of block funded services in the draft report, particularly as a tool to deal with areas that may not be adequately addressed by a market driven approach.*

## **6. GOVERNANCE OF THE NDIS (Chapter 7)**

The NDIA will be responsible for assessment of need, case management, authorising of funding proposals and determining the value of the vouchers provided by the NDIA to people with disabilities to purchase services and supports.

ANGLICARE Sydney sees considerable merit in the structures which have been proposed for governance, which provide for independent and transparent processes through the NDIA. A corporate model of governance is required with independence from day-to-day government control. The administrative arrangements for dealings with the relevant minister need to be specified in legislation, be on an arm's length basis and be clearly defined.

ANGLICARE Sydney supports the structure which ensures that the Board has specific skills to run such an agency but they will receive information and guidance about disability related issues from the independent advisory Council.

It is pleasing to see that there is a focus on the establishment of accountability and appeals mechanisms to give people confidence in the integrity of the process but without unintended impacts on the viability of the NDIS.

## **7. DELIVERY OF DISABILITY SERVICES (Chapter 8)**

ANGLICARE Sydney recognises the need for reliable information about service providers to be available in the most cost efficient form for potential service users. We support the development of a system to provide information and support to clients which will also monitor their well being. The

importance of the role of the case-worker cannot be understated as considerable assistance will be required for service users to navigate through the range of options, prepare their plans and lodge them for approval. ANGLICARE Sydney currently assists clients to manage packages and has established a strong reputation amongst those families.

ANGLICARE Sydney also supports the development of an electronic client data base which will reduce the need for clients to constantly retell their stories to each new service provider. This is in line with the current Federal initiative to roll out a system of electronic medical records for the nation. The administrative burden is high for many people with disabilities and their families and carers.

A major initiative will be the development of a quality framework for service providers, including nationally consistent standards, arrangements that encourage the diffusion of best practice and the establishment of an innovation fund.

## **8. COLLECTING AND USING DATA (Chapter 10)**

In order for the NDIS to ensure financial sustainability, provide cost effective services and interventions and good performance from service providers, ANGLICARE Sydney recognises that it is essential to set up systems for data collection and evaluation of services, and develop a capacity for independent research. ANGLICARE Sydney recognises that currently there are deficiencies in the processes to develop an evidence base and welcomes the development of such systems which can be used across the disability service provision sector.

ANGLICARE believes that these recommendations should be implemented as soon as possible. The potential within the NDIA to coordinate national research will be of great benefit to the sector.

## **9. EARLY INTERVENTION (Chapter 11)**

ANGLICARE Sydney supports the emphasis in the NDIS on whole-of-life planning. In this context, early intervention needs to be seen as a part of that life plan. It has been demonstrated that there are interventions which when implemented at a young age result in positive outcomes later in life. It is important that ongoing assessment, follow-up and 'top up' interventions are carried out throughout the person's life. The strategies used at age 4 may not be sustainable or effective in later years. Early interventions may well be delivered at a later stage in life if the disability is not as a result of childhood onset.

Rigorous assessment of early interventions (as with all approaches) needs to establish the efficacy and cost effectiveness of these programs. It is noted elsewhere in the Commission's report that there may be some therapies which will not be funded by the NDIS due to the lack of research evidence to support them. It could be that once sufficient research evidence is available that the list of appropriate supports that would be funded under the NDIS would be expanded.

## **10. FINANCING THE NDIS (Chapter 12)**

ANGLICARE Sydney in its previous submission supported a Medicare- style levy on personal income to provide support for those people with congenital conditions. Those people who acquired disabilities not covered by another form of insurance would also be covered in this manner. This is to ensure that the cost of the NDIS is spread equitably over the whole community.

The Commission's preferred recommendation is that funding of the scheme be from consolidated government revenue and that this funding will sit outside the usual budget process. It will be the responsibility of Treasury to ensure that the required funding is available. This National Disability Insurance Premium Fund should provide stable revenue to meet the independent actuarially-assessed, reasonable needs of the NDIS. This approach means that the Federal Government can use whatever is the most efficient tax financing arrangement at the time, or fund the NDIS from savings from spending elsewhere.

