INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

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ANGLICARE

THE CARE THAT CHANGES LIVES

Submission to the Inquiry into Services Provided or Funded by the Department of Ageing, Disability and Home Care

ANGLICARE Diocese of Sydney

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INTRODUCTION

ANGLICARE Sydney would like to thank the Legislative Council's Standing Committee on Social Issues for the opportunity to provide a submission to this Inquiry.

ANGLICARE Sydney is a Christian organisation operating a wide range of community services and programs across the Sydney Metropolitan and the Illawarra regions of New South Wales. Our range of services includes aged care both through nursing homes and community services; disability case management and respite; emergency relief for those in crisis; foster care and adoption including children with special needs; counselling and family support services (including Family Relationship Centres); youth services; shops which provide low-cost clothing; chaplains in hospitals, prisons, mental health facilities and juvenile justice institutions; and emergency services in times of disaster.

ANGLICARE Sydney receives significant funding from the Department of Ageing, Disability and Home Care (ADHC) for its community aged care and disability support programs. Therefore, in view of this relationship with ADHC, ANGLICARE is in an excellent position to comment upon the matters raised under the Terms of Reference to the Inquiry.

Outline of this Submission

The structure of ANGLICARE's submission generally follows the Terms of Reference for the Inquiry, namely:
1. Levels of funding and extent of unmet need
2. Variations in service delivery
3. Flexibility in client funding arrangements
4. Compliance with Disability Service Standards
5. Adequacy of complaint handling/grievance mechanisms
6. Program evaluation
7. Other matters.

The Terms of Reference for this Inquiry overlap with a number of issues also covered in the Federal Government's Inquiry into the Not-for-Profit sector, the final report from which was released in early 2010. ANGLICARE Sydney's view is that a number of the Productivity Commission's findings and recommendations are relevant to this current Inquiry. Consequently, ANGLICARE's submission makes reference, where relevant, to some of these recommendations.

1. LEVELS OF FUNDING AND EXTENT OF UNMET NEED

There are a range of issues that need to be considered in relation to determining the levels of funding given by ADHC to service providers. The issues of concern to ANGLICARE that are outlined in this section have already been raised in the Productivity Commission's Inquiry and reflect ANGLICARE's experience in its relationship with ADHC.

1.1 Need for full indexation of Government funding

ANGLICARE Sydney seeks to provide the best levels of care within the available funding. An important issue for ANGLICARE has been that funding provided through ADHC has not kept up with increases in real costs. Increases in

operational costs including staff wages have the effect of reducing the amount of care that can be provided.

This issue was dealt with as part of the Productivity Commission's Inquiry into the Not-for-Profit sector. The Commission recommended that:

> *Recommendation 10.2: In order to ensure that not-for-profits can sustain their workforces, and as wages are a major factor in the successful recruitment and retention of staff, Australian governments purchasing community services need to base funding on relevant market wages for equivalent positions. Costings need to take into account the skill sets required to perform the purchased services and be indexed appropriately to market wage growth within that industry sector.[1]*

ANGLICARE's view is that, not only is appropriate indexation of funding needed, but that there needs to be a better mechanism than indexation to the Consumer Price Index (CPI) to keep the funds for a service at its full dollar value. The CPI does not necessarily cover actual cost increases experienced by services, in which case the funding for programs can be declining in real terms within a couple of years. In this respect, ANGLICARE Sydney agrees with the Productivity Commission's finding that,

> *Cost estimates should cover all relevant and reasonable costs required for the service or activity, including evaluation and other appropriate overheads; and contract prices should allow for cost variations related to industry-specific cost factors and the impact of policy changes.[2]*

By way of illustration, there was a 1.7% indexation increase recently in ADHC funding. However this was insufficient to cover a 2.5% increase in wage increases over the period. Wages are a key determinant of costs, comprising over 70% of operational costs in some services. ANGLICARE Sydney is concerned that both ADHC and its Federal counterparts will ensure that funding is fully indexed during the transition in Government responsibilities for the provision of aged care and disability support by 2015.

