Carers ACT Australia

mental health community coalition ACT

KOOMARRI

ACT Mental Health Consumer Network

PRODUCTIVITY COMMISSION INQUIRY INTO A LONG-TERM DISABILITY CARE AND SUPPORT SCHEME

ACT COMMUNITY SECTOR COLLABORATIVE RESPONSE TO THE DRAFT REPORT

This submission represents the collective input of a number of ACT organisations, the clients they serve and other organisations in the community sector which were consulted in the development of this submission. This submission is not intended to replace others from community sector representatives or the individuals and families who access their services. Rather, it is intended to offer a shared voice and broad perspective from recognised leaders in the field of disability and related areas of the ACT community sector.

The Productivity Commission has highlighted a number of areas on which it is seeking feedback. We have attempted to address a number (but by no means all) of these issues. Additionally, we have highlighted a number of issues which the group believe require further consideration and/or clarification prior to finalising the Productivity Commission's report in July 2011 and/or before implementation of a National Disability Insurance Scheme. Should the Productivity Commission wish to discuss any aspects of this submission, this can be arranged by contacting Louise Gray, Director of ***Louise Gray Consulting Services***

Preliminary Comments:

- The Productivity Commission's findings are welcomed as an important recognition by government of the need for radical reform in how disability care and support is funded, managed and delivered.

- Additional, significant funding is essential if people with disability are to access the services and supports they need and if the people who care for them are to also have access to quality of life. It is therefore not surprising to see the Productivity Commission's recommendation of a doubling in existing funding levels. This is welcomed.

- Above all, implementation of the proposed scheme must ensure that no individual is worse off as a result of the new arrangements. The proposed model is heavily reliant on a system of assessment of individuals to determine their support needs and associated funding. Where a person is currently in receipt of an individual support package of funding, will they be reassessed? If that assessment deems their current funding level to be in excess of their entitlement under the new scheme, how will this be transitioned?

- We note that the Productivity Commission Inquiry is taking place in an environment of change and reform, particularly in the health, aged care and mental health sectors. The reforms being proposed are designed to create seamless service systems that will better meet the needs of the aged, people with disability, people with mental illness and their Carers. The recommendations of the Productivity Commission’s draft report must be considered in the context of, and be aligned with the significant concurrent reforms occurring in those sectors.

- The ACT population is relatively small when considered in the context of other State/Territory populations. When developing a formula for the allocation of funds under a National Disability Insurance Scheme, it is important that the ACT not be disadvantaged as a result of its size.

- The inclusion of the non-government sector in the development and implementation of any long-term disability care and support scheme is essential if the nature of the sector is to be understood and transitioned effectively into a new framework and the needs of people with disability and their Carers are to be met while maintaining a viable network of service provider options.

Chapter 3 - Who is the NDIS for?

The Intersection of the Aged and Disability Sectors

The Productivity Commission draft report: Inquiry into Caring of Older Australians offers an opportunity to ensure consistency and reduce duplication of effort through careful review of the recommendations of both that report and the Disability Care and Support draft report. It is also essential that the Productivity Commission take into consideration any Department of Health and Ageing reforms also currently under way.

The draft report proposes that the National Disability Insurance Scheme not cover people who acquire a disability after they reach pension age, proposing two possible approaches[1] to managing the interaction between the two disability and aged care systems.

After reaching the pension age, individuals with disability would be subject to the co-contribution arrangements set out in its parallel inquiry into aged care. As the Commission itself notes, this arrangement is unlikely, however, to be relevant to those who acquired a disability early in life as they would not have been in a position to accrue savings, property, household assets or superannuation due to a limited earning capacity over the working age period of their life.

Differences in the care philosophies, assessment tools and service planning mechanisms of the two sectors raise concerns about how these differences will be managed to ensure continuity and quality care for people with a disability as they age. Additionally, the two systems differ in how they are staffed, with the skills and experience base presenting potential challenges to a more directly linked approach. Staff of aged-care service organisations may not understand the needs of people with disabilities, especially if those needs are linked to a disability which is not related to ageing, e.g. intellectual disability or cerebral palsy. This may be compounded for those people with disability who have a higher risk of early onset of ageing related conditions, such as dementia, Down syndrome and some intellectual disabilities. Individuals with this type of disability may find themselves in a state of limbo in which no disability-specific support and no ageing-related service has the right mix of skills and supports to assist their participation in society and to maintain their quality of life.

