ANGLICARE
in every Community AUSTRALIA

Submission to the

Productivity Commission Inquiry into a National Disability Long-term Care and Support Scheme

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Contents

Executive Summary

The Productivity Commission inquiry into the feasibility of a National Disability Long-term Care and Support Scheme is a welcome opportunity to demonstrate to Government the breadth of knowledge and experience existing in the sector and the degree to which such a diverse group of organisations, such as those in the Anglicare Australia network, agree that it is time for change.

The disability support sector is as diverse as it is large. With over three million people in Australia experiencing disability many of those are accessing services for a variety of needs. And yet, the disability support sector is developing along with the needs of the clients they serve, as a result, it has been noted that the system supporting the sector has remained static.

In a new system designed to care for the long-term needs of people experiencing disability and the people who care for and support them, Anglicare agencies would like to see a philosophy adopted that has the client as central to all matters that arise concerning their care and support. In this way, care and support plans and funding packages are tailored to meet their particular needs ensuring that care is more effective. In addition to an individualised approach to care, Anglicare agencies agree that the system supporting the provision of care must be as flexible as possible, increasing the ability of workers and informal carers to access the type of care required without being restricted by the limitations of the system. Likewise in regard to choice; people experiencing disability are equals in society and should be treated as such. This includes options for care and the ability to engage in the determination of their own care arrangements. It is these three principles –

individualised approach ***flexibility*** ***choice***

- that are the foundations of a long-term care and support plan that is considered feasible by Anglicare agencies.

The high level of agreement which Anglicare agencies experienced in the founding principles of a care and support scheme extended also to the areas where constructive targeted change could have the greatest effect on the disability support sector. For some time services have adopted needs-based approaches to care recognising, importantly, that not all needs are the same. Need exists in a context which is influenced by factors unique to the individual. Anglicare agencies suggest that this type of approach to service delivery, especially in the areas of diagnosis and assessment, can greatly improve the efficacy of care and support arrangements.

Funding is another area where fundamental reform is required to adopt modern principles of service delivery and best practice. The Government's own research has pointed to the benefits of individualised funding and as such funding models should be explored that adopt needs-based, individualised processes. Any scheme is going to be an expensive venture for funding bodies however funding that supports the sector to deliver services that meet the needs of clients will in the long run produce its own savings in met need, reduction of duplication and potentially a reduction in demand.

Quality staffing and workforce planning was an area of great concern for Anglicare agencies when considering the long-term viability of the sector. It was observed that the disability workforce is an ageing workforce with little recruiting of younger workers. Investment is required in the satisfaction and motivation for disability sector employees as the love of the job can only sustain staff for so long. Human capital is the core infrastructure of the disability support sector and is in need of attention.

Research and development is the final principle area of effect for reforming the disability support sector to enable it to efficiently and effectively develop information on which to

improve practice. Research and its translation can have huge impacts on the way that systems run and the methods in which care and support are provided. Investment in this area has the potential to increase the efficacy of service delivery which has other potential positive flow on effects.

Primary recommendations, outlined below, have been made based on the consultations with the Anglicare Australia. Further, more detailed recommendations can be found in Appendix 1 along with a comprehensive report from Anglicare Australia's consultations and again at Appendix Two in a consolidated list of recommendations.

Recommendation 1: That needs-based methodologies be applied to new and existing services with the view to reforming systems to respond to client need.

With further consideration of:

a. the efficacy of diagnosis and assessment procedures for determining need in the context of a client-centred, needs-based methodology;

b. the contribution of disability support staff to the assessment process.

Recommendation 2: That an in-depth analysis of potential funding models is undertaken based on pre-determined operational frameworks, with a view to establishing a nationally consistent Disability Funding Programme.

With further consideration of:

a. disability support funding models being responsive to client need particularly taking in to account remoteness and complexity of need;

b. the principles of flexibility, individualised support and client choice;

c. administrative consistency across jurisdictions and service types.

Recommendation 3: That workforce planning and management are considered as integral to the establishment of a viable long-term care and support scheme and are included in planning and implementation of the scheme.

With further consideration of:

a. possible partnerships between government providers and the sector to improve disability sector workforce issues.

Recommendation 4: That a dedicated research and development stream be considered as integral to the feasibility of a long-term care and support scheme.

With further consideration of:

a. management of the research and development stream to be housed within the Australian Institute of Health and Welfare.

Introduction

The National Disability Agreement (NDA) and the draft National Disability Strategy (dNDS) are excellent starting points for the National Disability Long-term Care and Support Scheme (the Scheme). These documents demonstrate the goodwill that exists in Government to ensure that people living with a disability enjoy quality lives to the standard of their expectation and can participate fully as citizens of Australia. Goodwill, however, does not always translate into effective, quality systems that meet their stated objectives.

> *Governments recognise that achieving improved outcomes for people with disability their families and their carers is contingent upon the effective coordination of efforts across government services*[1]

The inquiry into the Scheme is a welcome opportunity to outline very clearly the type of reform needed to ensure that people living with a disability and those who care for a person with a disability can live a full life with dignity. It is the type of action required to see the good will of both the Government and the Disability support sector come to fruition.

Former Prime Minister Rudd expounded that the *Australian Government believes that we need to rethink how we support people with disability and identify what new approaches are needed* and that this change will be a *transformative change to the disability service system - how it is delivered, funded and administered*.[2]

This is an exciting and pivotal step towards generating real change for a group of people who have been continuously overlooked or relegated to the shadows. It is as Mr Rudd named it- historical social reform, the outcomes of which, whether positive or negative, may affect people with a disability for some time to come.

Anglicare Australia is the peak body for a national network of locally based Anglican care organisations serving the needs of disadvantaged Australians and their communities. The Anglicare network provides a wide range of services to people in need; and works to address issues of injustice across the nation. In 2009-10 Anglicare agencies served over 615,000 clients in rural, remote, regional and urban communities using the services of 13,000 staff and nearly 13,000 volunteers and spending over $886 million. Anglicare Australia seeks to influence social and economic policy to advocate for a society where the contribution, dignity and participation of everyone are equally valued.

Anglicare Australia makes this submission on the basis that it is advocating on behalf of all people living with a disability and for the people who care for and support them. The comments contained herein are based on the observed and researched experiences of Anglicare staff and clients and *aim to provide practical information for the use of the Productivity Commission in its assessment of the feasibility of a National Long-term Care and Support Scheme for carers and people living with a disability*. Anglicare Australia would like to acknowledge all the network members who contributed to the development of this paper.

This paper is the culmination of extensive consultations with the Anglicare Australia network (Appendix 4). This main section covers the major themes and actions arising from those consultations whilst at Appendix 1 a detailed report on the outcomes of consultations can be found. Throughout the body of the submission references will be made to the consultations undertaken and directions given to the appropriate/supporting section of the consultation report.

[1] Council of Australian Governments. 2009. *National Disability Agreement*. Canberra. Clause 12, p 4.
[2] Rudd, K. 2009. *Prime Minister's Speech 23rd November at National Disability Awards*

Item 26 of the NDA states that the parties agree to make a priority for initial efforts:[3]

- Better Measurement of Need
- Making Older Carers a Priority
- Service Planning and Strategies to Simplify Access
- Increased Workforce Capacity
- Quality Improvement Systems based on Disability Standards
- Population Benchmarking for Disability Services
- Increased Access for Indigenous Australians
- Access to Aids and Equipment
- Improved Access to Disability Care
- Early Intervention and Prevention, Lifelong Planning and Increasing Independence and Social Participation Strategies

Many of these same objectives arose in the consultations with the 19 Anglicare network agencies that provide services to nearly 5000 clients with almost 100,000 per annum client contacts across the country. The sector is aware that change is occurring, from developments in respective states and territories to the rhetoric that comes from the top levels of Government. Yet, change has been slow to filter through to the systems that operate on the ground. The disconnect between the rhetoric and reality is still great with stories such as individuals not receiving a service because they are on the 'wrong' side of an arbitrary line despite it being the choice of the client to use that service due to preference and proximity; such as adapting aged care assessment tools to work with children; or families feeling trapped and isolated because they are unable to receive the support that they need.

As the changes from the NDA and dNDS and indeed any changes that come from this inquiry filter through, Anglicare Australia on behalf of its member agencies recommends that the Commission consider as integral to its assessment of the feasibility of a national long-term care and support scheme the foundational principles of *flexibility*, *individualised approach* and *client choice* and the core issues: *client need*; *appropriate funding models*; *research and development*; and *workforce planning*.

[3] Council of Australian Governments. 2009. *National Disability Agreement*. Canberra. p 8

Principles

Many frameworks, strategies, policies and initiatives are now being produced with stated principles; a positive step in the right direction. The stated principles inform the audience of the values and basic beliefs or premises on which the initiative is based. The National Male Health Policy and the proposed National Women's Health Policy adopted principles of equity, prevention, needs across the life-course, targeting those most disadvantaged and an evidence base.[4] The Framework for Protecting Australia's Children has adopted a human rights focused set of principles including the right to grow up healthy, to be involved in decisions, to be protected by those around you, to be supported by systems and institutions and that policies and interventions are evidenced based.[5] The draft National Disability Strategy as proposed by the Gillard Government takes a human rights approach having adopted the principles as delineated in Article 3 of the Convention on the Rights of Persons with Disabilities.[6]

Throughout our consultations three value statements were repeated frequently when discussing the disability support sector and working with people within it. These were that systems should be ***flexible*** enough to adapt to situations and clients; that the client should be the ***centre of care*** and support and finally- that the client has a ***choice*** and agency in determining their own care.

Flexibility

Flexibility, as a guiding principle for a long-term care and support system, rests on the capacity to work to create the desired outcome rather than the outcome being determined by the system. In a dynamic service sector where the needs of clients can vary from case to case; options must be available to workers and informal carers to provide or obtain the care required by the person experiencing disability and not be confined by the limitations of the system.

Individual approach

An individualised approach calls for the client to be the core consideration in all matters with a genuine commitment for meeting their individual needs. This is a foundational principle having great impact on the types of systems developed for a long-term care and support scheme. Individualised support not only recognises the contribution people can make to their own care acknowledging that it can differ over time but also values that contribution. It also recognises that people experiencing disability are deserving of their dignity and of our respect.

Choice

Following on from the recognition of the contribution people make to their own care and the respect owing to them as equals in society, options must be provided in this sector just as in mainstream society. The provision of options for people living with disability and the people who care for them is a demonstration of the extent to which they, too, are considered as part of the citizenry. It is not enough to provide one option and expect it to be acceptable. The provision of choice creates opportunities for people living with disability to take control of their care, engage on an equal footing and experience the benefits of participation.

[4] Department of Health and Ageing. 2010. *National Male Health Policy*. DOHA: Canberra
[5] Department of Families, Housing, Community Services and Indigenous Affairs. 2009. *National Framework for Protecting Australia's Children*. FaHCSIA: Canberra.
[6] Australian Labor Party. 2010. Draft National Disability Strategy.

Principle Areas of Effect

This section covers Anglicare agencies perceptions of the main areas where change and improvement are needed for a long-term care and support scheme for people living with disability to be viable. The outcomes of consultations Anglicare Australia undertook with its member organisations can be found at Appendix One.