Recommendations:

1.1 **Funding received from ADHC be fully indexed to reflect the true cost increases and market wage growth within the community aged care and disability support sectors.**

1.2 **The State and Federal Governments ensure that full indexation of funding occurs during the transition in State and Federal responsibilities for aged care and disability support to 2015.**

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[1] Productivity Commission 2010, *Contribution of the Not-for-Profit Sector*, Research Report, Canberra, pxlviii
[2] ibid, p275

1.2 Need for greater clarity of funding obligations

The Productivity Commission's Inquiry also discussed, at some length, the need for Australian governments to provide greater clarity to Not-for-Profits of the funding obligations of each party to a funding agreement. The Commission's view was that governments should fully fund those services that they would otherwise provide directly, particularly where such services are considered essential or part of the social 'safety net'.[3] The Commission recommended that:

> *Recommendation 11.1: Australian governments should, in the contracting of services or other funding of external organisations, determine and transparently articulate whether they are fully funding particular services or activities undertaken by not-for-profit organisations, or only making a contribution towards the associated costs and the extent of that contribution.*[4]

ANGLICARE's experience has been that the level of funds provided by ADHC, while intended to fully fund a service, often have to be supplemented with additional organisational funds. For instance we receive no capital funding for day centres within which community aged care services are delivered; the funding received only covers the cost of service delivery but not set-up costs.

The failure to fully provide for, or to keep up with changing costs, makes it more difficult for service providers to meet service outputs. Yet part of the difficulty is that ADHC does not reveal how funding adequacy is determined for a given set of service outputs. Even though funding diminishes in real terms, the expectation remains that service outputs will still be achieved.

Recommendations:

1.3   ADHC undertake to fully fund those services provided on its behalf by Not-for-Profit organisations.

1.4   Independent and transparent cost estimates of all reasonable and relevant costs be estimated for programs.

1.3 Need to reduce the compliance burden surrounding funding contracts

A significant cost factor for Not-for-Profits such as ANGLICARE is in the processes surrounding tendering, reporting and acquittals. The Productivity Commission Inquiry found that:

> *There is considerable dissatisfaction in the Not-for-Profit sector concerning the delivery of government funded human services. The very clear message from the sector is that current government tendering, contracting and reporting requirements impose a significant compliance burden and constrain the efficiency and effectiveness of service delivery. There is a sense of frustration that often these arrangements do not appear to result in improved service delivery outcomes for clients.*[5]

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[3] ibid, p290
[4] ibid, p xliv
[5] ibid, p308

ANGLICARE Sydney believes that such concerns have also arisen in our relationship with ADHC. This, however, needs to be set in the context of ANGLICARE's wider relationship with Government departments, both State and Federal. While there can be specific issues with an individual department such as ADHC, it is the need to simultaneously comply with the differing requirements of one or more departments which can create difficulties for ANGLICARE, particularly within the one service or program.

From this viewpoint, ANGLICARE welcomes the transition about to take place over the next few years, whereby the Commonwealth will become responsible for aged care services and the States will become responsible for disability services. ANGLICARE's view is that this transition should resolve many of the conflicting compliance requirements of different departments, provided that the responsibility for the care needs of groups which fall within both the aged care and disabilities areas can be resolved successfully.

ANGLICARE Sydney notes the State Government's commitment to work with the sector to reduce the amount of 'red tape' for Non-Government organisations, outlined in the report *Non-Government Organisation Red Tape Reduction*.[6] In relation to the compliance requirements of ADHC and other Government departments more generally, ANGLICARE Sydney contends that the following improvements are now needed:

a) **Streamlining funding applications and tenders, including across different Departments and levels of Government:** Most of the State and Federal Government funding available to the Not-for-Profit sector is accessed via a tender process. Each tender is specific and different from every other tender – with different criteria and demands. The process of tender application is unnecessarily costly and time consuming. Even where a relationship already exists with a department such as ADHC, Not-for-Profits are required to pour the same extensive resources into fresh tender processes. Streamlining the process, such as through reliance on information established through previous tenders and through referees, would reduce the administrative and resource burden on agencies and also provide a more equitable tender environment. The State Government's commitment to reduce the information required from NGOs in the tendering process by July 2010 should be noted in this regard.[7]

b) **Removal of multiple contractual and reporting arrangements across departments:** Every Government department, including ADHC, has a different funding agreement or contract with different accountability requirements. This creates issues in terms of multiple reporting and is extremely resource intensive, requiring considerable commitment of staff time by Not-for-Profits. In general, having one simplified contract with any government department with one end date and simplified reporting requirements would be helpful. This would also reduce auditing requirements. The State Government's commitment to develop a small suite of contracts is noted.[8]

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[6] NSW Department of Premier and Cabinet, December 2009.
[7] ibid, p15
[8] ibid, p16

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

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

Recommendations:

1.5   ADHC should review and streamline its tendering, contracting, reporting and acquittal requirements in the provision of services to reduce compliance costs, as outlined in this submission.