The recent Home and Community Care (HACC) reforms stressed that clients would not notice a difference in their support but that the difference would lie simply in which level of government was covering the costs, with the age of 65 being the trigger for Federal government to step in. While it is early days in this area of reform, it presents an opportunity to consider how people with disability will fit within the various government structures which support disability, ageing, health, mental health, children

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[1] Regardless of the option ultimately implemented, the signatories to this submission support the option of applying a younger age threshold to Aboriginal and Torres Strait Islander people given their lower life expectancy.

and family services and the like. Issues arising from the implementation of the HACC reforms may serve as useful lessons for implementing the National Disability Insurance Scheme.

The Intersection of the Mental Health and Disability Sectors

Models of assessment should be based on individual need, rather than the seriousness or otherwise of the clinical diagnosis. This reduces the likelihood of someone with an illness generally considered “mild to moderate” such as depression or anxiety being excluded from the scheme despite having more complex social and community support needs. The draft report suggests eligibility for tier three individualised support would require a person to have a ‘permanent’ disability and have significant limitations in communication, mobility or self-care. In the UK, eligibility for social care is currently graded into four bands which describe the seriousness of risk to independence and well-being or other consequences if these are not addressed. Indicators of the highest band, critical, include where significant health problems have or will develop, vital involvement in work, education or learning cannot or will not be sustained, vital social support systems and relationships cannot or will not be sustained and vital family and other social roles cannot or will not be undertaken. The UK approach appears to be a more person centred and holistic approach that values the broader well-being of the person. [2]

The suggestion that the National Disability Insurance Scheme would not assist people living with mental health[3] conditions who did not require regular daily supports is concerning in its lack of detail and understanding of the needs of the many people living with mental illness in the community. It fails to address the high incidence of dual diagnosis whereby the mental health needs of people with disability often go undiagnosed and untreated and it ignores the very real support needs of people who suffer spectrum or cyclical disability as a result of mental illness. To fail to include these in a National Disability Insurance Scheme suggests that other cyclical conditions such as multiple sclerosis or spectrum disorders such as Autism and Aspergers would also not be covered.

The focus in the draft report on the medical treatment of mental illness is somewhat limiting. ACT mental health peaks support a social model of mental health that looks at the whole person, including their family situation, employment, living conditions and well being. The emphasis on categorising types of disability could be replaced with a focus on the impact the disability has on the life of the person, including their

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[2] *Prioritising need in the context of Putting People First: A Whole system approach to eligibility for social care*, UK Department of Health, 25 February 2010.

[3] The term psychosocial disability should be used when the mental illness significantly interferes with the performance of major life activities, such as learning, working and communicating. In the context of the National Disability Insurance Scheme, the use of the term psychosocial disability is preferred. Using this language makes it easier to understand where the boundaries could be drawn within the scheme – including the support needs of someone with a psychosocial disability, but excluding the clinical and medical treatment received through the health system.

opportunities for social inclusion, participation in employment, education and cultural activities.

Case Study:

Judith came to Australia with her parents when she was 17 years old. Her father was having difficulty finding work due to his limited English language skills. Her mother was feeling depressed due to the fact that she needed to live a long distance from her family. Judith was an active young girl who liked to play sports and meet with her friends however after her move to Australia she was diagnosed with depression. She is worried about her future in Australia and feeling lonely because of her mental illness. She does not want to further her education and has lost hope for the future. Judith often becomes aggressive towards people because she feels no one can understand her. Her father contacted Mental Health ACT and was able to find medical treatment for her depression. Her father also contacted a community worker that helps her to get around and be more involved in sporting activities and social gatherings. Unfortunately the community worker is only able to see Judith once each week due to high workload. Judith needs help to improve her social life and medication is no magic cure. The National Disability Insurance Scheme would help Judith to improve her social connections, improve her English, and look at future work options, as well as pick up social skills to adapt in Australia.

The mental health sector is not limited to medical services provided by psychologists, psychiatrists and social workers. In fact, the community managed mental health sector is moving away from a medical model of service delivery. The Mental Health Coordinating Council in NSW recently completed a project mapping the services provided by the community managed mental health sector.[4] This work demonstrated how the community managed mental health sector provides a wide range of services including accommodation and support, peer support, family support, counselling and outreach which are similar to the supports described in the draft Productivity Commission report.

Chapter 4 – What individualised supports will the NDIS provide?

Disability Support Pension Reform and Income Support Considerations

Access to financial support is a significant driver of choice and empowerment for people with disability. It is important that people with disability in receipt of Disability Support Pension maintain their access to funds to support their ongoing costs of living while also aligning with funding for direct care and support through the National Disability Insurance Scheme. To that end, it would be inappropriate to seek to blur the lines between service funding through the National Disability Insurance Scheme and income support funding through existing pension arrangements.