Client Need

Identifying need is a basic premise to most large scale projects. In fact, many organisations would not embark on an expensive project if in the first instance, the need was not articulated and the response to address that need, outlined. The National Disability Care and Support Scheme is one such large scale project. It has the potential to affect millions of people in Australia who are, care for or have contact with a person living with disability.[7] Over three million people have been identified to have limitations in core activities of mobility, self-care and communication and of these over one million have profound and severe limitations.[8] This is a large proportion of the Australian population who rely on the Australian Government to ensure that the supports required to assist them to become fully participatory in society are not overlooked.

Consultations with the Anglicare Australia network reinforce the notion that need is affected by the contexts and circumstances of an individual's existence.[9] Each person's life abounds with aspects, attributed with personal meaning, which positively and negatively influence the quality of that life. In attempting to effect change for improving the quality of life, decisions are made within and are influenced by those aspects. The impetus for the change is often a noted discrepancy between a person's current and desired experience. Usually, this gap or discrepancy is described as a '*need*'.[10]

Throughout the social policy and justice histories needs have played an integral role for the planning and development of policy and program responses. However over the course of those histories there has never really been a consensus on what needs are and there is even more contention over the derivation of particular types of needs.[11] Petersen argues that to validate need, it should be endorsed through open discussion with final consensus on needs which are '*so important, unmet or sufficiently reoccurring that action is warranted'*.[12] Distinctions in need have been made however and responding from a strengths-based, capacity building framework it is the contention of Anglicare Australia that consumers and providers of health and social services are well aware of their needs within their own contexts and given the opportunity to express them are well able to articulate need without hesitation. This submission is a case in point.

For the purposes of a conceptual framework the needs identified by Bradshaw[13], particularly *perceived* and *normative* needs resonate most closely with the types of need identified by Anglicare Australia network members. Perceived need and normative need are concepts that differentiate between what people have decided for themselves they need (perceived) and their observed needs from external parties such as government for instance (normative). Focussing on perceived, expressed needs allows support workers and informal carers to target support strategies to the direct requirements of the client and support them in place

[7] Australian Bureau of Statistics. 2004. *Disability, Ageing and Carers: Summary of Findings Australia*. Canberra. Cat 4430.0

[8] Australian Bureau of Statistics. 2004. *Disability, Ageing and Carers: Summary of Findings Australia*. Canberra. Cat 4430.0

[9] See Appendix 1 Section 1.1.3 Individualised Life-course Approach

[10] Kaufman, R., & English, F. W. (1979). *Needs assessment: Concept and application*.

[11] Asadi-Lari M, Packham C, & Gray D. Need for redefining needs. *Health Quality Life Outcomes.* 2003;1:34.

[12] Petersen, D. & Alexander G. 2001. *Needs Assessment in the Public Health: a practical guide for students and professionals*. New York: Kluwer Academic Publishers; 2001.

[13] Bradshaw, J. 1972. The Concept of Social Need. *New Society*. 496:640-643

and in context. Whilst keeping informed of normative need, ie those needs that have been identified through the assessment of population studies, observed trends and amalgamated anecdotal and empirical evidence, workers are able to inform their practices on the micro scale by being aware of what is happening on the macro. This kind of work has paved the way to develop strategies that get to the heart of an individual's life requirements by providing evidenced based quality responses to individual need. By extension, this type of practice will allow a system such as the proposed National Care and Support Scheme to respond to the delicate and specialised needs of eligible participants while managing the broader context of disability in Australia. (viz: Through harnessing the wealth of knowledge and experience in the sector and underpinning it with support structures based on evidence.)[14]

Having identified that needs are different and that one context or situation does not necessarily reflect the other, the concept of policies for the masses or a 'one size fits all' approach to support or service delivery - especially considering the change in need and circumstance over the progression through life stages and developmental milestones, for example day care to a school environment - is not congruent with the individualised need of clients. In such situations a *'systematic procedure for setting priorities and making decisions about allocation of … resources*' is then required.[15] This brings the discussion to how to identify need and the resources that should be applied to meet it.

Need in relation to Diagnosis and Assessment

Consultations with the Anglicare Australia network indicate that much work is required in the areas of assessment and diagnosis.[16] As with many aspects of disability and with life, the core elements contributing and attributed to it are inter-connected and dynamic, each having its own effect on outcomes. Assessment and diagnosis are major aspects of providing care and support to people living with disability as it is these that later determine the level and extent of care that will be provided to any one individual. Anecdotally, diagnosis and assessment processes have in the past pigeon-holed clients into strata of severity and extent of care. What does this say of the value placed on the client's own understanding of their care requirements and by extension the specific nature of those requirements?

Overwhelmingly agencies are moving toward a strengths based approach to care; building capacity of those who interact with community services. They are making a shift away from the welfare model and, to employ a well used phrase, *to give people a hand up rather than a hand out*. The basic premise of this approach – and this relates to more than just the disability sector – is to work with clients, to empower, build resilience and capacity in their given context or situation, which is often termed "in place". Again this goes to the heart of client-centred practice or a needs-based approach which empowers the client to determine their own life outcomes, to enjoy the fruits of modern society, be counted among the many rather than the few and as the social inclusion agenda stipulates, have their voice heard.[17]

Much of this discussion is not new. Options and advice have been provided to Government on several occasions on ways to manage the disability support sector, in particular, supporting people with a disability in a manner that is acceptable to their sense of dignity and quality of life. Fortunately, on this occasion the current inquiry with its broad terms of reference, is sandwiched between a relatively new Intergovernmental Agreement on a national approach to disability and the proposed National Disability Strategy. The outcomes of this particular inquiry then are almost certain to lay the ground for real wide ranging reform, making its investigation into needs assessment methodologies particularly important

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[14] See Appendix 1, sections 1.1.4 *Sustainable Services*, 1.4.1 *Cohesion and Opportunity* and 1.14.2 *Staff*

[15] Witkin, B. R. (1984). *Assessing needs in educational and social programs.* San Francisco: Jossey-Bass. Cited in Young, G.L. *1994.* Needs Assessment in Program Planning. *College Quarterly Winter.* Volume 2 Number 2 p. 35

[16] See Appendix 1, sections 1.1.2 *Assessment and measuring* and 1.8.1 *Assessment*

[17] Department of the Prime Minister and Cabinet. 2009. *A Stronger, Fairer Australia: National Statement on Social Inclusion*. PM&C: Canberra

Many people with a disability, their families and informal support networks rely on the services provided by governments through community services. Most studies put people with a disability in the lower spectrum of all scales: income, employment, education, housing and so on.[18] With potentially over 40 per cent of people not receiving the level of support they say they need[19], pressure on services and demand on the government budget is only going to increase. As an entrée into the disability sector, efficacious diagnosis and assessment tools and procedures in collaboration with other operational supports have a huge role to play in easing the burden of care on an over-extended, ageing system. Reshaping the edges however, cannot achieve the desired outcomes; it is going to require genuine commitment and large investment to develop the appropriate tools that will allow early diagnosis of conditions or for individual need to be identified through assessment, thereby allowing effective care and support, targeting of resources, minimisation of duplication and extraneous expenses, ultimately providing savings in due course.

Disability support workers have much to add by way of assessment and diagnosis. Working in the field affords them insight and experience to the manifestations and responses to disabling conditions, not to mention the formal training they have received. When discussing tailoring assessment and diagnosis procedures to the needs of the individual client it seems reasonable and logical to include those professionals and informal supporters who work and will work with the client on a regular basis. Disability support workers have expertise in the area of disability support and as such can add value to the process by providing advice and recommendations on operationalising or better yet, humanising, assessments bringing them out of the clinical setting and into the life of the client.

It follows that a national scheme aiming to provide long-term care and support to people with disability and the people who care for and support them should adopt best practice principles not only in business but also in the social justice principles of the sector in which it operates. Client-centred, needs-based, and individualised approaches all focus on tailoring the service to the client and have the client, where possible, drive their own care and support. These practices are the closest we have come to respecting the rights of the individual and valuing their contribution.

Recommendation 1: That needs-based methodologies be applied to new and existing services with the view to reforming systems to respond to client need.

With further consideration of:

a. the efficacy of diagnosis and assessment procedures for determining need in the context of a client-centred, needs-based methodology;

b. the contribution of disability support staff to the assessment process.

[18] Australian Institute of Health and Welfare. 2009. *Australia's welfare 2009*. Australia's welfare series no. 9. Cat. no. AUS 117. Canberra: AIHW.

[19] COAG Reform Council. 2010. *National Disability Agreement: Baseline Performance Report for 2008-09*. COAG Reform Council: Sydney.

Appropriate funding

In 1999 the Department of Family and Community Services commissioned a report into the application of a Case Based funding model[20] to disability employment services. The report advocated for funding models to promote, *inter alia*, flexibility, viability, effectiveness, collaboration and suitability for the client's given context. For some time the Government has been aware of the benefits that can be had from identifying strategies that are founded on the specific needs of the individual. After several years of trials, it was found that case based funding improved the long term outcomes for people who have their individualised needs met.[21] Most recently, in 2010, the Department (FaHCSIA) has reported on the benefits of an individualised funding approach. In this latest report, for people living with disability, individualised funding had '*improved their control, choice, independence and self-determination in their lives.*'[22]

The sector is calling for a review of current funding models for them to catch up to the standards that are being practiced in the field and which are being highlighted by the Government's own research. The AIHW in 2003 when assessing the effectiveness of funding unmet need identified that:

> *Flexible services geared to individual needs, often involving individual funding packages, are undoubtedly appreciated in the community. Further, the processes established in some jurisdictions to allocate this funding seem to have been successful in distributing new funding* ***perhaps further and wider than otherwise****. Flexibility, even within the individualised funding approaches, was valued; as one participant emphasised—'one size does not fit all'.*[23]

Funding in relation to service delivery

Funding is at the core of services provided in the community. Irrespective of who controls funding, be it managed through a service or directly by the individual or family who is experiencing disability and irrespective of the entity providing the funding – government, community organisation or indeed through self-funding – the specific services funded to provide support to people living with disability have a direct link to outcomes.

The AIHW recorded in 2003 the dissatisfaction within the sector at the removal of transport[24], a common part of service delivery, from funding packages and attributing it as an 'extra' support service; the cost of which was not subsidised. The intervening years have provided evidence enough for the unmitigated error in judgement that this evidently was. Clients are now making tradeoffs between social engagement and participation – not to mention access to health professionals – and other health and wellbeing needs as one can often come at the cost of the other without a service as fundamental as transport.

The consideration of issues that seem to be viewed by government as extraneous, but which can, in reality, determine the outcomes of care and support, is essential to reforming or even improving the disability support sector. Issues include (but are not limited to) transport, as mentioned, behaviours of concern, co-morbidity and dual-diagnosis and the remoteness of the client's residence. For example, in 2003 about half of all people experiencing disability actually experienced two or more types of disability. Further, the number of long-term health conditions experienced by one person increased as the number of their conditions increased;

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[20] Rural and remote disability employment funding model

[21] Department of Education, Employment and Workplace Relations. 2007. *Disability Employment Network Case Based Funding Model Evaluation Report*. DEEWR: Canberra

[22] Fisher, K.R., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., Laragy, C., D'aegher, L. & Thompson, D. 2010. *Effectiveness of individual funding approaches for disability support*. Occasional Paper 29: pg viii. Social Policy Research Centre, Disability Studies and Research Centre: University of New South Wales

[23] Australian Institute of Health and Welfare (AIHW) 2002. *Unmet need for disability services: Effectiveness of funding and remaining shortfall*. Cat. no. DIS 26. Canberra: AIHW.