1.6   The State Government should take steps to overcome inconsistencies between the tendering, contracting, reporting and acquittal requirements between different State and Federal departments.

1.4 Unmet community needs

Ageing parent carers of children with a disability

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

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

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

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

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

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

There is evidence in the research that services such as the Support Coordination program funded by ADHC are meeting needs among ageing parent carers. However ANGLICARE's research also points to areas where service provision could be enhanced; this is dealt with later in the submission.

Community aged care – clients with dementia

When providing a personal service, such as showering or grooming, dealing with a client who has dementia takes more time. For mainstream services as opposed to dementia specific services, this increases the cost of service delivery and puts pressure on the meeting of service outputs. Similarly for mainstream services providing day centres, staffing needs may be higher where there are greater numbers of people with dementia.

Given that dementia is on the increase in the community, the issue of more funding for services and, hence, the better meeting of the needs of this group deserves consideration.

Flexibility in meeting needs

HACC funded services focus on providing person-centred care. However clients can be afraid to temporarily leave a service because it places them at risk of having to wait until another vacancy becomes available. Some HACC services have long waiting lists; therefore it is an incentive for the client to stay on regardless of whether they need help with the activities of daily living.

·In addition, the current system gives an incentive to service providers to retain clients, in order to justify service funding. However there needs to be greater freedom and incentive for people to move in and out of the system, and with more entry points, to ensure that they are receiving the most appropriate care. This

would shift the emphasis of care more towards the rehabilitation and capacity-building of clients and their carers rather than retaining them within the care system.

Recommendations:

1.7 Further funding and program development be provided to meet the needs of ageing parent carers of adult children with a disability.

1.8 Additional funding be provided for services to better cater for the needs of the growing number of dementia sufferers in the community.

1.9 Reforms to the care system be considered which shift the emphasis of care more in the direction of rehabilitation and capacity building of clients and carers.

2. VARIATIONS IN SERVICE DELIVERY

The Terms of Reference indicate that the Inquiry is interested in variations in service delivery, waiting lists and program quality between services provided or funded by ADHC, and ADHC Regional areas.

ANGLICARE Sydney operates across ADHC regional boundaries. Consequently ANGLICARE deals with different ADHC regional offices. ANGLICARE has experienced inconsistencies in its relationships with ADHC offices. Different regional offices can have different forms for completion. The extent and priority given to communication with ANGLICARE can vary greatly. Some regional offices are more proactive than others. Some offices make it a priority to make contact with organisations that have won tenders and to follow-up progress on the establishment of new services. Others don't give such communication the same priority.

ANGLICARE Sydney has also found that communication is hampered by the constant change in ADHC's regional staff. Rapid staff turnover means that ANGLICARE staff need to repeatedly brief ADHC officers about issues connected with our service provision. ANGLICARE's observation is that this problem of staff movement and hampered communication is more significant with ADHC than with most other Government departments. It is uncertain whether the higher levels of staff movement stem from transfers within the department or staff leaving the department.

Waiting lists are a major issue. Domestic assistance (eg. household cleaning) and personal care (eg. showering, grooming) both have long waiting lists. Both in-home and out-of-home respite also have long waiting lists. ANGLICARE Sydney's belief is that waiting lists vary significantly by organisation and that some organisations hold onto long waiting lists rather than transferring clients to other organisations.

The existence of many different service providers means that it will always be a challenge for clients to navigate their way through the system and arrive at the best service provider to meet their needs. Since there are so many different providers, they also tend to have different policies and procedures. This is confusing for clients as they exit one service and enter another.