Our view is that if the Commission's preferred option is not adopted by the Federal Government, then the Government should instead legislate for a levy on personal income.

## **11. WORKFORCE ISSUES (Chapter 13)**

ANGLICARE Sydney recognises the considerable workforce issues related to the successful implementation of an NDIS. The workforce required covers a range of professions and would include direct care workers, nurses, allied health professionals and case-managers. The range of skills will vary widely. There is the potential for severe shortages, particularly with an ageing population and competition for direct support staff between the disability and the aged care sectors.<sup>24</sup>

The Productivity Commission sees workforce and recruitment issues as being among the greatest challenges to be faced in setting up the NDIS.<sup>25</sup> In order to attract people into the workforce, strategies such as providing higher wages, advertising campaigns, strengthened career paths and career profiles, and promoting better working conditions have been canvassed.

The process of recruitment and training will require considerable lead time before implementation of the scheme from January 2014. Both carers and paid support staff will need training and the establishment of monitoring systems to maintain standards and ensure safety and wellbeing for both the worker and the person receiving the service. Training should include formal training but also 'hands-on' experience. Those working in case management and other allied professional roles will come with a prerequisite set of skills but will require significant training in the processes required by the NDIA.

### **11.1 Transitional arrangements**

From the viewpoint of existing service providers, the expansion of self-directed funding and consequent withdrawal of block funding does pose significant challenges. What will this transition

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<sup>24</sup> Productivity Commission (2011) *Disability Care and Support. Draft Inquiry Report, Volume 2*, Canberra, p13.16

<sup>25</sup> *ibid*, p13.39

look like for organisations moving from block funding to a more market-driven model, in being able to maintain staffing levels and expertise? The potential for casualisation and de-skilling of the workforce through proposed systemic changes needs to be considered.

ANGLICARE Sydney has developed a strong, steady and committed workforce. This is a critical element in providing the quality of service that families are used to and would want in the future. The sector is dependent on its workforce and this area demands special attention from the Commission to ensure viability into the future. To operate at best practice standards, Not-for-Profits must seek to be employers of choice and to do this must offer better conditions, opportunities for career advancement and education and competitive pay rates. Smaller organisations may be more vulnerable in being able to sustain highly valuable programs under an NDIS.

ANGLICARE Sydney agrees that a strong commitment by government will be needed to increase staffing levels in an already over-burdened support system. Additional resources and access to training will be needed by the sector to establish and/or extend services that promote the ability of people with disability and their families to direct their own care.

The Commission noted that in a previous report into the Not-for-Profit sector it was found that the majority of service providers did not think that government funding covered the full cost of providing services and that government agencies do make a contribution rather than fully funding services.<sup>26</sup> The Commission's report states that the NDIA would at least initially play a major role in regulating prices, since it would reimburse service providers for items covered by people's packages. This would constrain wages given that labour costs represent a large share of total service delivery costs. In view of the fact that government has not fully funded services in the past, service providers should be reimbursed at a price that supports an efficient and sustainable service sector. This will be essential in order to support wages that are sufficient to attract workers into the sector.

### **11.2 Preserving the Not-for-Profit Character of the Sector**

The Productivity Commission's report notes that Not-for-Profit organisations account for 73% of service providers, compared with 22% Government agencies and 5% For-Profit organisations.<sup>27</sup> The underlying values of many Not-for Profits remain extremely important to the delivery of the quality of their caring service and the demand from families requesting it. It is noted, for instance, that one of the primary motivators for people working in the disability sector is the desire to help others; by comparison the desire for high wages is much further down the list.<sup>28</sup> Such values in the workforce reflect the ethos of many Not-for-Profit organisations.

By way of example, ANGLICARE Sydney is a Not-for-Profit organisation and has a history of well-established trust and commitment from their many client groups. Families have come to rely on the services provided by ANGLICARE to be of a high ethical standard and with a level of care and support that should characterise Christian organisations. There would be the hope and expectation among our client groups that ANGLICARE would be there for them in the new system.