[24] Australian Institute of Health and Welfare (AIHW) 2002. *Unmet need for disability services: Effectiveness of funding and remaining shortfall*. Cat. no. DIS 26. Canberra: AIHW.

in some cases over six long-term health conditions were experienced by people with five or more disabilities. Moreover, and perhaps logically, the more conditions experienced by one individual, the more likely it was that they would need help with 'core' daily activities of self-care, mobility and communication. The combination of particular disabilities had more marked effects on people's activity, participation in major life areas and related need for assistance.[25] This type of scenario could directly affect upwards of two million people in Australia, and countless others who care for and support them.

It doesn't take much to demonstrate the scale or complexity of cases that occur right across the country. Anglicare Australia is not advocating for a funding system which matches the disability sector in complexity but one which supports it and allows it to operate dynamically, catering to the needs of those it means to support. A funding programme developed for the Scheme should not dictate how services are run, nor rule out appropriate services by proscribing specific types of equipment or locations. It should be supportive of the types of services needed by clients and responsive enough to allow agencies to provide those services required by their clients.

Strategies coming from the Anglicare Australia consultations include assessment triggers for remoteness and complexity of need attracting additional funding support packages; support provided in hours rather than in dollars; extension of the individual funding package across the board with mechanisms in place to monitor capabilities of families and individuals to manage; brokerage etc.

Adopting models such as funded support hours or brokerage as methods of delivering or obtaining services, as suggested by Anglicare agencies, reflects the principles laid out earlier of flexibility, client-centred service and choice. Funded hours allows the client to be assured of services over time without a gradual decline in real value, thus ensuring that they have continued choice over the duration of their funding period to allocate those hours as they or their supports see as appropriate. Brokerage is oriented toward the needs of the client through establishing independent mediation between the client and the service; sourcing the best outcomes for the client whilst protecting their interests. Rather than setting themselves up against services, brokers are able to work with services in the best interests of their clients to negotiate the best possible outcomes for the most efficient expenditure of the funds.

There are countless models that the Scheme could adopt and it will take an in-depth analysis of options based on a pre-determined operational framework (that is to say, funding reflects the service delivery rather than service delivery being bound by the funding) to settle on any one or several of these options. However the Commission chooses to assess funding feasibility it needs to keep in mind that people who experience disability are not all the same nor are their needs or the contexts in which care and support are provided.[26] May the Commission also be reminded of the very real cost of unmet need when making its recommendations to government on funding models for a long-term care and support scheme.

Recommendation 2: That an in-depth analysis of potential funding models is undertaken based on pre-determined operational frameworks, with a view to establishing a nationally consistent Disability Funding Programme.

With further consideration of:

a. disability support funding models being responsive to client need particularly taking in to account remoteness and complexity of need;

b. the principles of flexibility, individualised support and client choice;

c. administrative consistency across jurisdictions and service types.

[25] Australian Institute of Health and Welfare. 2009. *Disability in Australia: multiple disabilities and need for assistance*. Disability series. Cat. no. DIS 55. Canberra: AIHW.

[26] Australian Institute of Health and Welfare. 2009. *Australia's welfare 2009*. Australia's welfare series no. 9. Cat. no. AUS 117. Canberra: AIHW.

Quality Staffing and Workforce Issues

Human capital is the core infrastructure of service systems. Business management theory states that satisfaction with the work they carry out and the purpose of that work are two of the major components to retaining a productive workforce.[27] Adopting the concept of motivators to attract and retain staff the Anglicare Australia consultations uncovered quite specific examples of actions that can be taken to improve the disability workforce issue.[28]

Work force planning and management is a system wide approach requiring consideration of the whole whilst addressing individual parts. There are quite clearly articulated internal and external factors that contribute to the motivation, satisfaction and productivity of staff[29], which, though applied locally can be useful in consideration of the bigger picture. Elements such as pay, working conditions, inter-hierarchy relations, organisational policy and job security all relate to job satisfaction which according to theory, will dictate a person's level of satisfaction with their work, but will not motivate them to perform to a higher standard. Elements such as responsibility, recognition, possibility of growth or advancement and indeed the work itself can all be highly motivating, leading people to work harder, perform better and often, when motivation is high, under poorer conditions.[30]

It is possible that Government has un-wittingly, or otherwise, taken advantage of the goodwill that exists in the disability support sector. Workers in this sector are prepared to and have put up with a great deal because of the love they have of the job and their capacity to care. An anecdote from South Australia: one government official, when confronted with the gravity of attempting to run services with decreased staffing levels told a disability support worker to 'try not to care so much', when this is in fact what has been keeping the disability support sector going for many years.

It is necessary, in order to safeguard the ongoing engagement of the sector, for a care and support system, which aims for long-term viability, to adopt strategies promoting workforce satisfaction with their working conditions and ensures that avenues for growth are present to maintain high levels of motivation. For example, many of the comments from the Anglicare consultations centred on job security in the first instance with some workers working for two to three agencies (satisfaction influencer), to career pathways and advancement (motivator). The sector as it is currently structured is unable to provide guaranteed pathways for young workers into higher responsibility or recognisable positions.

It is not the objective of any community organisation to run at a profit. Nor is it their objective to survive for their own sake. Long-term viability of independent services and even of services as part of larger well-resourced organisations, for the sake of the clients who access those services, will be dependent on the sector's ability, with great assistance from government bodies, to ensure that workforce planning and management are high on the Scheme's quality agenda[31] and are made a consideration of the NDA and dNDS. It is a common interest of both the disability sector and governments to address these workforce issues as the sector is reliant on its human capital for long-term viability.

> *Close to 11,000 outlets delivered CSTDA-funded services in 2007–08—an increase of almost one-quarter since 2003–04…In 2007–08, three-quarters of outlets were classified as non-government, and one-quarter government. State/territory governments operated most government outlets (2,380 of 2,664, 89%), while most non-government outlets were income tax exempt charities (5,841 of 8,169, 72%).*

[27] Herzberg, F., Mausner, B. & Snyderman, B. 1959. *The motivation to work*. New York: John Wiley & Sons
[28] See Appendix 1, section 1.14.2 *Staff*
[29] Tosi, H.L., Mero, N.P. & Rizzo, J.R. 2000. *Managing organizational behavior*. Blackwell Publishers
[30] Tosi, H.L., Mero, N.P. & Rizzo, J.R. 2000. *Managing organizational behavior*. Blackwell Publishers
[31] See Appendix 1, sections 1.7.3 *Quality* and 1.14.3 *Quality in practice*

The proportion of service type outlets classified as non-government has remained stable since 2003–04.[32]

Recommendation 3: That workforce planning and management are considered as integral to the establishment of a viable long-term care and support scheme to be included in planning and implementation of the scheme.

With further consideration of:

a. possible partnerships between government providers and the sector to improve disability sector workforce issues.

Research and Development

The remit of the AIHW is to provide information on Australia's health and welfare, through statistics and data development that inform discussion and decisions on policy and services.[33] Given the scope of this role and its already substantial work programme relating to disability it seems a logical choice to manage a dedicated research stream attributed to the long-term national care and support scheme.

Consultations with the Anglicare Australia network identified the lack of inductive research and equally important, research translation, in the field of disability.[34] A legacy of the Rudd Government is an intense focus on evidentiary support for policy and program decisions. In terms of service delivery this has meant increased attention on efficacy, applicability or relevance of solutions to policy problems and a greater focus on best practice. But before research findings can be used to determine policy or change behaviour it must be translated in a way that is accessible to the people who are going to use it.[35]

Research contributes to the evidence base on which decisions should be made and tested. However, evidence that research provides is not the only criteria considered when weighing the benefits of a particular solution against the costs. Research and its translation for application can improve service delivery, thereby contributing to its efficiency and cost effectiveness. Furnishing all stakeholders - Government, service deliverers, informal support networks – with the relevant knowledge and ensuring that knowledge is accessible can, in the first instance, target services to those who will benefit most from them and second develop services which will return the greatest effect. It is reasonable to expect that in doing so the sector would engage in continuous improvement processes resulting in reductions in service usage and demand; not to mention other incidental efficiencies such as minimising duplication, increasing resource leverage, growing capacity for quality improvement including reporting and evaluation, and minimising unmet need.

Recommendation 4: That a dedicated research and development stream be considered as integral to the feasibility of a long-term care and support scheme.

With further consideration of:

a. management of the research and development stream to be housed within the Australian Institute of Health and Welfare.

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[32] Australian Institute of Health and Welfare 2009. *Disability support services 2007–08: national data on services provided under the Commonwealth State/Territory Disability Agreement*. Disability series. Cat. no. DIS 56.Canberra: AIHW.

[33] AIHW. 2010. 'About us' accessed August 2010 from http://www.aihw.gov.au/aboutus/index.cfm

[34] See Appendix 1, sections ??? and ????

[35] Population Reference Bureau. 2010. 'Research best practice: Translation and dissemination'. Accessed August 2010 from http://www.prb.org/Journalists/Webcasts/2008/dissemination.aspx.

Conclusion

Throughout this submission strategies and examples have been provided that could go some way to establishing a disability support scheme which is responsive to the needs of people living with a disability and the people who care for and support them. Words have been used in the description of these strategies such as individualised support; client-focused; flexibility; integration; mainstreaming; viability; quality; choice etc

Whatever new scheme is recommended by the Commission or adopted by Government, if any, these are the values and principles that should guide its development. Any system guided by a philosophy which holds these values as primary will see its way clear to providing a care and support system that can be valued by people with a disability and their carers and can be considered with pride by the men and women who work within it.

Appendix 1: Anglicare Australia Consultation Report

Introduction

This section covers the detailed discussion held regarding the feasibility of a system that cares for and supports people living with a disability for the long-term and which also supports carers. It covers the kind of values and structures that Anglicare agencies believe to be necessary for building such a system and for it to be effective. Many of the issues are repeated under several of the key questions from the Commission indicating the intricacies and extensive connectivity of the sector.

The terms of reference for the Productivity Commission indicate clearly the separate components of the scheme that are to be assessed. Anglicare Australia has distinguished these components to focus on Design, questions one to 10; Administration and Governance, questions 11 and 12; Costs and Financing, questions 13 and 14; and Implementation and Transition, question 15. The consultations and this paper have been structured to reflect these components.

Design

The following comments relate to the design of the Disability Support Scheme and the aspects which relate to content and practice.

1.1 Focus and identification

Who should be the key focus and how they may be practically and reliably identified?

An effective service and support system which adopts principles of inclusion and person-centred care would include all persons experiencing disability regardless of acquisition.