Recommendations:

2.1 *Communication guidelines be established to create greater consistency across ADHC regional offices in their dealings with Not-for-Profits.*

2.2 *The issue of high levels of staff movements within ADHC be addressed.*

2.3 *More funding be provided to overcome persistent waiting lists for certain services resources.*

2.4 *An ADHC 'one-stop-shop' be established as an entry point for all referrals and assessments.*

2.5 *More collaboration take place between services to create more consistency in policies and procedures for clients and to ensure best practice.*

3. FLEXIBILITY IN CLIENT FUNDING ARRANGEMENTS

The Productivity Commission's Inquiry into the Not-for-Profit sector concluded that while the purchaser-provider model remains the best model for service provision in most situations, client-directed service delivery models may be more appropriate in some situations. Inter alia the Commission recommended that:

> *Recommendation 12.1 ...where truly competitive markets develop and clients face real choice in the services available to them, governments should consider moving to client-directed service delivery models. This transition should be conditional upon there being appropriate safeguards in place to protect and empower vulnerable clients (or their carers) in exercising choice and ensure an acceptable minimum level of service quality and provision*[9]

A direct funding pilot was initiated by the Department of Disability, Ageing and Home Care (DADHC) in 2007, where 10 clients in the Attendant Care Program received direct funding for the purchase of personal care services and the ability to hire their own staff.[10] The evaluation reported on a range of care improvements, including the improved quality of attendant carers, lower turnover rates, better training, flexibility, reliability and greater efficiency. As a result of these improvements, participants indicated that they were experiencing improved health and wellbeing, confidence, self-esteem, and increased participation in social, economic and community activities. The program was regarded as being cost effective, especially in terms of improving relative care outcomes for the same or lower costs, when compared to traditional care arrangements.

Client-directed care programs have also been trialled in other States, including:

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[9] Productivity Commission 2010, *Contribution of the Not-for-Profit Sector*, Research Report, Canberra, pL.

[10] Fisher, K.R. and Campbell-McLean, C. (2008), *Attendant Care Program Direct Funding Pilot Evaluation*, SPRC Report 11/08, final report prepared for the NSW Department of Ageing, Disability and Home Care, Submitted March 2008, Published: August 2008

- *Dept of Human Services, Victoria:* A preliminary evaluation report of the Direct Payments Pilot was released in August 2007, with the 10 participants reporting successful outcomes in terms of flexibility, control, managing their expenditure and negotiating a relationship with their service provider. A full evaluation report is due for release in 2010.[11]

- *Victorian Transport Accident Commission:* Established a self-purchasing program for individuals with severe injuries, where the funds can be paid directly to the client. The evaluation identified several benefits, including client empowerment and satisfaction, service availability, flexibility and cost stabilisation. Drawbacks included the labour-intensive implementation phase and an initial lack of clarity between brokerage and case management.[12]

A review of the literature suggests that some of the benefits of client directed care can include:

- Increased levels of satisfaction among clients
- Savings in administration costs
- Greater flexibility and choice for both clients and carers.

ANGLICARE Sydney is aware of different models of client-directed service delivery and the advantages and benefits that can come with these. However ANGLICARE is also concerned that, as recommended by the Productivity Commission, there be appropriate safeguards in place to protect and empower vulnerable clients (or their carers) in exercising choice and ensure an acceptable minimum level of service quality and provision.

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

- A system of client-directed care must be designed to avoid burdening clients who lack the appropriate skills or finances to manage their own care. Such programs require much input from these individuals and their families, especially where it involves having to negotiate an individual workplace agreement with paid care staff. While many people will be willing to assume responsibility to find, hire and manage a service which suits them, there are other clients who will not want this responsibility and will be burdened by choice. There is a danger that by cutting out service providers, Governments will shift the administrative cost and responsibilities to clients.
- Not all people have the literacy, experience and help needed to assume full autonomy – some groups such as CALD and ATSI groups may be further disadvantaged by a client-directed care system. Client-directed care is less likely to be taken up by older people.
- Successful client-directed programs are dependent upon the provision of support for service users, such as case management, brokerage services,

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[11] LDC Group (2007), *Evaluation of the Direct Payments Project*, final report prepared for Community and Individual Support, Disability Services, Department of Human Services, August 2007, Armadale.

[12] Howe, A. (2003), *Is Consumer Directed Care a Direction for Australia?: A Position Paper prepared for Alzheimer's Australia*, Melbourne.

financial agents, advocacy and counselling. This will result in increased costs for Government to put a proper system into place.