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<sup>26</sup> *ibid*, p13.18

<sup>27</sup> *ibid*, p13.5

<sup>28</sup> *ibid*, p13.9

Transitioning to a more market driven approach must not diminish the importance of these values. However, the Commission's report largely conceptualises the workforce issues in terms of supply and demand. There is little reference to the Not-for-Profit character of the sector, the impact of its values and ethos and how this translates into the quality of relationships between NFPs and their clients. The ongoing issue of workforce recruitment and retention in this sector will involve an understanding of the culture of NFPs and the type of people that they attract as workers.

The Commission's reforms have the potential to increase the involvement of For-Profits in the sector. When new systems are introduced and new money is potentially available, this can be a time when For-Profit organisations enter the sector. This is not necessarily a bad thing. However there is a greater risk of For-Profits 'creaming' the easier or more lucrative clients. What protective measures does the Commission envisage would be put in place so that people with disabilities and their families are given protection from unfair or predatory treatment by organisations in the new system?

### **11.3 Meeting the Needs of People from Non-English and Indigenous Backgrounds**

The Commission's report recognises the additional difficulty that people from indigenous or Culturally and Linguistically Diverse (CALD) backgrounds have in negotiating the disability services sector.<sup>29</sup> ANGLICARE Sydney also recognises that the indigenous and CALD communities experience serious systemic disadvantage in accessing appropriate services.

There is a stereotypical view that the lack of access among some CALD groups is self imposed, as CALD communities are more self-reliant on their own family support networks. However the access issue is related more to lack of appropriate information and a lack of CALD specific services and CALD staff. The NEDA/FECCA<sup>30</sup> joint submission to the Productivity Commission raises the additional issue of the failure to acknowledge the need for cultural competence as part of the workplace skills shortage in order to improve the effectiveness of meeting the needs of people from CALD backgrounds. Again this is an area where a market-driven approach would need to be supplemented by the continuation of targeted block funding.

In addition, issues have been raised by FPDN around the effect of geography on the provision of disability services, the different way that 'disability' as a construct is viewed by indigenous Australians and the need for services which are culturally acceptable. It is now more clearly seen that the level of disability among indigenous people is significantly higher than the population in general and that this may still be an underrepresentation of the actual scale of this disability. As with the CALD community, block funding may be most appropriate to address their specialised needs.<sup>31</sup>

## **Recommendations**

***19. As part of transitional arrangements involving the NDIA, service providers should be fully reimbursed at prices that will promote not only an efficient but also a sustainable service sector***

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<sup>29</sup> Productivity Commission (2011) *Disability Care and Support. Draft Inquiry Report, Volume 1*, Canberra, p3.9

<sup>30</sup> National Ethnic Disability Alliance and Federation of Ethnic Communities Councils of Australia (2011) *Submission to the Productivity Commission Inquiry into the Long term Disability Care and Support*.

<sup>31</sup> First Peoples Disability Network (Australia) Submission to the Inquiry into Disability Care and Support, August 2010.

*20. The Productivity Commission report recommend that the Government consult with Not-for-Profit providers on workforce recruitment, retention and training.*

*21. The Productivity Commission's report highlight the likely need for the continuation of targeted block funding in order to provide specialised CALD and indigenous services.*

*22. The proposed NDIS apply a cultural competence approach as part of its design, implementation and monitoring processes, effectively setting a cultural competence standard for staff recruitment and training.*

## **12. IMPLEMENTATION (Chapter 17)**

In this draft report, the Commission has laid out a blueprint for a coherent response to the significant problems that bedevil the provision of disability support services. However the report acknowledges that while many people need help urgently, implementation cannot occur overnight.<sup>32</sup>

The Commission has adopted a cautious approach to implementation in view of:

- It involves two major new national programs on a scale much larger than the sum of all the current state-based disability and accident arrangements, so careful and detailed preparatory work will be needed.
- Different pathways and contingencies are possible and need to be planned for.
- No matter how careful the planning, the introduction of the NDIS, a wholly new and very complex scheme, will inevitably encounter some early difficulties.

