Submission
No 21

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

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ParaQuad
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Inquiry in services provided or funded by the Department of Aging Disability & Home Care

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promoting *independence* after spinal cord injury

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BACKGROUND

ParaQuad NSW is a not-for-profit organisation formed in 1961, and provides vital care, support and clinical services to people with a spinal cord injury (SCI), their families and carers. We currently have a membership of 1,700 people with SCI.

For the past 49 years, ParaQuad NSW has assisted with the provision of services to the SCI community through:

- Transitional, respite and permanent accommodation;
- Spinal specialist nurses, occupational therapists and social workers to support individuals and families
- A Home-based personal care program currently servicing over 80 individuals across NSW
- Education and training programs for people with SCI and specialist services who are providers of care
- Community and corporate awareness training on provision of accessible services and programs

ParaQuad receives funding through ADHC for:

- Residential Services at Ferguson Lodge $2.6M. Under " Stronger Together" ParaQuad received an additional $5.5M contribution, which was matched by a contribution from the Motor Accidents Authority, towards the capital redevelopment of this facility , which is scoped to provide care for 40 people with SCI.
- A contribution of $93K to supervise and support a Transitional Housing Program in Sydney and Newcastle (5 Studio Units / 5 x 2-3 bedroom homes, 1 3 bedroom unit)
- A funding contribution to information, support & advocacy in the Hunter Region and;
- A contribution of $106K to support the clinical case management services within the Primary Health Care Team.

2009 SURVEY OF MEMBERSHIP

Historically, ParaQuad has bridged the gap in the provision of services to the SCI community. In 2009 we conducted a membership survey which identified that people with SCI in NSW continued to have the following concern and requests:

<u>Equipment and individual needs</u>

- Interest free loans are required for new equipment when PADP can't supply
- supported exercise programs and equipment to support fitness require funding

<u>Information and support</u>

- support for young carer
- to attend activity groups
- assistance for day trips
- emergency short term care
- ageing planning, facilitating changing of premises, perhaps tax relief for changes due to ageing e.g. stamp duty relief for changing homes
- care and support for carers, especially aging carers
- group outings

<u>Attendant Care – Home Care</u>

- Clients stated that the limited availability of Attendant care packages available disenfranchised individuals, especially if they receive their injury in their 50's

- low cost in-home personal care is required for over 65's to support life at home
- more attendant care services, particularly bowel care
- outreach services rural and remote
- emergency respite care longer hours of daily care
- home maintenance help should be funded separately to care

Accommodation

- housing and accommodation options for people with physical disabilities are required in the Central Coast, Hunter region and the ACT - nursing homes are not appropriate for young people nor do they have the expertise required to care for people with SCI
- Additional respite care
- Major concern re needs for supported accommodation when parents die

General Support Required

- support for better tax relief for people with SCI living on investments tax relief for post-pension level incomes
- financial support for vehicle modification costs

IN ORDER TO ADEQUATELY ADDRESS ISSUES FOR OUR ORGAINISATION THE FOLLOWING IS SUBMITTED AGAINST THE TERMS OF REFERENCE FOR THE ENQUIRY.

a. The historical and current level of funding and extent of unmet need

The extent of unmet need is difficult to ascertain as there is no real data available which can identify the number of people with SCI currently living in NSW. In trying to research this issue ParaQuad employed a researcher to investigate the demographic profile of people with spinal cord injuries in New South Wales. In addition we tried to determine the location, age, nature of annual incidence of people living with spinal cord injuries (SCI), the support landscape and profile of support services already in place for people with SCI, the level of need for particular age groups, the range of disability within people with spinal cord injuries and access to care issues in non-metropolitan and rural and remote areas.

The information asked for related to age, postcode, cultural group/language group and gender. Additional information that was relevant was the date of injury which gave an indication of how long the person had been living with SCI.

Key barriers to conducting this research were:

- Hospital separation data had only been kept since 1995. In addition, people with SCI are not always re-admitted to designated spinal units when they need treatment for health issues, but are more likely go to mainstream hospitals where hospital separation data is not always clear, dependant on reason for admission.