1.1.1 Inclusivity

The purpose of the disability support scheme, particularly assessment and the allocation of support resources, should not be to rule people out through limiting inclusion by severity or method of acquisition. The purpose of a support scheme should be to ensure the needs of *all* people living with a disability are clearly identified and strategies developed to meet them. Concern among Anglicare agencies is high for those individuals, described as square pegs, who do not neatly fit into pre-defined, round-hole categories of ability, functionality or entitlement and how these people will be supported in a new scheme.

1.1.2 Assessment and Measuring

In terms of identifying people for inclusion in a system that supports people living with a disability, Anglicare agencies agree that assessment and measuring systems need structuring to match the individualised approaches currently being adopted in the field as best practice.

Disability is a broad category ranging from physical to intellectual and mental impairment, minimal to broad functionality. Within all conditions there are varying levels of severity and therefore, of need. If a scheme that supports people living with disability is wholly inclusive the issue becomes less about identifying who and more about the level of need.

This is not to say that people are not 'missed' in current practice, as of course they are, and the processes that are required to improve engagement of these groups is further discussed in section 1.2. However, the extent to which a particular individual has involvement with the system, for example low/minimal need to higher complex need, is identified through assessment and measuring procedures. An approach to sustained, equitable and adequate care over the life-course, or duration of disability for those conditions which are not permanent, that recognises the diversity of disability and changing needs and capabilities over the life-course is one that takes an individualised person-centred approach.

Overwhelmingly, Anglicare agencies agree that current processes of assessment and measuring of disability are inadequate and not reflective of the values that underpin service delivery in the disability support sector. Further that the associated levels of care

subsequently allocated to people living with a disability, based on assessment, can often be inappropriate for their needs and wishes. Funding and resources are usually allocated via matching the categorisation of severity and functionality to care requirements. Anglicare agencies suggest that a system of assessment based on need, as determined by a multidisciplinary team that includes the client themselves, their immediate informal support network and the professionals who work with them, replace current techniques. It is suggested further that such assessment techniques be developed through a dedicated research program attached to the scheme, as discussed at section 1.1.5. Such assessment will better equip assessors with tools to develop strategies to support individuals and agencies establishing care plans tailored to their life circumstances rather than to identify what an assessment matrix dictates they are entitled to.

In such an assessment system, support staff working with the person would be required to contribute to multi-disciplinary assessments and on occasions be the lead assessor. A network of mechanisms and supports to accommodate this is crucial. It would include the flexibility and trust to allow service providers to make judgements based on their expertise and experience and be reliant on the qualification and training of sector staff (discussed at section 1.14).

Recommendation 1: Development of tools and assessment measures to identify need in the context of the individual for the purpose of establishing appropriate individualised care plans and funding packages.

1.1.3 Individualised Life-course Approach

Strong support exists in the network for needs based practice rather than an entitlement base. The view has been to couple this with a **life-course** approach recognising that a person's needs are different at the progressive stages of their lives and developmental milestones and within particular situations. The men's health policy[36] released earlier this year recognised that health and wellbeing needs and the social determinants affecting health shift over time and that strategies to reduce or prevent ill health may not be equally effective at every stage of life. Likewise for people living with a disability or carers of people with a disability, informal supports range according to each individual's physical, emotional, financial capacity to provide support, levels of exhaustion and other external factors that make up a person's life. Again, should the scheme take an inclusive approach the values that underpin the scheme will guide its development. With a life-course approach, identifying care needs then becomes an exercise in consideration of the person in their given context. The level of impairment and the definition of a condition alone are not good indicators of the extent of need or of quality of life. The extent of support and care a person needs must be and can only be considered and assessed in the context of an individualised life-course approach.

Recommendation 2: That the scheme adopts an individualised life-course approach to identifying the level of engagement for people living with a disability and people who care for and support them.

1.1.4 Sustainable Services

There is no doubt that any new scheme should adopt the person with a disability (and their carer/s) as the core focus of its activities. Consideration should also be given to the network of agencies and other organisations that deliver services. It is inevitable that the system developed to provide long-term care and support to carers and people living with disability will involve a hierarchy of networks and support services that will operationalise the scheme's strategies that will in turn meet its objectives. The majority of disability services, though funded by government, are provided in the community. Anglicare agencies alone provide services to more than 5000 people across the country. Consideration must be given to the flow on effect to services, which carry out this important work, of limiting or expanding the group of people who may be supported by them, and the implications this may have for the ongoing viability or sustainability of the disability support sector overall.

[36] Department of Health and Ageing. 2010. *Male Health Policy*. Department of Health and Ageing: Canberra.

Some elements for consideration include:

- If funding follows the client; how can smaller agencies serving smaller pockets of clients in isolated rural or metropolitan areas be assured of survival thereby ensuring the possibility of choice for those areas?
- For clients with unusual needs; how can they be assured of services in the long-term that are fitted to them rather than slotted into the 'closest fit'?
- In terms of residential services; should base funding be applied directly to the service to allow for increased operating costs?
- If exclusion principles, rather than including everyone, are adopted for who is eligible for the scheme, what happens to ineligible clients?

1.1.5 Research and Development

Workers in the field of disability support are the first to state that not enough is known about assessment, service provision and the efficacy of either on the spectrum of conditions that may occur in this sphere. Research and development is essential to growing the knowledge base for the prevalence and prognosis of conditions, identifying trends in acquisition, effective practices for supporting people with a disability and their carers long into the future, and mechanisms to appropriately and reliably identify need. The fact that it is simply unknown how some of the most prevalent disabling conditions arise and that many others arise from medical procedures or treatment indicates that research is essential to prevention, intervention and long-term care.[37]

To ensure currency and effectiveness in service delivery and as a mechanism to ensure that the scheme objectives remain adequate and appropriate, an operational stream dedicated to research in disability and related issues could be established and funded through profits of the National Disability Insurance Scheme, should that recommendation be adopted. The stream could be referred as a function of the Australian Institute of Health and Welfare for it to manage.

Recommendation 3: That a dedicated stream of research and development be attached to any new service structure or support scheme to further the knowledge base for supporting people with a disability.

1.2 Population groups

Which groups are most in need of additional support and help?

All people living with a disability and those who care for them are deserving of a support system that allows them to readily identify their needs and provides structures that will allow those needs to be met. However, it is unfortunately the case that some groups are more fairly represented in the support sector than others and that those 'missed' groups are unduly disadvantaged in an already disadvantaged sector. Some of these groups need particular support to enable them to engage in the first instance and obtain the necessary support to meet their needs and also to make the system **equitable**.

Groups that would benefit from additional support and help include (but are not limited to):

- People living with multi-faceted disabilities combined with extreme behaviours of concern.
- Culturally and linguistic diverse people, including the small and emerging CALD groups, who experience other difficulties trying to navigate the system which compound any negative effects.
- People living with an intellectual disability combined with a diagnosed mental health disability.
- Disengaged young people and young parents, and particularly their children.
- Children of parents with a disability.

[37] Australian Institute of Health and Welfare 2008. Disability in Australia: trends in prevalence, education, employment and community living. Bulletin no. 61. Cat. no. AUS 103. Canberra: AIHW.

- Indigenous people living with disability.
- Aging carers who possibly are not aware of the extent of support that is available to them for their caring role and who might themselves have additional health and other support needs.
- Regional and remote areas as these areas are the most difficult to service logistically.

Diagnosed mental health disability has been a recurring issue in the Anglicare Australia consultations. It has been raised repeatedly as an issue that requires particular attention especially in cases where the diagnosis is combined with other conditions. Dedicated services for this particular issue are rare as is detailed knowledge of effective support practices for people with a dual diagnosis.

Recommendation 4: That specialist support programs within services are established as part of an interconnected service program to engage 'hard to reach' and vulnerable population groups within regions.

1.3 Service innovation and creation

What kinds of services particularly need to be increased or created?

The National Disability Long-term Care and Support Scheme should adopt principles which maintain the integrity of the service and rather than harbouring competition and secrecy; and promote collaboration, cooperation and partnership.

1.3.1 Case Management

Several options were canvassed for services to be carried through or developed to meet the current and future needs of clients in a system that centred on the client. Many organisations agreed that efficient and effective case management should be the lynch pin of a holistic network of support services.

As is common across the human services, supporting people with a disability is more than developing a checklist and ensuring that all the items are 'ticked'. Working in the Disability support sector means working with people; working with the person with a disability themselves, working with their families or guardians, advocates and other agencies and also working with government. Often this can be a complex process with a multitude of competing priorities mostly with the best interests of the person living with disability in mind. As can be imagined, these competing priorities can result in clashes and, unless guidance and leadership is shown by key support workers, overly complicated, expensive and fragmented support plans.

Families engage with many different services and are often worn out or distressed by the complexity of the system. A case management approach can effectively coordinate the spectrum of issues that can occur in an inclusive, client-centred, organised manner. Take this example from Western Australia:

> *Bob is a 22 year old male who has an acquired brain injury, suffered when he was run over on a pedestrian crossing aged 10 years. Bob's care is covered by the insurance commission and they have appointed a case manager who in turn has contracted service provision to Anglicare to provide Bob with support. Bob's mother is his legal guardian.*
>
> *The plan for Bob is to support him to live independently away from his mother and it is the view of his case manager and Anglicare that he is quite capable of doing this given appropriate support. Only by living on his own and being allowed to take risks can he continue to grow and develop. Although his mother nominally has agreed to the plan she constantly undermines the efforts of our Agency to promote Bob's independence and wants him to live at home. Bob's wishes in this are very clear in that he does not want to live with his mother and wants to pursue an independent life like any other young adult.*

It appears to all the professionals involved that Bob's mother is carrying a lot of unresolved guilt about the accident and her perceived failure to protect her son so over compensates for this by constantly rescuing him, which in turn prevents his learning and development. She is a professional woman and is able to put her view very effectively. As Bob's legal guardian the contract is in fact with her not Bob and as such she has a major say in shaping our service. However from an ethical and practice policy view Bob is our primary client and as in our view he is quite capable of making decisions about his own destiny so we should be shaping our services around his wishes.

One of the consequences of Bob's ABI is that he has a degree of psychosis which can normally be controlled by medication but this has some undesirable side effects. From time to time Bob decides that he wants to be free of this so stops taking his medication, usually with disastrous consequences. When he last did this we could see that he was becoming increasingly psychotic and irrational and required hospitalisation. We had to withdraw our support because of the risk to our staff from his behaviour and strongly advised his mother as the guardian to call in emergency psychiatric help. She refused to do so as she did not want him to face the ordeal of compulsory admission and instead tried to care for him herself. Concerned about the escalating risk to all involved as an agency we took a decision that we would call the mental health services in ourselves even though this was against the wishes of both Bob and his mother. He was subsequently admitted as a compulsory patient but soon stabilised on medication and is back living independently in the community and much happier after the intervention.

Here you can see that despite the family's earnest interest in the welfare of their son it was proving to be not only distressful for Bob but expensive, resource intensive and time consuming. Bob's experience demonstrates the complexities in working in this sector and the importance of having qualified case managers to work with all the interested parties to obtain the best outcomes for the client.

Other difficulties arise where the carer is impacting on the quality of life of the person with a disability by confusing their own needs, which are not irrelevant, to those for whom they are caring or, in the worst cases, abusing the power and resources entrusted to them for the care of their loved one. These examples are one extreme of a spectrum, highlighted to illustrate the importance of an impartial interlocutor with appropriate qualifications and experience to act in support of the client.