The Commission has taken the view that these would be more manageable and less likely to be serious if the scheme started on a relatively small scale. ANGLICARE Sydney supports the cautious approach recommended by the Productivity Commission in the roll-out of the two large NDIS and NIS.

### **12.1 Targeted consultation and 'test bed' trials**

The Productivity Commission report foreshadows ongoing consultation with service providers and a trial of various aspects of the NDIS approach in a 'test bed' area of 10,000 people. Given the diverse nature of the Australian communities, including urban and rural differences and socio-economic differences, ANGLICARE Sydney recommends that consideration be given to more than one such trial.

As mentioned at the beginning of this submission, ANGLICARE Sydney is a significant provider of disability support services, particularly in Western Sydney. Western Sydney is home to large numbers of CALD people and people from lower socio-economic groups. We would request that we be included in any targeted consultations with the sector and believe that we would make a valuable contribution to ongoing development of the new system.

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<sup>32</sup> Productivity Commission (2011) *Disability Care and Support. Draft Inquiry Report, Volume 2*, Canberra, p17.1

In addition, we suggest that consideration be given to our clients in Western Sydney being considered as part of a 'test-bed' group for the new system. As a major provider in the area, ANGLICARE has the advantage of providing a number of layers of support service, often from the one location. This may be of assistance to people with a disability and their carers in seeking to put together a suite of supports, whether through a single provider or as part of the self-directed funding option.

#### ***Recommendations***

***22. Test bed trials be conducted in a number of different areas, reflecting different urban and rural and socio-economic contexts.***

***23. ANGLICARE Sydney's request to be part of ongoing consultations and test bed trial be noted.***

### **13. CONCLUSION**

Anglicare SYDNEY appreciates the opportunity to contribute to this national consultation and looks forward to the final report into disability care and support in Australia.

**Peter Kell**  
**Chief Executive Officer**  
**ANGLICARE Sydney**

## SUMMARY TABLE

### Endorsement by ANGLICARE Sydney of the Productivity Commission's Draft Report Recommendations\*

	Recommendations	Supported	Qualified support/ amendments needed	Issue
Who is the NDIS for?	3.1	X		
	3.2	X		
	3.3	X		
	3.4	X		
	3.5		X	Ease of movement between systems
	3.6	X		
	3.7	X		
Individualised Supports	4.1	X		
	4.2	X		
	4.3		X	More clarity around upfront contributions
	4.4	X		
	4.5	X		
	4.6	X		
Assessing care and support needs	5.1	X		
	5.2	X		
	5.3	X		
	5.4		X	Relationship of assessors to care recipients
	5.5	X		
	5.6	X		
	5.7	X		
	5.8	X		
	5.9	X		
Decision making power	6.1		X	Safeguards and accountability around 'cashing out' of individual budgets
	6.2	X		
	6.3	X		
	6.4	X		
	6.5		X	Discounting individual budget by 20%
	6.6		X	Information and



				formation of organisations
	6.7		X	Appeal mechanism needed
	6.8	X		
	6.9	X		
	6.10	X		
Governance of the NDIS	7.1	X		
	7.2	X		
	7.3	X		
	7.4	X		
	7.5	X		
	7.6	X		
	7.7	X		
	7.8	X		
	7.9	X		
	7.10	X		
	7.11	X		
	7.12	X		
	7.13	X		
Delivery of Disability Services	8.1	X		
	8.2	X		
	8.3	X		
Disability within the Indigenous community	9.1	X		
Collecting and using data	10.1	X		
	10.2	X		
	10.3	X		
	10.4	X		
Early intervention	11.1	X		
	11.2	X		
Financing the NDIS	12.1			
	12.2			
	12.3	X		
Workforce Issues	13.1	X		
	13.2	X		
	13.3	X		
	13.4	X		
National Injury Insurance Scheme	16.1			
	16.2			
	16.3			
	16.4			
	16.5			
Implementation	17.1	X		
	17.2	X		

	17.3	X		
	17.4	X		

\*excludes additional recommendations that are needed, as discussed within this submission.

## REFERENCES

ANGLICARE Sydney (2010) *Submission to the Inquiry into Disability Care and Support*, Submission prepared for the Productivity Commission, August 2010.

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