- Clients may not receive sufficient funds to account for the real costs of their care under 'cash for care' models.
- The potential impact on salary and benefits for disability and/or aged care sector staff, including differences between those employed by traditional service providers and those employed directly by carers and clients.
- Potential to alter the relationship between the primary carer and care recipient. For instance, 'who is the client?' becomes an issue where there is both a carer and an adult with a disability. Where there is conflict between the two, who will hold the funds and make decisions for adults with a disability?
- Maintaining the strength of traditional service providers, to continue to cater for service users (especially older people) who would prefer to use a service agency as a source of receiving care, as opposed to using family, friends or other private carers.

Recommendations:

3.1   *ADHC undertake much larger pilot programs of client-directed care models, across different service types.*

3.2   *When considering client-directed care, the State Government identify and adequately fund the provision of necessary support systems.*

3.3   *Evaluation processes also be put into place alongside any proposed systems of client-directed care.*

4. COMPLIANCE WITH DISABILITY SERVICE STANDARDS

ANGLICARE Sydney is satisfied with the Disability Service Standards, as well as the HACC standards. Both sets of standards have much in common. However the existence of the two sets of standards leads to multiple compliance and reporting requirements for programs funded within both streams.

This duplication is also an issue for community aged care programs, since there is no single set of standards to report against but rather a plethora of standards and frameworks that creates significant overlap at a time when community care programs are increasing, in number and service type. Although a common National Quality Reporting Framework is being piloted it is yet to be endorsed or implemented nationally.

There are significant variations in the expectations that various Government Departments place on programs in order to meet accreditation standards. These variations take up considerable resource and staffing time. One agency can have a mix of funded programs where various reporting mechanisms and processes are very different for HACC and Commonwealth funded programs.

Recommendations:

4.1 *A common set of standards be established for the Disability Services Program and HACC. People with a disability be included in the consultation process for such a revision.*

4.2 The different approaches between State and Federal Governments for monitoring and assessment frameworks be reviewed with the aim of bringing about a consistency of approach.

5. ADEQUACY OF COMPLAINT HANDLING AND GRIEVANCE MECHANISMS

ANGLICARE Sydney has had a good experience of complaint handling procedures administered by the NSW Ombudsman's Office. We believe that the approach taken by the Ombudsman is transparent, fair and simple. ANGLICARE does not see any need to alter this system.

ANGLICARE is aware, however, that passing the responsibility for aged care to the Federal Government may mean that elements of this system may be lost in this transition.

Recommendations:

5.1   *No change be made to the existing procedures involving the NSW Ombudsman.*

5.2   *The Government seek to preserve the key elements of this system during the transition in Government responsibilities in the sector to 2015.*

6. PROGRAM EVALUATION

6.1 Need for evaluation of service delivery

ANGLICARE Sydney believes that ADHC mostly carries out evaluation in relation to policy and procedures, finance and governance, but relatively little evaluation of service delivery. There is little by way data collection on the impact of services on the well-being of clients. There is too much emphasis on service outputs and not enough on client outcomes. There is a need for the evaluation of client outcomes to be expanded and the findings shared with Not-for-Profits. This information would assist in bringing about program improvements and enable comparisons between providers, to identify best practice models and to further improve services.

The Productivity Commission's Inquiry into the Not-for-Profit sector has highlighted the necessity of evaluation for productivity improvements and has strongly recommended the funding and implementation of evaluation practices among Not-for-Profits. The Productivity Commission is also recommending the use of evaluations to help identify the contributions of Not-for-Profits on individuals and the community, and to help shape data collections. While these are all worthwhile objectives, ANGLICARE Sydney's experience is that:
- there are many kinds of evaluations and there is no agreed best practice in the area
- evaluation is costly and can be resource intensive
- larger organisations would be in a better position to carry out robust evaluation than smaller organisations
- funding should not be made contingent upon evaluation being carried out; evaluation should have the goal of improving Not-for-Profits' service delivery and enriching the whole sector

- there is a lack of expertise in most organisations to carry out robust evaluation.

Recommendations:

6.1   Evaluation of services, particularly in the meeting of client outcomes, be expanded by ADHC.

6.2   The current limitations of evaluation practice be addressed by ADHC in further expanding the evaluation capabilities of the sector.