- State Spinal Services have only existed since 2003 – so data is limited

- ADHC were unable to quantify the number of people with SCI receiving funding for Attendant Care / Home care services

- Centrelink do not routinely collect data on Type of Disability
- The National Injury Surveillance database was seen as a useful line of inquiry, however access was denied due to privacy concerns
- Preventing double counting is a big problem as there are no "unique identifiers" which allow separation of data

Therefore unmet need can only really be determined by anecdotal evidence which is gathered at point of contact with individuals receiving service or via targeted consultation and survey. From this perspective we know that there is consistent difficulties with :

1. Accommodation for people with high level physical disability. Whilst ADHC has funded the redevelopment of Ferguson Lodge, there is still no commitment by ADHC to fund the operations of the new facility. The building is due for completion in February 2011 and, at present, there are no funds to make the facility fully operational for the 40 beds available.

2. Access to Attendant Care packages;

3. Access to Community participation packages for people with physical disability;

4. Reduced service availability in rural and remote areas;

5. Waiting lists for seating and therapy programs;

6. Limited support for people who have mental health or psychosocial health issues

b. Variations in service delivery, waiting lists and program quality between:
i. services provided, or funded, by ADHC,
ii. ADHC Regional Areas,

Funding streams for services and programs are confusing, bureaucratic and bound by policy frameworks which are predominantly targeted at people with an intellectual disability.

There is significant variation in the numbers of services available for people with high level physical disability in comparison to intellectual disability or brain injury. This is evidenced by way of:

- ADHC policy frameworks which predominantly target needs of people with intellectual disability
- Lack of recognition by ADHC staff that people with physical disability have normal cognitive function; therefore do not often require case management as they are able to make independent choice and decisions related to their needs.
- Lack of partnership with NSW Health re the provision of therapy services or equipment services;
- There is a disconnect between NSW Health, ADHC and Housing in the provision of services. Thus there is a need for a system of comprehensive service planning between these key agencies.

There is concern that Homecare will not provide any services to a person if they are considered too high needs, in preference they leave them with nothing. This leaves the most vulnerable without any support within the community

Delays in processing one-off funding for clients on the Attendant Care program can delay the purchasing of essential equipment. Some clients may sit in a high Band for Enable

(which does not necessarily mean that they are high income earners and can afford to purchase their equipment). As such, they wait for equipment that will ensure the safe provision of care or to assist them to live more independently in the community.

Attendant Care High Needs Pool staff (ACHNP) do not contact clients when assessing their priority, and do so merely on the supporting documentation provided. Clients are not contacted by the program until there is a package for allocation.

Clients living in the community with diminishing compensation funds experience high levels of stress while awaiting contact from and the commencement of government services to enable them to remain in the community.

The lack of available attendant care packages available and lack of alternative options for people with a high level physical disability has a direct impact on the number of younger people in aged care facilities requiring support from another underfunded ADHC program.

c. Flexibility in client funding arrangements and client focused service delivery

There have been some significant changes made by ADHC to ensure that funding arrangements for some programs are client focused and flexible to meet need. This is especially evident in the launch of self funding models within:

- Attendant Care and;
- Life Choices & Active Aging Program.

There are however ongoing concerns regarding availability of funding and places defined within these programs. While it is understood that there are always funding restrictions, the weighted priorities appear to leave some of our most vulnerable without access to services.

ATTENDANT CARE

ADHC staff within the Attendant Care Program in NSW are responsive to clients who are on the program and are supportive of client needs within the framework of the guidelines.

Whilst it is excellent to see individual requests considered, there has been little done to ensure that all people with a disability have equal opportunity to gain access to services. The availability of packages remains limited and often restricted. Below are a number of examples and cases which outline the process for getting assistance for some of our clients:

CASE 1: This first referral took 12 months

- *28.04.09 – Referral made to Homecare. Advised branch at capacity not accepting referrals*
- *1.05.09 - Application for attendant care and high needs pool (HNP) faxed. Advised at a later date that application had been given a low priority.*
- *01.07.09 - Referral to Homecare accepted with new FY funding*
- *23.07.09 – Homecare assessment – determined that personal care needs were too high for program. No services will be provided*
- *05.08.09 – Review of ACHNP priority requested*
- *04.09.09 – Further review of ACHNP priority requested*
- *28.09.09 – Advised that client had been referred for assessment*
- *02.10.09 – Assessment for HNP conducted*
- *20.10.09 – Report submitted to DADHC from assessor*

- *28.10.09 – Advised that report from assessor had been received*
- *24.11.09 – Email received advising that services had been approved*
- *15.12.09 – Assessment for HNP care services from Homecare – advised that services would commence mid-January*
- *Services commenced in end of March/April 2010*

CASE 2: A further example of restrictions to service availability can be given by way of a case on which staff member at ParaQuad is currently working:

A ParaQuad Social Worker was recently referred a person who is Ventilator Dependent and who is 22 years post injury. Up until this point, the client has funded his own care and support needs in the community from his compensation funds. Unfortunately these are running out, and it is estimated that he has around 9 months of his finances left.