Case management is an approach where, through relationships built with the client and their support network and based on their own extensive knowledge and experience, the case manager can assist the client and their family to coordinate the various services, support workers and competing priorities involved in their care, navigate the care system, have the client's needs met and their goals reached.

1.3.2 Self-Directed Care

A multi-faceted system with a diverse and varied client base needs a multi-faceted approach to care and support. It is important to move toward an individualised support approach which offers **choice** for the person living with a disability and those who care for and support them, but which does not re-create systems already in place. The current system of self-directed care has met with a mixed response ranging from ideal to less than ideal. Generally considered an effective approach to client inclusive and directed care, the main concern is uneven outcomes. While some families are very well equipped to manage funds and can achieve the best outcomes over the life-course of their loved one, other families are not as well equipped and struggle to source the needed level of care needed.

It has been suggested that to for the new scheme to be most effective self directed care could be an option for families. It was strongly agreed within the Anglicare network however that wrap-around mechanisms need to be put in place, possibly through a case management-type approach, to ensure that individuals or families are coping with this method and for where

they aren't, to establish supports or pathways to complementary or alternative management strategies which still maintain the element of client-directed care.

Recommendation 5: To allow flexibility within funding systems to allow

- ***for comprehensive client-directed care ;***
- ***for clients to transition to complementary or alternative funding management systems should they be required and***
- ***agencies the scope to develop strategies to appropriately identify and engage clients in need of support.***

1.3.3 Housing Options

Flexible housing opportunities will be key to developing a care and support scheme for people living with a disability and the people who care for and support them. Returning to the social determinants, housing is a major factor in contributing to or detracting from health and wellbeing. Anglicare Sydney in a recent research paper has identified that inadequate housing and income are two of the main drivers of social exclusion in Australia.[38] Income and participation will be discussed under section 1.5.

Housing provides people living with a disability an opportunity to maintain their independence within the community; and by extension to live with dignity. It was discussed earlier the importance of independence to one young man and the extent that he was willing to go to obtain it. Approximately 30 per cent of the services provided by Anglicare agencies focus on maintaining an individual within their own home in the community. This includes social networking and community participation but most of it is focussed on developing skills to live independently, providing in-home supports and infrastructure, mentoring and transition planning. Another third of services are dedicated to residential and respite services. This indicates the importance placed on maintaining a person's independence and dignity as far as possible, in their own home.

Earlier this year, Anglicare Australia conducted a rental affordability snapshot[39] looking at the major cities in Queensland, South Australia, the Australian Capital Territory and all of Tasmania. Working on a rental affordability baseline of 30% of income, the results found that there was almost nothing in Brisbane, Adelaide, Tasmania and Canberra that was affordable to low income earners. For aged and disability pensioners, who have a slightly higher payment, the only affordable housing was in share housing. This survey was a snapshot only. It didn't look at the condition of the houses which people on low incomes might live in. Nor did it take account of energy and transport costs associated with those houses, which are growing at a rate of knots for many. Access to appropriate, safe, secure and affordable housing underpins the capacity of everyone to make a positive contribution to society and to maintain their sense of dignity and independence. Agencies agree that there are a variety of options required to manage housing opportunities for people living with a disability. Included among them is access to reasonably priced housing for people with a disability, including the expansion of existing social housing programs, incorporating a disability housing quota within the National Rental Affordability Scheme, and setting appropriate minimum standards for housing construction as proposed by one of the major parties in the recent election campaign.[40]

Residential care and respite, with particular attention on emergency and crisis care, are other housing options to be further explored and improved in a new scheme to ensure the integrated efficacy of other support structures. Whether you subscribe to a hierarchy of needs theory, social determinants or human rights frameworks (or any other social theory; adequate housing, which - includes residential and respite care services for people with a disability, is integral for both long and short term care. It has been further suggested that residential support be provided with an educational/life skills focus and funded through

[38] King, S., Bellamy, J. & . 2010. State of Sydney Report: The Depth and Diversity of Social Exclusion. Anglicare Sydney: Sydney

[39] Anglicare Australia. 2010. Rentals unaffordable across Australia. Media Release.

[40] Policy announcement. Gillard. 2010. Housing standards- {Complete reference}

partnerships of the Departments of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and Education, Employment and Workplace Relations (DEEWR).

Other options for respite include holiday respite or medical tourism, where families from regional areas holiday in cities and devote some part of their holiday to accessing allied health and other support mechanisms not generally available to them in their area.

Recommendation 6: That flexible housing options are factored into a National Disability Long-term Care and Support Scheme.

1.3.4 Community Supports

Much of what was discussed in terms of service creation focussed on the improvement of existing services, indicating the need for updating, rather than the recreation of entire service system. However, an area where there was strong agreement for targeted activity and possible service creation was community engagement and integration.

It is important for people living with a disability to have meaningful connections with friends and family and in the community more widely. Work, social networking and recreation are as meaningful for a person living with a disability as they are for other Australians. However, people living with a disability are often segregated: in classrooms, the workplace, even in society where recreation activities are purpose specific for people living with a disability. Mainstreaming of disability would encourage other members of the community to develop a personal understanding of what it is to live the experience of disability ;introduce into the communal lexicon language that is supportive and inclusive; lead to some changes in attitude ,culture and eventually behaviour, and that will see people living with a disability included among 'everyday Australians' rather than be pushed to the fringe as they currently are.

The responsibility falls not only to the wider community but also to services and the families of people living with a disability. Positions could be created within services to advocate for and begin work on the cultural shift in local communities. These people, who may be Social Inclusion Officers or Disability Liaisons or whatever their title, would be responsible for bringing the community and the disability support sector together for seamless integration of both within their local communities.

Recommendation 7: That community engagement and integration options are considered within the scope of a National Disability Long-term Care and Support Scheme.

1.4 Early intervention

Ways of achieving early intervention?

1.4.1 Cohesion and Opportunity

A **cohesive service system** is required to facilitate early intervention and prevention. Anglicare agencies agree that early intervention and prevention are an integral part of support mechanisms for people with a disability and that a service structure that takes a life-course approach to early intervention and prevention will most effectively reduce adverse impacts y that would otherwise arise.

Currently the disability support industry is a fragmented sector with, for clients, many 'wrong doors'. In the time it takes a client to find the appropriate service the opportunity for prevention or early intervention can be lost. Needs change over time for people with a disability as they improve or digress with their abilities, as they move through developmental milestones, as their life goals change and as they or their carers age; and it is important that those changing needs can be picked up through all intervention and prevention strategies.

Carers, and the individuals themselves, are often experts in their own right regarding their specific conditions and experiences. However, it is often the experience and expertise that comes from working across a range of service types, conditions, and particular contexts, as is

the case with disability support workers, which is the basis for identifying opportunities or developing strategies for early intervention. The disability support scheme, as proposed by Anglicare Australia would consequently provide a comprehensive network of support, research and public health services. It follows then that the operation of such a scheme would take many resources making cost containment pressures inevitable. To be most effective, and efficient over the long term the scheme would need support early intervention and prevention measures both on an individualised micro scale and on a population based macro level. The distinction being made here is between public health and primary health, one being in regard to the health and prevention of ill health across the population and the other multi-disciplinary responses to a person's health and its threats. Broad brush health and public awareness campaigns (such as the risk of diving into unknown bodies of water or shallow pools, the need to use seatbelts, effects of alcohol consumption during pregnancies) are examples of successful non-targeted public health campaigns which reduce the incidence of traumatic injury, but do not eliminate it: accidents still happen and conditions develop.

It is after these circumstances occur that the spectrum of need and subsequently the opportunities for early intervention for people living with a disability are made evident. Again, it is the people who are working with and supporting the individual who will recognise these opportunities and who will require systemic support which accepts the individualised nature of intervention, recognises the qualification, expertise and judgement of the workers and supporters recommending the intervention and which can provide resources to implement early intervention strategies. A cohesive system with pathways to and between specialist support services, with a life-course approach, a workforce that collaborates and works in proactive partnership rather than reactive silos, and supported by a robust research and development stream will facilitate identification of opportunities for early intervention and prevention and therefore minimise later costs and draw-downs on resources while improving the quality of life for the person living with disability.

Recommendation 8: That the scheme recognises where opportunities for early intervention originate and that support is provided to implement early intervention strategies.

1.5 Participation and community work

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

1.5.1 Assessment and benchmarking

Anglicare agencies would like to see in a new scheme a system of assessment and benchmarking which reflects each individual's own capacity to participate in work, which does not impose severe work tests or benchmarks. In considering the common understanding of 'participation', Anglicare agencies would like to see a broadening of the term to include the social contribution that people can make to society.

In considering the practical aspects of it, agencies are concerned with the amount of time the person with a disability has to be in paid employment to attract government support. For people living with disability these benchmarks, in their view, have grave implications for pension security. Whether real or perceived, there is fear and distrust of government services by some disability pensioners and there is a common view that working too much will affect their Disability Support Pension (DSP) payments which, once lost, are seen to be difficult to reclaim.

The problem lies in the conflict between the expectation to work and the limited support elsewhere in society to ensure that people living with a disability have the means and opportunity to participate in that paid employment. Employers receive a subsidy for work that is eight hours a week or more for at least 13 weeks.[41] Anglicare members say that this benchmark can often be detrimental to the health and wellbeing of a person living with a

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disability, and is an unreasonable expectation for many. And yet because the assessment indicates only that they are capable, and does not reflect fluctuations in need and ability, there is no cause nor incentive to build flexibility or ongoing support into work arrangements.

It is for these reasons that in each case, a person's determined capacity to work ought be based on consideration of personal circumstances and abilities over the duration of their expected employment or participation in community work.

Recommendation 9: to develop assessment processes which minimise the emphasis on benchmarking and focus' on the needs and capabilities of the individual. (Individualised approach)

1.5.2 Choice

In terms of engaging a person with a disability or a carer in the workforce there are several factors that make an impact: the willingness of employers; the capabilities of the person or carer; the degree of public acceptance; and transport costs and availability, to name a few. Limiting any or all of these factors limits a person's choice in how they want to live their life and the satisfaction they are able to receive from the work that they do.

For example, how can a carer engage in meaningful work when they are unable to find appropriate ongoing afterschool care for their children who have a disability? Or in some cases, maintain work when the afterschool care caters only for the child up to the age of 12. Whatever the public policy imperative, there is no choice for that parent. Whether it's about establishing universal minimum standards so that all school programs can support children with a disability or whether the onus is on workplaces to provide flexible working arrangements; in instances such as these there needs to be enough local capacity and resources to provide options for families not only in afterschool care but also for the gamut of support needs that, once met, enable carers and parents to work.

Organisational attitudes, as well as those in the wider community, inhibit the choice of people living with a disability to engage in work due to, perhaps unintentional, prejudicial policies and procedures. For example, even though Government is an equal employment opportunity (EEO) employer, people with disability who may be well capable of carrying out the work duties but will find themselves excluded from employment because they are unable to meet the obligations of the recruitment process itself. Anglicare agencies agree that mechanisms need to be established, in partnership with DEEWR, to allow flexible recruitment processes and to enable support workers to advocate/liaise on behalf of clients throughout recruitment. It has also been suggested that an EEO quota be established and that some positions may be identified only for people living with a disability. These principles also need to be expanded to include community organisations as well as business.