6.2 Funding for evaluation

It is possible that evaluation could become another kind of compliance burden which the Productivity Commission is keen to minimise. ANGLICARE Sydney's view is that Government should pay for evaluation to be carried out within program budgets, and that evaluation should only be mandatory for programs above a certain dollar value. There is a need for regard to the size and nature of programs in arriving at the scale of evaluation that may be required.

Recommendations:

6.3   Should evaluation of ADHC funded programs be extended as a result of this Inquiry, that the State Government pay for evaluation to be carried out within program budgets.

6.4   Evaluation should only be mandatory for programs above a certain dollar value.

6.3 Return of data to Not-for-Profits

Each government funded program has its own reporting requirements and separate database system. This requires data entry at the service end but provides minimal reporting back to the services or the return of such data. It is generally not possible to access the program data once it has been entered in either the State or Federal Government databases, and so a system of double entry of data is required – which is extremely time consuming and inefficient for Not-for-Profits.

Currently a significant amount of data is being captured by governments in various databases for various programs across the country. However there appears to be no intention to consolidate and analyse this data for high level reporting back to the sector on performance and outcomes. There is a consistent focus by government on inputs into the programs but very little reporting of outputs or outcomes back to the sector. Benchmarking and regular reviews of performance in key funding areas would be possible if such global data analysis was carried out.

Recommendation:

6.5   The current data capture system for ADHC-funded programs be reviewed, with the aim of providing maximum data access to services for their own reporting and internal evaluation purposes.

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7. OTHER MATTERS

7.1 Practical measures to better support clients and carers

ANGLICARE believes that what clients and carers require is access to substantial care packages, information and education, accessible respite and accommodation and other support options – both emotional and financial. For each carer the circumstances may vary as to whether they are sole or dual carers and whether they have other family support or experience cultural barriers in terms of service access. This section of the submission outlines practical measures to be considered as part of further enhancing ADHC's role in assisting ageing Australians, people with a disability and their carers.

Case coordination and management

Case coordination and management is an important component in assisting clients and carers. However to be effective, it needs to reflect best practice, be well resourced and be strongly client focussed. Case management for many disability programs are centred on outcomes for the person with a disability, not the carer. For those services which consider case management for both, there are long waiting lists.

Recommendation:

7.1   *Funding be provided for case coordination involving both the carer and care recipient, and also to provide longer term case management for both carer and care recipient.*

More supported accommodation

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

Recommendation:

7.2   *More supported accommodation be provided, including the provision of accommodation which would allow ageing parent carers and their adult children with a disability to co-locate in the same or adjoining facilities.*

Respite care

A major need for carers is the availability of respite services. This applies across the spectrum of carers taking care of people with disabilities, chronic illness and at the end of life. In ANGLICARE Sydney's view, there is still a shortage of both emergency and planned respite beds. There is limited subsidised respite for people

with disabilities such as vacation respite care, overnight respite or weekend day programs and respite options for children under 16 years with disabilities.

Recommendations:

7.3 **More short term respite accommodation for adults with disabilities be provided, both planned and emergency accommodation.**

7.4 **Funding for more community-managed respite houses be provided for both emergency and planned respite.**

Guarantee of booked respite care

Planned respite cannot be guaranteed in those subsidised respite houses that are managed by Government departments (ADHC or FaHCSIA).

Recommendation:

7.5 **Advance bookings in ADHC-subsidised respite houses needs to be guaranteed.**

Out-of-home respite for people with challenging behaviours

There is a lack of residential respite for people with disabilities who also have behavioural problems. There is a waiting list for an ADHC-funded behaviour intervention service for a young person with a disability. But respite is difficult to find until the behaviour can be managed. Therefore there is a need to reduce this waiting list.

Recommendation:

7.6 **Behaviour management services receive a funding boost to reduce the waiting list.**

Respite beds in nursing homes and hospitals

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

Recommendation:

7.7 **Tighter regulations be put into place to ensure that respite beds in nursing homes are planned and managed as exclusive respite beds.**

In-home respite for ageing carers

Many carers are uncomfortable with out-of-home respite. In an in-home respite situation, staff become familiar with the client receiving care, whom the client learns to trust. The care giver too becomes more confident in the respite care as they observe the staff person giving care such as personal care/ showering, activities

around the house, going for drives etc. It is then more likely they will be willing to leave their loved ones in respite situations.