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[4] Mental Health Coordinating Council, *Sector Mapping Report* 2010, 33.

Carers have expressed concern about the Productivity Commission’s suggestion that the Carer Payment, Carer Supplement and Carer Allowance should be rolled into the scheme, noting that these payments are made direct to the Carer in recognition of the demands of their caring role and the fact that they are unable to support themselves through substantial paid employment. These payments are often a Carer’s only source of independent income.

Natural Supports

How decisions around individual support funding for children with disability will be made requires further clarification. While the expectation that parents and families will provide a significant amount of “natural” supports to their child with disability, the costs are often so significant that even a family with dual income and a relatively strong financial base will struggle to keep pace with them. A standardised funding model which looks at the assets and income of a family may not allow visibility of the often staggering costs associated with the costs of buying or converting the family home to cope with the needs of a child with disability. Nor do standard funding models allow for the changing needs of a child with disability and the financial costs borne by the family. Likewise, how this funding will change as the child becomes an adult and wishes to access a greater degree of independence is unclear.

The draft report addresses the challenges associated with employing family members as support workers when the tasks they perform may be reasonably expected to be given as natural support. The issue of employing family members as support workers as a general prospect is also discussed, although the employment of friends, neighbours and other less formalised relationships is not seen as having these same issues. Some clarification of the differences in this area is needed. Carers and support workers share many common roles, and cross-overs and challenges are likely to present as issues whenever the support worker has a second relationship with the person with disability, whatever this relationship might be. One option may be to pay the primary carer for at least a percentage of the support and care they provide with payment not to be restricted to friends, neighbours and other like relationships.

There are also some inherent risks and challenges associated with individuals managing their own funding to procure supports and services through informal networks. Not only does this place the individual at risk of accessing a service which does not meet the necessary standards, noting that the disability service industry does not currently require a minimum standard of education or qualification for its staff, but it also reduces the level of certainty which organisations require in order to plan effectively. With the cessation of block funding, disability service providers will lose the capability to base their forward development on a reasonably secure funding base.

Front-end deductible

The concept of co-payment and a front-end deductible is recognised as a proven method of encouraging only legitimate claims. However, where a person with disability is residing with and receiving care from another person or persons, some consideration to the capacity to pay up front costs should be given. It may be that, as with Health Care Card users, some groups of people may be given a waiver for up front fees as per the Medicare bulk billing model.

Chapter 5 - Assessing care and support needs

Assessment tools

Careful and appropriate assessment of the needs and preferences of individuals with disability and their Carers will also be critical. The first option would allow the aged care sector to use the National Disability Insurance Scheme assessment tools, which would avoid the duplication and repetition which comes with seeking to satisfy the requirements of different systems. People with Individual Support Packages who choose to transition from the disability system to the aged care system would no doubt require a level of commitment by government that their funding and support levels will be maintained following a shift from one sector to another. Without a single common assessment process, this may be challenging to implement.

Focus group discussions with families as part of the development of this submission indicated that there continues to be a degree of stigma attached to acknowledging that disability exists and any reliance upon government assistance to access the care which is required. People with disability and their Carers often under state the level of care and support they require. In some cultures, this is more prominent a feature than in others. It will therefore be important for the assessment toolbox to encompass in-depth consideration of the many aspects of the whole family and the diversity of their challenges, so that the assessment can be fair, equitable and robust.

Chapter 6 – Who has the decision-making power?

Giving people choice

Fundamental to the proposed scheme is the concept of individual choice, both in an individual's choice to manage their own Individual Support Package and the services they select. The scheme and how it is funded must take into consideration that, to support this choice, a range of services must be available. This means that analysis and appropriate support for the various different service models and providers will be required, including analysis of the capacity for those providers to operate in the context of no block funding.

A move to more flexible and individualised approaches to service delivery and funding requires an even greater commitment to provide independent support to decision-making for those people with disability who do not have the experience, knowledge and skills to operate as empowered consumers in an "open market". Access to advocacy services will ensure that all people with disability are informed, empowered and assisted to realise the full benefits of changed funding and service delivery arrangements but not all people with disability will require this support and, if they do, they may only require it at certain points.

Competitive pressure

A perennial issue for organisations which receive government funding for service provision is the need to balance effective market competition for work with a focus on collaboration and cooperation within the relevant sector. While competition drives efficiency, effectiveness and quality, it can also erode cooperation between service providers who may be reluctant to share best practice ideas lest they lead to loss of clients and associated funding. In a move towards individually based funding, this may become more of an issue as organisations focus on winning business. It would be useful if the proposed National Disability Insurance Agency could play a part in benchmarking, sharing best practice and encouraging or rewarding collaborative approaches.

