Submission
No 23

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

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About Family Advocacy

Family Advocacy is a state-wide advocacy organisation which promotes and protects the rights and interests of children and adults with developmental disability. The organisation has a high presence and profile across the State:

- building the capacity of families to undertake an advocacy role;
- developing leadership skills in families;
- making representations to Government regarding legislation, policy, funding, monitoring and practice and the extent to which they reflect the needs of people with developmental disability;
- providing advocacy related information and advice.

Introduction

The Family Advocacy submission focuses on term of reference(c) Flexibility in client funding arrangements and client focused service delivery.

We will demonstrate that whilst there have been positive developments in ADHC provided and funded services, families continue to experience significant barriers to a good life as a result of rigidities in current respite and accommodation services.

The submission will provide examples of how ADHC has adopted person centred language but the lives of people with disability have remained the same because little or no attention has focused on issues of culture in services and values, knowledge and skills of workers.

The submission will look at programs of after school and holiday support for teenagers with disability and case management to demonstrate that ADHC decisions as to the services it purchases can limit the opportunities for people with disability and their families to have an ordinary life.

Inequities in the system in terms of access to services and funding will also be described.

The submission will conclude by outlining positive developments in recent years leading to a set of recommendations that will pave the way for a service system that is more responsive to the life aspirations and needs of people with disability and their families.

Rigidities in respite services

The following de identified quotes are drawn from feedback from families of children with disability in contact with Family Advocacy.

> *"My son xx, was diagnosed with Aspergers in April 2003 aged 5 yrs old. We dealt (badly) on our own, when around the age of 7,I contacted a local agency who claimed to offer respite (they do for my girlfriend's down syndrome son). We were told that did not qualify for respite and due to his aggressive nature and behaviour he would be considered too dangerous for the staff. This was ironic as this was why we needed a break."*

> *"We are the parents of a profoundly disabled 5yo boy. He has multiple disabilities and requires one on one care. We have not accessed any respite as there is nothing appropriate to our needs available.*
>
> *When I first enquired as to what might be available I was told by the local "interchange organization" that I had to leave the home for the period of respite care – as I work part time from home this was not considered appropriate.*
>
> *My other was request for someone to come into the home while I was doing my son's therapy as either a 'book reader', 'but patter' or 'entertainer' for my child. This was not considered an appropriate request – regardless of the fact that would give me enormous relief from his crying/complaining."*

Families in touch with Family Advocacy report many difficulties in getting the type and extent of support they feel will make a difference. Examples include:

- The level of service provided to a family is often reduced as a result of contingencies in the service with no relationship to the need of family.
- Families completely loose support as a result of rigid program eligibility boundaries. For example a family whose child turned 6 went from 8 hours of support to nothing.
- Change of service policy with no reference to the needs of the person with disability or family. For example, one family reported their service changed its policy so that it no longer provided personal care and required a 3 hour minimum start. This made the service completely unresponsive to the person's personal circumstances.
- Families of children with very high support needs are often rejected by a service because the support need is 'too high'.
- Families often report that difficulties arise when their family member with disability is supported by staff who are not attuned to the person. Many services seems reluctant to acknowledge the impact of the knowledge, skills and qualities of staff on the person being supported.

  When staff are not attuned to the needs and communication of the person with disability, difficulties can arise and can be expressed as OHS concerns. As a result, the person with disability is then penalised by restriction in service or opportunities. Families want services to acknowledge when difficulties arise as a result of factors in staff. Families stress that the person with disability should not be blamed and penalised for these for staff failings.

- Many families express frustration that their support worker is prevented by agency policy from looking after all children of the family. In one family, this meant that when parents go out, they use a respite agency for the child with disability and must find a babysitter for the other child, even where the support is provided at night when it is anticipated that both children will be asleep. Similarly, another family was concerned that when a support worker was taking a child with disability to the park, she was unable to take a friend of the child. This prevented the child with disability from having ordinary experiences.
- Families report enormous administrative costs associated with current arrangements:
    - The cost of brokerage – families report that whilst individualised flexible packages available though some agencies provide the family the desired control over how the money was spent, the agency seemed to take an extraordinary percentage for what appeared to be very little work.
    - An approved respite provider used agency staff for a 4 hour shift so that parents could attend a wedding. The total cost was $470 which used a very significant proportion of the family's respite allocation. The family had a sense that they could never do it again.
    - One family described that the respite agency organised support such in such a way that the family received 90 minutes of direct support and in addition paid for2x 50 minutes periods for travel from their respite allocation. The family did not live in an isolated area and knew of many capable local people who could provide the support. It seemed that the agency had no motivation to be economical with the family's scarce respite resources.