1.5.3 Support and limitations

Anglicare agencies agree that investment of energy and resources in work around perceptions and public support for the full participation of people living with a disability and carers can impact greatly on inclusion and opportunities for choice. There has been discussion around the lack of public awareness of the issues involved with living with disability or caring for someone living with disability. This again relates to the extent to which people with disability are or are not integrated into mainstream society and the responsibility the general public has a part of that community to understand and respect everyone's right to participate as an equal.

General assumptions are made in the community that carers are fully functioning and able to work and if so, are able to earn enough to fulfil their caring role. There is little recognition of the effect of caring duties on the diminishing capacity to work. Locally responsive, appropriate mechanisms to support carers and people with disability to develop capabilities, not only to enter the workforce or other community program roles but also to maintain them, with no detriment to their health and wellbeing, are required. As are programs and processes to better edify the general public, specifically to create greater awareness,

understanding and support for people with disability and their carers to engage in appropriate community and employment participation opportunities.

1.6 Decision making and appeals

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

1.6.1 Choice

Many of the comments from Anglicare consultations have centred on flexibility of the system and the degree to which clients and families should be able to direct their own care. This type of vision does require additional resources to establish or expand services, particularly in rural and remote areas, to allow for choice. Whether funds are directed by the client, their family, an advocate or the service provider, practice has shown that where clients are involved in the decision making process concerning their care, they fare better and are more satisfied with the outcomes. Even in other areas of the community service sector there is a push to include clients in a range of planning and decision making processes not only about their own care and support but also regarding strategic planning for the organisation, its mission and objectives. This idea was particularly reinforced by the Productivity Commission's inquiry report into the third sector and has been championed by Mr Robert Fitzgerald[42], presiding Commissioner for that inquiry.

Where clients and families are furnished with options and choice the observed effect has been that clients are more satisfied with the outcomes due to the degree of control they had in determining them. And so it follows that due to this higher degree of satisfaction rates of litigation (in this sector), conflict and reported grievances will decrease. However, it is acknowledged that the power of choice does not dismiss the need for complaints processes or appeal mechanisms. People living with a disability and carers are deserving of respect and the same standards of quality in their lives as other Australians. As such it behoves us to ensure that they be integral in decisions regarding their own care and the services which provide it but where this fails have recourse available to individuals, families, guardians, advocates and services when decisions have been made and actions taken that are believed not to be in the best interests of the person to whom they apply.

1.6.2 Conflict resolution

The case management approach may be useful in facilitating the decision making process which involves the client and their immediate supports to determine care which best supports their needs. As mentioned above however, where this does not meet the needs of the client or where the power of choice has been removed, an option to remediate the issue could be the less adversarial approach adopted by the Family Relationship Centres established to complement the federal court system. Mediation, conciliation and family inclusive approaches as utilised in the justice system have shown to be effective mechanisms for resolving conflict. This model could be adapted for the disability sector in conjunction with standard complaints and appeal processes.

Recommendation 10: That models of appeal and conflict resolution which reflect inclusive and respectful practices be explored.

[42] Fitzgerald, R. 2010, February 18. Presentation at Anglicare Australia Community Sector Issues Forum.

1.7 Service delivery improvement

How to improve service delivery- including coordination, costs, timeliness and innovation?

The key recommendations of the Productivity Commission Inquiry into the contribution of the Not For Profit sector (mentioned above) are particularly pertinent here.

1.7.1 Cooperation and Collaboration

In terms of service delivery in a scheme that is going to effectively support people for the long-term, collective opinion has been returning toward a cooperative and collaborative approach to ensuring that people with a disability and the people who care for them are receiving support that will improve their health and wellbeing. The Social Inclusion Agenda as well as the Homelessness Framework are major Government initiatives both of which have highlighted the importance of a joined up approach to service delivery and support. Anglicare agencies agree on areas where cooperation and collaboration can be improved to increase the quality of care for people living with a disability.

- Disjointed and market based funding principles. The disability support sector is fragmented and operates in silos particularly in regard to competition for funding. Competitive tendering creates tensions between services which can inhibit sharing of information and belies the goodwill services have to work with each other. Funding mechanisms need to be established to reflect the shifting attitudes toward client-directed care and service integration. In the past funding formats have encouraged small, isolated programs which has fragmented and weakened the system and powerbase of the sector. As a result some small agencies may not survive. Similarly, the disjointed and fragmented approach to funding within Government departments would benefit from review as current systems are administratively burdensome and ineffective at identifying duplication of programs or opportunities for creating economies of scale through local partnerships.
- Services build their programs on the funding that they receive and the lack of certainty around re-current funding can have impacts on that provision.
- Disjointed and complex service navigation. Anglicare agencies agree that improved service integration and clearly identified consumer pathways coupled with cooperative case planning and sharing of information will improve the quality of care and support provided to carers and people living with a disability. This type of service structure, however, requires systemic support in the form of flexibility in expenditure of funding; allocation of resources and the criteria on which need is derived.
    - Case coordination by a key contact will maximise the effectiveness of shared information and collaborative planning thereby maximising efficiencies and minimising duplication of effort and utilisation of resources. This will also improve navigation through complex systems and reduce the level of “service exhaustion”, including eliminating the need to describe case histories repeatedly, as experienced by carers and will increase their capacity to care for their loved one.
    - The importance of case coordination and an integrated service system is particularly important in regional and remote areas where resources and services are limited.
    - Consumer driven collaborative case planning and management will ensure that checks and balances are in place to maintain quality care standards and through communication and collaboration, personalised pathways will be developed particular to the person living with a disability.
    - Where a person is not already linked into a service or collaborative team of support professionals, Anglicare members agree that mechanisms need to be developed so that those people are not lost within the system. For instance, upon diagnosis of a disability a case manager from a community sector organisation could automatically be assigned to offer the family or individual

the human support that an information pack cannot provide. Mechanisms such as this ensure that the family or individual are connected to and have knowledge of supports that are available to them and can call on as appropriate. This strategy implies that there should be no 'wrong doors' in the sector and that the first point of contact should be able to offer initial support whilst linking the family or individual into the appropriate supports before they hit crisis point. Mechanisms for achieving this end include a disability liaison attached to medical practices and hospitals; or a combined pool of resources for agencies to draw on to establish an initial period of preliminary support, monitoring and review while the client decides in what way they would like to receive and direct their support if at all.

All of these strategies are reliant upon a sector that can work in partnership, cooperatively and without hesitation. Moreover, it requires the support of the governing bodies to do so efficiently.

- Burdensome Administration. It has been observed throughout the network that overly officious and burdensome reporting and administrative requirements have an impact on the agency's ability to provide services at the local level. On a larger scale however, too many bureaucratic processes inflates the cost of implementing the scheme and therefore diminishes the collective buying power.

Recommendation 11: That Government and the disability support sector commit to principles of flexibility, individualised service provision and client choice to allow the development of innovative and effective services which promote partnership and collaboration, and which adhere to nationally consistent quality standards.

1.7.2 Entitlement vs Need

In consultation with the Anglicare network it was increasingly clear that agencies see the importance of the distinction being made between entitlement and need. Feedback suggests that though current funding is regulated by the former it should be guided by the latter. In terms of an individualised approach to service delivery, what two people with similar conditions need can be vastly different, however, in the current system they are entitled to the same or similar funding packages. Secondly, entitlements are provided in dollars and as time progresses the value of the entitlement decreases. As it currently stands, funding is inflexible, comes from particular streams limiting the capacity of the individual and agencies to be flexible in service purchasing, and is tied to particular outcomes and deliverables.

Anglicare agencies suggest that funding of support packages be provided as hours and on an individualised basis. When based on need as identified by the individual and multi-disciplinary team who has ongoing contact with that person, stressed families facing further complications are better served by their resources and are in less danger of purchasing ineffectual or excessive services. Additionally, funding provided as hours would allow agencies to expand their support to any given individual, as funding will not be tied directly to client work excludes associated costs such as transport. In this way, funding packages may be tailored to the individual, maintain their value over time, and have the capacity to respond to local contexts whilst providing appropriate supports in a timely and efficient manner.

Problems may arise from a model like this if agencies can "cherry pick" the easiest or the best clients due to minimal need or not accept clients who are perceived to be more intensive or complex in their level of need. One strategy would be to introduce a trigger in the assessment process to attract extra funded hours for complex and challenging cases to both address need and eliminate the perception of "hard" cases.

Additional supports and associated costs that could be included to improve service in a support hours model might include:

- Transport
- Training
- Equipment
- Recurrent supplies

- An index for complex care requirements (as above)

Recommendation 12: That commitment is made to investigating a flexible approach to funding including consideration of the hours and brokerage models.

1.7.3 Quality

Quality assurance in service provision is increasingly becoming an integral part of program delivery within the sector and within Government. The Government's recent consultations on quality frameworks and national standards in homelessness and out of home care sectors respectively is evidence of the shift toward building in quality assurance processes from the front end of service delivery.

The disability support sector is a broad ranging dynamic sector with diversity in the types of programs and funding models delivered. However, Anglicare members agree that a nationally consistent, if not national, quality process be established and adopted to ensure that quality services are being delivered and that the outcomes of the quality assurance process is made available to the public and, more importantly, to prospective clients to inform their choice.

As mentioned, the scope of the disability support sector is monumental and as such there are possibilities that people who require and ask for support are missed. For example, those, as above, who undertake to direct their own care but are not able to maintain it at an acceptable level. In situations such as this, how can it be assured that care standards are being met or conversely that funds are being appropriately spent? It is the opinion of Anglicare agencies that time and energy needs to be devoted to developing a quality assurance process to ensure that care standards are being achieved regardless of the method in which they are delivered, eg through self-directed care or funded support hours.

Another aspect to the improvement of service delivery in the sector and relating to quality is that of qualifications, training, professional development and support of its staff. It almost goes without saying that the quality of the training and support of the workforce impacts greatly on the efficacy of the supports driven and maintained by those people. As repeatedly mentioned, the disability support sector is a human services sector and as good business management states, a satisfied workforce is a productive workforce. The disability sector workforce is further discussed at section 1.14.

Recommendation 13: That nationally consistent service standards are developed and adopted in each jurisdiction.

1.8 Entitlements

The factors that affect how much support people get and who decides this?

1.8.1 Assessment

It is the view of Anglicare Australia members that the approach taken for assessment is in need of review and reformation as discussed in section 1.1. The general consensus is that as a determinant of entitlement, assessment processes should adequately reflect the needs of the clients and rather than merely meet clinical criteria.

People living with a disability are more than their condition. They have aspirations, goals and life needs. Considering these factors alongside functionality, health and behaviour requirements as they too contribute to a person's quality of life will be instrumental in developing a scheme that responds to and supports people with a disability. A holistic approach to assessment, based on appropriate and reflective processes which include the family and support workers having input into the assessment, is key.

1.8.2 Entitlement vs Need

Thinking currently focuses on "how much" rather than "what type" of service is required to meet the needs of the individual and this is often affected by people's knowledge of services.