Implementation of a scheme which will allow individuals to access the supports they need must not lose sight of the importance of a stable and sustainable service delivery network to provide those supports. While individual support funding models are currently in place, albeit not on a consistent or equitable basis, moving to a system based wholly on such a funding model may pose challenges to a viable service delivery network. In order to plan effectively, non-government service providers require medium to long term financial information to allow them to project demand, costs and investment in staffing and infrastructure. This is particularly important for not-for-profit entities which operate within tight financial constraints. If funded solely on the basis of individual support plans, there is potential for long-term financial certainty to be destabilised while the administrative costs of managing a large number of individual contracts is likely to add to the workload of many organisations.

The reconciliation of service sustainability with freedom of choice is no simple matter, and, while market influences will ensure that preferred providers remain viable simply through generating ongoing demand for their services, some smaller and more specialised providers will struggle to remain afloat. An example of the type of organisation which might require block funding might be those small, not for profit entities which provide education and one on one support to clients with a specific disability in the ACT (eg: autism, epilepsy etc). Staffed with perhaps two full time employees and largely focused on delivering services to educate schools, workplaces and the community, it is unlikely that such organisations will attract sufficient individualised funding to allow them to continue the full scope of their activities. This type of organisation will be faced with the decision to focus solely on one on one support services and the funding associated with that, amalgamation with other services to shore up infrastructure and base funding or simply closure.

Where the government is also the provider of services, it will be important that they be required to operate on an equal footing to non-government service providers. This includes across reporting, standards, client referrals and benchmarking. The independence of the proposed National Disability Insurance Agency will support this. Where the market either fails to respond to demand, or where that response is delayed, the need for government to balance this role with the capacity to fill service gaps will also be important. While the service provision role of government will place expectations on government to perform within a competitive market, where that market does not support the immediate needs of people with disability there must be some fall back to ensure that those needs do not go unmet. Government has the responsibility to do this.

Chapter 7 – Governance of the NDIS

From State/Territory to Federal Funding

Further clarification of how funding would be allocated across States/Territories and regions is important. While recognising that funding will effectively follow the need for services, and this will be based on the individuals with disability and where they are located, the existing model of funding has led to the establishment of jurisdictional differences which will need to be “normalised”. Whether the intergovernmental agreement referred to in the draft report could capture the responsibilities, impacts and actions necessary to ensure that the services themselves will continue to be available to people with disability is unclear.

A nationally consistent scheme is likely to benefit people with disability through increased portability of funding and an enhanced capacity to choose and purchase the services which best suit their needs. In those States/Territories with relatively small populations and/or regional and remote access challenges, it will be critical that the attribution of funds reflects the needs of all people with disability regardless of their location. Similarly, where States/Territories with strong economies have been able to invest more heavily in disability services through their own Budgets, it will be important to balance a fair and equitable national system with the not unreasonable State/Territory based focus on maintaining the existing level of resourcing. In New South Wales, significant funding has been injected into disability services in recent years. It will be important for other jurisdictions to be funded up rather than drawing the NSW investment down when seeking to achieve consistency across the nation.

The cost and availability of services will differ significantly according to State/Territory, with remote and regional areas limited in choice and subject to higher costs as a result of location. The economies of scale which are possible for some services in more populated areas will never be achieved by those services supporting people with disability in more isolated areas. It may, therefore, be challenging to balance how funding is allocated with ensuring the capacity of the sector to respond within existing parameters. Some early analysis of how this will be managed may be useful prior to determining the financial allocation process.

Chapter 8 - Delivering disability services

Red Tape Reduction

At present, the requirement to report to local, State/Territory and federal government in respect of different programmes and their associated funding schemes is time consuming, administratively burdensome and arguably of limited value. The need to capture a variety of different data can be seen as intrusive and duplicative by clients and their families and/or carers while also directing scarce resources away from direct service provision. In the ACT, work has commenced within the Department of Disability, Housing and Community Services to establish a pre-qualification regime which will reduce the impost on service providers regarding government procurement while their project to develop an outcomes based purchasing framework is designed to streamline reporting. Building on this type of project to develop a simpler, more meaningful procurement and reporting process for disability service provision will be supported by a single national agency and framework for disability funding and service access.