The client contacted the staff within the Attendant Care Program and was advised that he would firstly need to liaise with Enable within NSW Health. ADHC staff did not offer to assist with this referral nor did they support this gentleman's request for assistance.

Both the Social Worker and the client have been liaising with Enable who have advised of the client's ineligibility for the Adult Home Ventilation Program based on the fact that he is:

- *Currently living in the community*
- *He is not in receipt of the Disability Support Pension and*
- *He has previously received compensation*

As this gentleman is 52 years of age he is also rapidly getting to the point where he will not be prioritized for either the Attendant Care Program or the High Needs Pool. Therefore within 9 months it is highly likely that this person will need to present at an acute hospital which is the only other alternative for someone requiring ongoing ventilation support.

There are often restrictions on the number of packages available and limitation on people being accepted on to any care program or package between the ages of 60-65.

CASE 3: Another case example which has had a negative outcome for an individual client and his family is outlined below:

ParaQuad accepted a gentleman, into our residential care facility, for transitional care whilst his home modifications were being done and he awaited allocation of an Attendant Care Package. As the client was 60 at the time of his injury, he was not prioritized on the wait list. The said client passed away at the age of 63 whilst still in residential care, despite having a fully renovated property to return to with his family. His family therefore went through the expense of modifying his home and never had the chance to live with him after his injury. Representation was made to Metro North ADHC staff throughout this time to support his application, however little was done, too late to assist this gentleman.

High Needs Pool:

Priority is given to clients that are currently inpatient in a hospital setting, not residential care. Clients that are living unsafely in the community are not considered a priority as they are not bed blocking. It should not require an (or multiple) admission to hospital for someone to access services.

Older people are no longer prioritized by ADHC, and there have been issues in relation to people over the age of 60 years being provided with a care package. This is experienced as people age with a disability and for people that are newly injured later in life.

Previously ADHC issued HNP packages to keep independent older people out of nursing homes (i.e when they are no longer able to self transfer but are independent in all other life areas) or to enable people over 60 years to be discharged into the community after their hospital admission. At the point of injury, people over 65 are unable to be assessed for CACP or EACH packages as they are community based packages that require assessment within the home. There are minimal options for people over 60 years.

Yong People in Residential Aged Care (YPIRAC):

Whilst this initiative has merit, the services that this program provides are quite vague and not transparent. There is no clear understanding of timeframes for assessment, types of funding packages, structure of programs, and ambiguity surrounding the services that can be provided within the sector.

This program appears to be underfunded, poorly resourced and is unable to effectively support young people to transition to supported community living or to remain mentally well while living in such an unsuitable environment.

Vacancy Management Program:

ParaQuad has raised concerns with ADHC Metro North and with the Director General regarding the bias of the Supported Accommodation Policy towards people with intellectual disability and although this is agreed there remains a disconnect between client needs and the policy framework.

CASE 4: A recent referral through the Metro North Intake & Referral line raised the following issues:

- *There was a clear lack of understanding of the needs of our client group, or an understanding of the purpose of Ferguson Lodge. The Social Worker was advised to contact ACAT to find suitable residential placement despite the client being in her 50's.*
- *Advice was given that every client that applies through the program required an appointed case manager (difficult to obtain case management when they have capacity to manage their own affairs and goals)*
- *The applicant found the process confusing as to complete the client profile and risk profile, the information requested is targeted at intellectual disability and not relevant for people with high level physical disability and high level cognitive functioning.. This creates challenges in trying to complete the documentation as accurately as possible when questions are not relevant to their circumstances.*

- *The applicant was attempting to get immediate placement, not a placement in the future, so was told that I need to demonstrate that all other options (including ACAT) were exhausted before being accepted for immediate placement. Unable to understand if there are no other clients awaiting placement at this facility why the client has to wait to be placed?*
- *The only other option for this client now is to go to a Nursing Home at the age of 50, this seems incredulous.*

Homecare:

Home Care appears to have wide variations in wait list times for access to services in different regions. There are marked differences in metropolitan regions also. Historically, some Home Care branches have had to close their books and not accept new referrals as they have no funding. .