Current practice is limited by frameworks targeted at the amount of services people get or are entitled to. Members agree that a fundamental shift needs to occur, redirecting emphasis onto the services that are provided to meet a client's needs.

As referred to previously, current funding does not allow for meeting the scope of need which one individual client may present with. Funding at present is tied to direct client work which agencies must adhere to in the provision of their services irrespective of whether or not that agency is responding to the stated need of their client. Clients are better served when agencies are able to consider the entirety of their person; to consider the whole and where (?) connections, opportunities, sensitivities, and areas of need lie to work with them in place and in context.

In allocating resources based on needs, as determined through formal assessment or through client directed case planning, it is important to consider the context in which a person lives. People who have a strong support network may not perceive themselves to have a need for particular support which, in an entitlements-based system, they would still be entitled to. It is an inefficient use of resources to allocate them to where they are not needed. Anglicare Australia is not advocating for less but for what is appropriate as determined by individual need.

Recommendation 14: That commitment is made to investigating a flexible approach to assessment and funding including consideration of a needs-analysis model for determining entitlement.

1.8.3 Inclusivity

As mentioned earlier a disability support scheme should not be focussing on who it can rule out but rather addressing the needs of people living with disability regardless of how it was acquired. Individuals and families accessing services and more so for those who aren't, are operating with high levels of stress and the coping mechanisms of each may be vastly different. A system that excludes only compounds the issues for people living their lives at breaking point.

Service delivery as a support mechanism ought to be able to address the individual needs of those accessing their service and to do so without systemic interference. It is appreciated that funding limits and guidelines for entitlement serve to also protect services from over engagement however this mechanism reduces the effectiveness of the services that agencies provide. The protection that it affords is not substitute enough for the comprehensive wrap-around supports that agencies might otherwise provide in a needs-analysis model.

Working with a client who does not fit the criteria for the scheme or for particular supports is like looking at that client through a tube; only so much can ever be seen at one time and with any support plan that is developed, something is always going to be missing. When Government is working toward deconstructing silos, it is inappropriate to expect the disability support sector to build them.

Recommendation 15: That a Disability Support Scheme does not exclude based on acquisition of disability.

1.9 Current good practice

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

1.9.1 The Potential of Quality Assurance

Many systems are currently in place in the states and territories that go some way to ensuring the quality of services that are in operation in the disability support sector. Anglicare Australia consultations found that services agree with the need of quality assurance processes. However, some feel that the degree to which services are currently audited and accredited is not as rigorous or purpose specific as they could be nor are the outcomes of such processes utilised for any ongoing public quality assurance validation.

Conversely the processes that are in place are intensive and thick with red tape, resulting in the commitment of time and resources with little to no productive outcome.

Auditing and accreditation occurs on various schedules within all of the states and territories however the outcomes/results of the audits are not made publicly available. In a system where it is proposed that service provision be dictated by client choice, quality assurance processes such as audits or accreditation could be used to generate public report cards or quality ratings that would inform consumer choice. In this way, agencies are contributing to their own sustainability by ensuring that they provide services that meet needs of their clients in a manner that is acceptable and appropriate as judged by their peers.

Recommendation 16: That nationally consistent service standards are developed and adopted in each jurisdiction (1.7) for the additional purpose of public information and informing consumer choice.

1.9.2 Good graces

As previously mentioned the current service system is compartmentalised and maintained by 'survival of the fittest'. The economic Darwinist approach that sees agencies competing against each other for funding perpetuates the divisiveness of the current disability support system. Conspiracy theories abound, however, there is hope. Services want to operate in partnership with other services and it is the grace and good intentions of services and their staff that ought to be fostered and carried through to a new system.

Service cooperation and collaboration result in projects and services which support the entire community in one way or another. In a recent article in the Council to Homeless Persons magazine, *Parity*[43], Anglicare Australia argued that to better include all those living on the edges, connections and partnerships are not only required within the networks of the community services sector but also with the greater community.

> *The challenge exists for everyday Australians to widen their world view not only to look in terms of their experiences but beyond them.*[43]

A new disability support scheme should harness the goodwill that does exist in this sector and support opportunities for agencies to engage with one another. In terms of providing client-centred care for people living with a disability, the whole service structure may depend on how well agencies are able to integrate their practice. Support for agencies to do this is required at every level beginning with Government; community services are the hub linking individuals with a disability to government services thereby implementing the government's public health and welfare agenda. One strategy to induct the sector into effective, collaborative relationships would be through the introduction of service integration grants similar to those announced by Minister Plibersek[44] to overcome homelessness. In that instance $3 million was provided for agencies to explore the various types of working relationships that result in an integrated and collaborative partnership between agencies.

1.10 Regional and remote areas

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

It is recognised across the Anglicare Australia network that issues around service delivery in regional and remote areas is of huge concern. It is further recognised that the issue goes beyond the disability support sector and acknowledged that regional and remote areas, in general, are under-serviced.

A major concern for agencies delivering services in regional and remote locations is the absence of transport, travel and time allocations in support package budgets. These aspects

[43] Chambers, K. 2010. 'How to Exclude Without Really Trying'. *Parity: Homelessness and Social Inclusion*. Volume 23, Issue 4.

[44] Plibersek, T. *Opening of The Road Home: Progress and Lessons Exhibition* (Speech). Parliament House, Canberra. 22 June 2010

of remote service delivery have huge impacts on services and can undermine the quality of service delivered, for example time spent with a client or available funds for purpose specific supports etc. This oversight would need addressing in a new support scheme through an indexed levy, for example, where the degree of remoteness attracts a funding bundle to accommodate additional costs; through support for services amalgamating across geographic regions to take advantage of economies of scale and to increase their geographic spread; or with therapy circuits – similar to court circuits – made up of allied health professionals and other key support workers.

Living in rural and remote areas does not rescind a person's entitlement to similar levels of care and support to metropolitan counterparts. Choice is as much of condition of citizenship in rural and remote areas as it is in the cities and as such efforts must be invested in raising the quality and scope of choices in rural and remote areas.

Recommendation 17: That strategies are developed to improve service delivery that include flexible approaches to provide adequate individualised support for people in regional and remote areas.

Administration and Governance

1.11 Equity of support

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

Much of what has been previously discussed has been aimed at ensuring that there is equity in support in the disability sector. The aim of which is to engage with all individuals living with disability to allow them to establish for themselves a quality of life which is acceptable to the greater community but more importantly, to them.

The following are highlights from the consultations which Anglicare agencies particularly regard as contributing to equity of support:

- Client directed care: Through ownership of the support process, individuals and their support networks may determine in which ways they will be supported, thus ensuring that their own identified needs are met.
- Responsive to need: Through a need-based resource allocation system underpinned by a multidisciplinary and family inclusive assessment process, the real needs of the person living with a disability may be indentified within the context of their lives and not in relation to a categorical scale. In this way, support and care plans are a personalised fit ensuring that needs are met as opposed to matching conditions with response packages irrespective of being 'fit-for-purpose' because that is what the entitlement is.
- Transparency of the system: Transparency of process and decisions is fundamental to building trust in a system. Trust comes from knowing that the decisions made and the actions taken are based on sound principles with appropriate information and consideration of the contexts in which the decision or action is taken. This comes from having quality standards and processes for practice at all levels from the governing administrator to the individual workers in the field.

1.12 Administrative requirements

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

1.12.1 Cooperation and collaboration

Anglicare agencies agree that to simplify the process of supporting mutual clients would be to work collaboratively in planning and implementation of support plans but in informing the development of those plans to also share information such as case histories and assessments with the permission of the individual involved, similar to the way the family court is now operating protocols with child protection agencies and Medicare Australia etc. We have discussed the potential of a lead case manager or a key contact who would, in partnership with the client, coordinate services and information thereby reducing duplication and excessive administrative processes from multiple applications etc. However, this would not negate each agencies responsibility to report on activities and outcomes.

Reporting is a burden recognised by government however much is yet to happen by way of reducing that burden for agencies. The Compact agreed to by Government and the Third Sector earlier in the year states that reducing red tape and streamlining reporting is one of eight priorities for action. The compact also states that government will work with the sector in creating plans for taking action in each of the priority areas. The National Disability Long-term Care and Support Scheme is a prime opportunity to demonstrate that the compact is not mere words.

Anglicare agencies propose common reporting frameworks to be adopted by all funding bodies to, in the first instance, reduce the level of paperwork for reporting on multiple funding contracts but secondly to produce a body of data that is reliable and able to be utilised for the continuous improvement of the support sector. It is recognised that reporting is an exercise in accountability and adds to the transparency of the system. Data that is currently required to be collected however is rarely utilised for informing consumer choice in determining the quality of a service; for the contribution of knowledge of disability and its impacts on quality of life nor for the improvement of service provision. The standardised data collection should be referred as a function of the Australian Institute of Health and Welfare to coordinate, analyse and distribute information to be utilised as a resource for people living with a disability and those with involvement in the sector.

Cooperation and collaboration is not necessarily the sole domain of the community sector. It has been noted by all agencies the confused and often overly complicated funding systems that are managed by both national and state funding bodies detract from time spent in service delivery. Streamlining between these levels of government with shared processes or guidelines; delineation of responsibility, for example which is a federal issue and which is a state and how will/can the two interact; or indeed agreement on shared information protocols, is going to trickle down and increase efficiencies down to the service delivery level and thereby avoiding the risk of creating a bureaucracy.

Recommendation 18: That a commitment is made to developing common practices and information sharing protocols for all levels within the disability support sector.

Recommendation 19: That the collection, analysis and distribution of data from the disability sector be referred as a function of the Australian Institute of Health and Welfare.

Costs and Financing

1.13 Adequate resourcing and sustainability

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

1.13.1 Source funding

Anglicare members agree that funding is an ongoing issue that requires addressing to ensure the sustainability of meeting adequate care needs. To this end, the proposed strategy of a NDIS has received varying in-principle support throughout the network.

Experience in the network has taught us that current funding models are reactive and in some ways responsible for the slow erosion of the infrastructure and support networks within the sector. Expectations of the NDIS are that it be able to rectify disintegrating infrastructure purchasing programs, support a research and development stream as well as providing for the care and support needs of *all* individuals who live with disability and their support networks.

Some concern exists how the NDIS will integrate with existing systems such as the newly established funding models of disability employment services in Queensland for example. Other concerns include the seed funding of such a scheme and how that will be generated. Due to the lack of public awareness of the issues surrounding disability and some might say ignorance to the possibility of acquiring disability, an additional tax may be met with conflict or contention in the wider community. Suggestions to overcome this have been to include a Medicare type levy or inviting dollar for dollar investment to raise the start up capital. It is recognised that however capital is raised, if the NDIS is implemented it ought to be established as a Government business or separate agency. Furthermore, in order to protect the funds and secure them for disability support, the reallocation of profits through standard revenue processes and their depletion through the budgetary process must be prohibited.

1.14 Practicalities

The practical aspects of a scheme, how to manage risks and costs, and ideas for attracting people to work in the sector?