Key messages arising from the experience of families using respite services

The disability service system encourages families to be dependent users of services who rely on government funding to 'fix' their situation. Whilst the menu of service types has increased, people must still choose from the limited menu and have little control over the 'what, when, where and by whom' of support. Consequently, paid support often does not make a difference in the lives of service users because it replaces rather than compliments the informal support provided by family and friends. At the same time, fundamental needs, such as the need for relationships are not addressed.

Understanding the purpose of respite

Services need to understand that for respite to be truly effective, it needs to build positive opportunities for both the person with disability and their family. If the resources are used to enable the person with disability to 'have a life', the family will have time to themselves and this will be a time of 'respite'

Services being in 'right relationship' with families

Services need to work in what Kendrick calls **'Right relationship'** with people with disability and families The concept of 'right relationship' builds on the notion that the formal service system is only one part of the support solution for any individual and that it is important for the person with disability and/or their family and the service to work together. Working in right relationship with one another involves:

- respecting, valuing, supporting the person to have a good life in the community;
- treating family as valued partners who can be trusted;
- doing planning around a personal vision for life, not around what a service can offer, in the spirit of 'this is a person's life, not our life';
- having the person and those closest to them contribute their abilities, gifts and talents and exercise control over their future;
- having shared values, vision and understanding of what it takes to provide a personalised service;
- having control of the majority of decisions;
- having the ability for people to have expectations, refuse options and negotiate on matters of concern, including the hiring and dismissal of staff;
- having processes that are people friendly, without having daily life consumed by bureaucracy. The service acts as the buffer against such requirements;
- having mechanisms that feed in information from the people who are being supported by the service.

Understanding vulnerability

People with highest support needs need more support not less

Service administration is not an end in itself

Current service administration practices are making support unresponsive to family need and unsustainable.

Rigidities in accommodation support

Eligibility for accommodation is often applied rigidly

> *A man in his 40s contacted Family Advocacy concerned that DADHC was not prepared to discuss accommodation for his brother with disability until his mother had tried every form of respite.*
>
> *The mother, in her 70s with serious health issues, was caring for 3 adult children with disability. The brother had committed that two of his siblings would live with his wife and children when the mother was not able to continue to care but he could not commit to support his oldest brother who had significant challenging behavior.*
>
> *The man approached DADHC to plan for his brother but DADHC refused to register the name for accommodation support because the elderly mother had not tried all forms of respite.*

Vacancy management

Supported accommodation provided by government and non government providers is managed as one system through a vacancy management process. Vacancies in existing houses and services are offered to the person in most critical need that matches the vacancy. There is seldom opportunity to choose where the person lives, who the person lives with or who supports them and how. People are often housed far away from their family or community.

Consequences of a crisis driven system

Accommodation support is crisis driven. It is allocated at the point of family breakdown and teaches families that crisis is rewarded with 'a bed'. A system built on such crisis intervention has many risks and unintended consequences including:

- people believing that crisis is the only way of moving from the family home;
- a reluctance to plan for or trial arrangements without having first secured funding;
- a generalised reduction in community capacity arising from too great a dependence on funded supports that push out welcoming inclusive practices and leave people with disability isolated;
- trauma and mental health problems for people with disability as well as their families;
- growth of unmet need to such levels that addressing it seems overwhelming for government policy makers and funders;
- people living in accommodation that is inappropriate to their needs;
- people being moved between vacant 'beds' in a way that is dislocating, destabilising and dehumanising.

The way forward

In order to improve the effectiveness of client focused service delivery, ADHC must:

- introduce a self directed approach in all areas of service provision (a full discussion on p)
- introduce an identifiable strategy that rebuts the notion that the only way for people with disability to move out of the family home is for them to move into a government allocated place. Family Advocacy has developed a proposal for a Supported Living Fund to meet this need. The Supported Living Fund is discussed below.