CASE 5: Waiting times to make telephone referral through the Referral and Assessment Centre are unreasonable. *On 11.05.10 a call was made to make a referral for domestic services for a client and waited on hold for 1 hour and 50 minutes before the call was taken.*

Active Aging & Life Choices Program:

ParaQuad has been successful in bidding to become an Approved Provider through this program. To date we have been unable to commence service due to the restriction on the number of packages available. As such, we have had to reduce staff hours which inhibits the service viability of this program.

d. Compliance with Disability Service Standards

In all aspects of service delivery, ADHC endeavors to build strategies and initiatives on the foundation of the Disability Service Standards. However there is often non - compliance related to Access for people with high level physical disability due to the following reasons:

- An entry and exit criterion to services and programs is restrictive and often biased towards younger people with an (intellectual) disability.
- Unless someone is injured in a motor vehicle accident, access to care and coordinated support is ad hoc and complex. Clients and families are expected to "ring around" and "discover" their entitlements.
- Policy frameworks are bureaucratic and often have no tangible relevance to the role of the ADHC funded service

e. Adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services.

Complaints forwarded to ADHC staff from services are often well received however there appears to be delayed action on following up matters raised. Where individual clients voice concerns, their complaints appear to be dealt with quickly, so as not to cause political damage.

Our experience with external advocacy services has identified that there is great opportunities for individuals to raise concerns outside the service arena, which is a concept that ParaQuad would support. In the past year we have worked well with:

- Office of the Ombudsman and
- Multicultural Disability Advocacy Service

f. Internal and external program evaluation including program auditing and achievement of program performance indicators review

Other than financial acquittals and the HADS database, there is little interaction with ADHC re the ongoing quality of services provided. The Integrated Monitoring Framework (IMF) was an attempt to improve this as to a point worked well. The concern however is that such a strategy is seen simply as an audit – not a quality improvement process. ADHC commenced scoping opportunities to set up their own quality framework however this appears to be a waste of resources when there are a number of good standards already in place which could give endorsement to ADHC funded facilities.

Recognising the importance of quality, ParaQuad has initiated review and accreditation with a range of providers to ensure effective systems of care, clinical and corporate governance. As such we currently hold certification under the:

- ISO 9000 Standards
- Quality Improvement Council Standards for Primary & Community Care
- FaCHSIA Disability Service Standards and
- We are currently engaged for a review under the Attendant Care Industry Management System Standards

Therefore for ADHC to require addition certification appears to be bureaucratic. It would be more meaningful to formally accept recognized Accreditation. If additional information is required, an annual report on KPI's identified within the Service Description Schedules should suffice in addition to HADS and the financial acquittals.

Other Issues / Suggestions

- There is a need for a "No Wrong Door Policy" with Health, Disability and Housing working together to ensure smooth transition to and in-between services and programs.

- Clients requiring assistance are often presented with a list of telephone numbers to call, at a time when they are under stress and trying to deal with a range of complex systems to maintain their independence. Another suggestion might be the development of a *Disability Advisory Service* which is empowered by the Departments of Human Services, Health, Housing & Transport to problem solve and achieve outcomes for individuals within the community.

- There is a lack of suitable supported housing options for people with co-morbidities. Often people with an acquired Brain Injury /intellectual disability/ mental illness and a spinal cord injury are placed in nursing homes as there is a lack of supported accommodation that can meet the support and particularly access needs of people with both a physical and cognitive disability.

- The landscape for compensation has changed dramatically in the past 4 years. People who received injuries 20+ years ago were not thought to have a normal lifespan, therefore not compensated accordingly. Thus we have a cohort of

individuals who have managed their funds well but are now requiring additional services and cannot be left without care. A detailed strategy needs to be explored to research and identify systems of management for this group.

REFERENCES:

1) ParaQuad : Accommodation & Support Needs Survey, 2009 - COR Consulting

2) ParaQuad : Attendant Care Survey, 2009 – Internal Quality Review

3) ParaQuad: Case Notes, De-identified case histories from client files