Recommendation:

7.8   Funding be increased for in-home respite care.

7.2 Practical measures for different carer groups

The needs and kinds of practical help that carers require will vary substantially depending upon the demographics of the carer and the type of disability experienced by the client.

Young carers

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

Along with the lack of mentors, it is ANGLICARE Sydney's view that more could be done by schools to assist young carers to better manage their situation. A starting point would be the provision of information for local school authorities. There needs to be more understanding from schools about the caring situation of young carers.

Young carers need computers with internet connection for their schooling as their families often lack money to purchase one and the young carer does not have the time to use computers in libraries. Some families cannot even afford the heavily discounted computers available through Centrelink.

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

Recommendation:

7.9   The specific needs of young carers be better addressed including increased case management, educational needs and the fostering of mentoring and social relations.

Ageing parent carers

Research indicates that many ageing parent carers are hidden and have never engaged with formal services[13]. For ageing carers in particular, their role has been a long term one, they have confidence in what needs to be done and there is

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[13] Carers Australia, (2005) *Ageing Carers: Succession planning and long term needs: A response to the federal Government's Budget Initiative 2005-9,* sighted on 16th April 2007 at http://www.survivingthemaze.org.au/Assets/pdfs/PolicyDocs/AgeingCarersSucessionPlanning.pdf p3

sometimes reluctance to hand over the care of their adult child to others. Many ageing carers have found services not suitable for their offspring or have had negative experiences which has made them reluctant to pursue further service access [14] For ageing carers there may also be issues with social isolation and a sense of self reliance which has inhibited their access to services.

For ageing carers there are a number of specific issues that need to be addressed:

- Assistance with services particularly in relation to respite, home care, residential placement and financial and legal support.
- Access to age appropriate social activities for the adult with a disability
- Access to programs which develop independent living skills in the adult child with a disability
- Education for the family on the service system as it currently operates and the services which are available should they choose to access them
- Provision of support with planning for the future regarding financial, residential or guardianship arrangements
- Provision of intensive support for first time respite users
- Appropriate linkages with the aged care system where appropriate for the carers' own aged care needs
- Ensuring the carer's own needs are addressed including caring for their own health and well being and future life planning.

Recommendation:

7.10 *In providing further funding and program development for ageing parent carers of adult children with a disability (see recommendation 1.7), specific issues be addressed as outlined above.*

Carers from CALD and Indigenous backgrounds

Some measures which would assist carers from CALD and Indigenous backgrounds include:

- It is foundational to a CALD or Indigenous respite service that clients and carers be linked to services and programs which reflect similar values, beliefs and understandings.
- There is an need for respite programs to be responsive and culturally sensitive. ANGLICARE maintains the importance of providing workers who are either from a similar background, speak the relevant language or who have received cultural competency training to ensure that the person with a disability receives a service which is respectful and conforming to their commonly held values and belief system.
- There is a particular need for more bilingual counsellors among CALD groups.

Recommendation:

7.11 *Measures to assist carers from CALD or Indigenous backgrounds be implemented.*

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[14] Ibid

7.3 Workforce planning

It is becoming increasingly difficult to find appropriately skilled and qualified staff for aged care and disability support programs and to properly remunerate such staff. Increased funding is required in order to raise the base wage rate in order to attract the appropriate people with skills into the sector. Attracting qualified personnel is reflected in the remuneration offered and as such Government must increase funding accordingly. To operate to best practice standards, Not-for-Profits must seek to be Employers of Choice and to do this must offer better conditions, opportunities and reasonable, comparable pay rates. This will encourage younger qualified people to see aged care and disability support as a real career option.

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

Recommendations:

7.12   Government provide increased funding is required in order to raise the base wage rate in order to attract the appropriate people with skills into the sector.

7.13   Other workforce planning measures such as better career pathway definition and benefits attractive to potential employees also be identified.

CONCLUDING REMARKS

I would like to thank the Legislative Council's Standing Committee on Social Issues for the opportunity to provide this submission to this Inquiry. I trust that our submission will provide useful material for the Inquiry's deliberations.

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