Establishment of consistent reporting, coordinated management of vacancies and a capacity to identify best practice is something which would be of benefit to disability service providers as well as to the clients they serve. The costs of ensuring that systems and processes are able to keep pace with this should not be underestimated, with many smaller organisations likely to struggle to implement significant change in data collection, management and exchange. In rolling out the scheme, it is important to adequately factor in the costs and time associated with key infrastructure projects such as this.

Chapter 11 – Early intervention

Children spend two thirds of their time at school and the education system is an obvious mechanism through which early interventions can make a sustainable difference. To maximise the amount of future savings through early intervention, early establishment of strong links between the National Disability Insurance Agency and the education system will be critical. This may present challenges as education is managed at the State/Territory level while the National Disability Insurance Scheme will be nationally focused. At a minimum, good communication channels will need to be developed so that the therapies provided by the education system and those funded by the National Disability Insurance Scheme are complementary.

The broad range of types of disability affecting children, when and how they are diagnosed and how that diagnosis translates into eligibility for services are access to service considerations where early intervention models under a National Disability Insurance Scheme may be strengthened. This is highlighted in the experiences of parents of children with rarer genetic diseases that are not widely understood or parents of children with periodic or spectrum disorders also face challenges with the various eligibility requirements for accessing support.

> *“'Eligibility' is a challenge to be overcome, requiring persistence, creativity and intellectual rigour.”* [5]

Unmet and Under-met Need – Vacancy Management

The needs of people with disability are not currently being met. In some cases, where people with disability are accessing some services, these services are either not meeting all needs or are not meeting needs in the most suitable way for the individuals. There is no common system on a State/Territory or national basis to a) capture information on the support needs of people with disability and b) map those needs against available services. A common vacancy management system would support the placement of people with disability with the service providers and service types which best meet their needs. This would also address the challenges faced by people with disability and their families/carers when seeking to access “the system”. A nationally consistent disability services scheme and associated process for matching people with disability with vacancies would be possible under the proposed model. Further, it would provide an opportunity to develop the disability services sector in a way which builds capacity to meet known need and projected future need. This would mean, for example, the assessment of future accommodation needs for people with disability could be more effectively planned for over time.

Chapter 17 - Implementation

Cost Shifting and Cross-portfolio Accountability

The requirements of people with disability cross many government portfolios. This has, perhaps, been a key contributing factor to the “maze” of information referred to in the draft report, which must be waded through in order to bring together the funding and services needed to meet all their needs. In the formative steps of establishing a National Disability Insurance Agency, and as the eligibility and assessment processes are refined, a mapping of existing service needs and access by people with disability across portfolios and levels of government may be useful.

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[5] Parent of a child with disability at a focus group hosted by Carers ACT.

With any government programme seeking to encompass such a broad area of need as disability, there is a risk of cost and responsibility shifting between portfolios, jurisdictions and, of course, budgets. This risk certainly exists when considering the links between the National Disability Insurance System and existing mental health services and programmes. People may continue to fall through the cracks. It is therefore important that parameters be clearly defined and understood to ensure that there is no unintended negative consequence for mental health services, including community based services that support people with mental illness and psychosocial disability. People with disabilities, including psychosocial disabilities need to be able to access integrated care and support across both sectors.

Assuming some people with psychosocial disability are included in the scheme, an important issue is the situation of people with mental illness or psychosocial disability who are ineligible for the scheme. Currently there are a wide range of services in the community providing support across the spectrum to people. Concentrated effort will be required to ensure a diverse range of services continue to be funded by State, Territory and the Commonwealth Government, outside of the scheme to meet the needs of these people.

Establishment Costs

Sufficient funding to establish and maintain the scheme itself will also be significant. The costs of rolling out such a scheme on a national basis, ensuring that there is sufficient information technology, infrastructure, staffing, overheads and associated support for the model will be high and this should be funded by government on a one off basis with ongoing running costs to be managed through effective funds management within the scheme itself. The importance of monitoring to ensure both quality of services and equity in access to funding suggest that an investment in establishing appropriate systems for these functions will be essential. This will lead to savings in the long term through the capacity to identify and share best practice and the ability to ensure that all claims on the scheme are legitimate and appropriate in funding level.

Representation

The proposed cross-government governance framework may benefit from the inclusion of non-government sector experts with experience in the disability arena. While the focus on experience in insurance and the reporting back to Heads of Treasuries is recognised as essential in developing such an ambitious funding model, the development and planning stage would undoubtedly benefit from the input of represents from the non-government sector who have worked within the existing funding framework and would be well placed to discuss service impacts and other real-life considerations for people with disability and the services which support them.