1.14.1 Values

Systems are a product of the values on which they are built. In building the scheme, recognition of the values held by the sector will continue to direct practice. Currently values reflect the shift in understanding and conception of living with disability and how best to work with people and their support networks to achieve the best outcomes. In determining the practicalities of a new support scheme, steps can be taken early to ensure that the systems built around values are purpose-specific and achieve what they are intended to achieve. For instance, in a system that has a guiding principal or value that clients should not only be included in their care planning but should lead where possible will develop streamlined and efficient strategies and mechanisms in the first instance rather than subsequently attempting to identify management strategies for inefficient and ineffectual systems. In the sector there is a shift away from the welfare and medical models toward a client-centred, rights based approach, and as such the scheme ought to reflect this in the operational aspects that are developed.

Several values have been expressed throughout this report for the basis of the scheme. An outline of some of these have been included below:

- The scheme should include all people living with disability regardless of type of acquisition.
- The scheme should support flexibility in funding and service provision, support individualised care and promote client choice.
- The scheme should not be overly bureaucratic.

- Research and development is integral to the advancement of knowledge regarding disability, its impacts and best practice for care and support.

1.14.2 Staff

Workforce issues are a concern for all sectors and it is no less the case in the disability support sector. The practicality of a long-term scheme for the care and support of people living with disability is that it operates in the human services sector and relies on the quality of its workforce to meet its objectives.

Current wages and inflexible working arrangements are perhaps the most discouraging aspects to attracting staff to the disability support sector. Until improvements are made in these areas staffing increases are not expected. Aspects of workforce planning that might be influenced to attract and retain staff as suggested by the Anglicare Australia network include:

- Wage increases that reflect qualifications and experience and which are on par with other sectors.
- Security of employment and opportunities for career advancement.
- Working conditions that support job satisfaction such as flexible working arrangements, professional supervision and particular consideration of workers' own caring duties as people in the disability workforce often also have caring roles.
- Additional tax incentives to attract workers to the sector.

Training and ongoing professional development is another area of influence to retain staff in the disability workforce. The sector has an ageing workforce and is in need of opportunity to develop new workers into qualified and experienced staff. Training and development incentives to attract and retain staff include:

- Professional qualifications in disability with a recognised professional body similar to the Australian Psychological Society or the Australian College of Nurse Practitioners.
- Ongoing professional development including supervision and in-service type organisational development.
- Dedicated promotion of the sector in secondary and tertiary institutions to attract new and younger workers.

1.14.3 Quality in practice

The potential of quality assurance and continuous improvement has been discussed earlier in this paper however it is reiterated here due to the extent to which Anglicare agencies agree that this should be a fundamental part of any care and support system to ensure that the systems and structures set in place stand up to scrutiny. Whether programs integrate, whether procedures are effective, whether clients are satisfied with the level of support received and their needs being met, whether administrative processes are efficient, whether jurisdictional relationships are being upheld, whether there is consistency in the application of assessment and equity of care; whether appropriate standards are being met are all practical questions which can be addressed through quality assurance and continuous improvement processes.

Standards have been suggested as one method of assuring that in the first instance, the systems and structures and procedures set in place adequately reflect the principles on which the scheme is based and in the second, provide a benchmark for assessment and review for improvement. Standards include accreditation of services and the qualification of staff, service or care standards or, at an administrative level, operational standards such as responding to claims or applications within certain timeframes. The Attendant Care Standards[45] and the Victorian Quality Framework[46] have been highlighted as exemplars of standards in practice.

[45] Find ref

[46] Department of Human Services. 1997. *Quality Framework for Disability Services*. Disability Services: Melbourne

Standards or on a higher level quality processes are not suggested to increase bureaucracy or to develop overly officious systems but to increase stability and consistency within a service oriented scheme which allow consumers to navigate the system with confidence and trust, to establish mutual expectations between service providers and administering bodies that can be built upon to provide space to develop innovative and mutually beneficial procedures and programs and to provide transparency and accountability and therefore commitment to ensuring the successful, efficient implementation of the scheme objectives.

Implementation and Transition

1.15 Rollout

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

Once established it is very likely that changes to the scheme will be difficult to make. Long-term comprehensive project planning is required to identify each area of the scheme, how it will operate and interact with the other areas of the scheme to ensure objectives are met before change is embarked upon. It is also important not to reinvent the wheel and to incorporate, as much as possible, the elements of the current system which have been identified to be effective or would be with some modification.

In developing and transitioning to a new scheme the time frame for implementation would be dependent on those elements within it and the degree to which underlying strategies need to be in place to enable activation of other plans. For instance in terms of workforce planning and qualification; if the recommendation to establish specific tertiary qualifications for working in the disability sector was adopted, timeframes would have to consider the time to develop the curriculum and to have students complete their qualification. This could be two to five years before that aspect of the scheme could be in place. Whereas others may be more easily and quickly implemented.

Therefore, Anglicare Australia and its member agencies would not predict the timing of transition nor of the new scheme coming online. However, these suggestions are offered for consideration in determining a transition plan and overall implementation of the disability long-term care and support scheme:

Integration with other relevant agencies and agendas at a federal and state level, such as Centrelink, Taxation Office, Health, Education and Employment and the Social Inclusion Agenda, must be considered in the planning stages with clearly articulated protocols for how these will inform, communicate with and otherwise interact with the scheme prior to roll-out.

Monitoring and evaluation mechanisms must be established upfront with ongoing review mechanisms built in prior to roll-out.

Planning the implementation of the scheme should take into account future resources.

Stakeholder engagement must be maintained throughout the entire process ensuring that those who are to be affected by the changes either by inclusion or exclusion are informed and have ample opportunity to respond to information.

These comments make up the Anglicare Australia consultations regarding the Productivity Commission inquiry into a long-term care and support scheme for people living with disability and the people who care for and support them. These comments have been provided for use in the Commissions assessment of the feasibility of the scheme and Anglicare Australia and its members appreciate the opportunity to do so. Should it be required, further information may be obtained from Anglicare Australia; contact details may be found at the commencement of this paper.

Appendix 2: Consolidated List of Recommendations

Primary Recommendations

Recommendation 1: That needs-based methodologies be applied to new and existing services with the view to reforming systems to respond to client need.

With further consideration of:

a. the efficacy of diagnosis and assessment procedures for determining need in the context of a client-centred, needs-based methodology;

b. the contribution of disability support staff to the assessment process.

Recommendation 2: That an in-depth analysis of potential funding models is undertaken based on pre-determined operational frameworks, with a view to establishing a nationally consistent Disability Funding Programme.

With further consideration of:

a. disability support funding models being responsive to client need particularly taking in to account remoteness and complexity of need;

b. the principles of flexibility, individualised support and client choice;

c. administrative consistency across jurisdictions and service types.

Recommendation 3: That workforce planning and management are considered as integral to the establishment of a viable long-term care and support scheme and are included in planning and implementation of the scheme.

With further consideration of:

a. possible partnerships between government providers and the sector to improve disability sector workforce issues.

Recommendation 4: That a dedicated research and development stream be considered as integral to the feasibility of a long-term care and support scheme.

With further consideration of:

a. management of the research and development stream to be housed within the Australian Institute of Health and Welfare.

Secondary Recommendations

Recommendation 1: Development of tools and assessment measures to identify need in the context of the individual for the purpose of establishing appropriate individualised care plans and funding packages.

Recommendation 2: That the scheme adopt an individualised life-course approach to identifying the level of engagement for people living with a disability and people who care for and support them.

Recommendation 3: That a dedicated stream of research and development be attached to any new service structure or support scheme to further the knowledge base for supporting people with a disability.

Recommendation 4: That specialist support programs within services are established as part of an interconnected service program to engage 'hard to reach' and vulnerable population groups within regions.

Recommendation 5: To allow flexibility within funding systems to allow

- for comprehensive client-directed care ;
- for clients to transition to complementary or alternative funding management systems should they be required and

- agencies the scope to develop strategies to appropriately identify and engage clients in need of support.

Recommendation 6: That flexible housing options are factored into a National Disability Long-term Care and Support Scheme.

Recommendation 7: That community engagement and integration options are considered within the scope of a National Disability Long-term Care and Support Scheme.

Recommendation 8: That the scheme recognises where opportunities for early intervention originate and that support is provided to implement early intervention strategies.

Recommendation 9: to develop assessment processes which minimise the emphasis on benchmarking and focus' on the needs and capabilities of the individual. (Individualised approach)

Recommendation 10: That models of appeal and conflict resolution which reflect inclusive and respectful practices be explored.

Recommendation 11: That Government and the disability support sector commit to principles of flexibility, individualised service provision and client choice to allow the development of innovative and effective services which promote partnership and collaboration, and which adhere to nationally consistent quality standards.

Recommendation 12: That commitment is made to investigating a flexible approach to funding including consideration of the hours and brokerage models.

Recommendation 13: That nationally consistent service standards are developed and adopted in each jurisdiction.

Recommendation 14: That commitment is made to investigating a flexible approach to assessment and funding including consideration of a needs-analysis model for determining entitlement.

Recommendation 15: That a Disability Support Scheme does not exclude based on acquisition of disability.

Recommendation 16: That nationally consistent service standards are developed and adopted in each jurisdiction (1.7) for the additional purpose of public information and informing consumer choice.

Recommendation 17: That strategies are developed to improve service delivery that include flexible approaches to provide adequate individualised support for people in regional and remote areas.

Recommendation 18: That a commitment is made to developing common practices and information sharing protocols for all levels within the disability support sector.

Recommendation 19: That the collection, analysis and distribution of data from the disability sector be referred as a function of the Australian Institute of Health and Welfare.

Appendix 3: Anglicare Australia Network Members

AUSTRALIAN CAPITAL TERRITORY	Anglicare Canberra & Goulburn ● St John's Financial Assistance (Sue)
NEW SOUTH WALES	Anglicare Diocese of Sydney ● Anglicare New England NW Anglicare North Coast ● Anglicare Riverina Anglicare Western NSW Anglican Counselling Service Anglican Retirement Villages The Buttery CASPA ● St John's Anglican Church Darlinghurst ● Samaritans Foundation ● Social Responsibilities- Diocese of Newcastle ● Work Ventures Ltd ●
NORTHERN TERRITORY	Anglicare NT ●
Q UEENSLAND	Anglicare Central QLD ● Anglicare North QLD Anglicare Parish of Heatley EPIC Employment Services Inc ● Spiritus ●
SOUTH AUSTRALIA	ac.care Anglicare SA ● Anglicare Willochra Laura & Alfred West Cottage Homes Inc St John's Youth Services
TASMANIA	Anglicare Tasmania ● Glenview Community Services Inc
VICTORIA	Anglicare Victoria ● Anglicare Ballarat Gippsland Anglican Aged Care ● Benetas Brotherhood of St Laurence ● E Qubed Inc ECHO Inc Melbourne Social Responsibility Committee St Laurence Community Services Inc ● St Luke's Anglicare ●
WESTERN AUSTRALIA	Anglicare WA ● Anglicare South-Bunbury Diocesan, Anglicare Council ● Parkerville Children & Youth Care Inc Social Responsibilities Commission, Province of WA
NATIONAL & INTERNATIONAL	Anglicare StopAIDS PNG The Anglican Care Network ● The Selwyn Foundation Australian Council to the Mission to Seafarers Mothers Union Australia The Anglican Trust for Women

● Disability support service provider