In order to improve the accommodation system immediately, ADHC must:

- Provide people currently in or about to move into the supported accommodation system with the unit cost of support and allow them to choose where it is spent and how (consistent with a self directed approach)

Supported Living Fund

The proposed Supported Living Fund would be a stream of government funding that enables men and women with disability to have a home of their own while families still have capacity to support the transition and be part of the solution.

Key features of the proposal

- The Supported Living Fund provides a new avenue of growth funding.
- The target group is adults with disability who meet the established criteria for specialist disability services AND are interested in having their own home with the assistance of formal and informal supports. **The feature differentiating the target group from the current ADHC system is that their families are not in crisis.**
- Families are given encouragement and support to plan. This includes information to guide and inspire, and assistance with planning, facilitation and support coordination.
- Government provides recurrent funding (from the Supported Living Fund) to pay for support that compliments the freely given relationships of family and significant others. Government thereby provides incentives for families to plan and put informal support in place.
- People with disability, their families and support networks are able and helped to direct their own support. Funds are not used to purchase a place in a group setting.
- The Supported Living Fund is part of an identifiable strategy that rebuts the notion that the only way for people with disability to move out of the family home is for them to move into a government allocated place. The identifiable strategy includes investment in vision and capacity building, support for high quality planning and individual service design, removal of disincentives and the development of acquittal and accountability mechanisms appropriate to a self directed approach.

The Supported Living Fund will make a significant contribution to building a sustainable disability system in NSW and will contribute to the development of:

- a preventative approach that moves away from high cost intensive support as a result of crisis;
- supported accommodation that is cost effective and evidence based;
- alternative pathways that support and reward families to plan for their family member with disability rather than expect government to pick up the pieces in a crisis.

Anticipated benefits of the Supported Living Fund

People with disability will:

- have a life of their own in a home of their own.

Families will:

- feel able to plan, leading to new pathways that build on people's strengths, relationships and resources and reduce reliance on crisis pathways;
- regain control of their lives with the concomitant improvement in health and wellbeing;
- be supported in their efforts leading to empowerment rather than passive dependence which is currently fostered by the system;

The disability service system will see:

- a reduction in crisis as people see clear pathways that support their initiative;
- an increased range of supported living options;
- the development of expertise in supported living to inform directions on building capacity;
- the development of expertise in supporting families to use their own initiative, reducing reliance on the service system.
- the development of an evidence base around individualised support and supported living;
- funding being used in ways that facilitate and assist to build new relationships and increase community inclusion with a shift away from the more traditional fee for service approach provided in current Business Rules.

ADHC has adopted person centred language but the lives of people with disability remain the same

There is a lack of real understanding of a changed paradigm

ADHC has adopted person centred planning as the framework to underpin service provision. It is of great concern to Family Advocacy, however, that ADHC and services have little understanding of the changed paradigm that is implied in the new language.

For example, ADHC Accommodation Directorate has recently adopted a policy of Lifestyle Support for people living in ADHC accommodation services.

Whilst Family Advocacy supports the general direction underpinning this policy we believe that the policy does not address the serious challenges that will exist in implementing this approach in congregate services. Without addressing these issues, there is a very serious danger that language will change without real and positive changes in the lives of people with disability.

An authentic commitment to a person centred approach requires an organisation to have:

- a strong mission and values that rest on the United Nations *Convention on the Rights of Persons with Disabilities* (2006);
- commitment to enhance the capacity of people with disability and families;
- willingness to share authority and responsibility;
- commitment to change when current structures, policies, processes and activities hinder the implementation of people's goals and aspirations;
- a change in organisational culture and significant development for staff to understand and implement a new approach.

In addition, in implementing this policy, ADHC has a responsibility to inform people with disability and families of the different processes and broader opportunities that are anticipated in a person centred approach. Without energy and resources devoted to capacity building in people with disability and families, the outcomes will be poor. People and families need to know that something else is possible. They need:

- a positive vision;
- a capacity to imagine better;
- a willingness to be involved;
- a belief that the service is genuine in opening new opportunities and will not thwart the vision and goals that emerge.

Examples of the empty rhetoric of the *Lifestyle Support* policy include:

- Action to implement changed opportunities for people with disability appears to be entirely family responsibility. This is despite the fact that the people in question live in ADHC houses (often geographically distant from the families as a result of ADHC Vacancy Management processes) and families are given no assistance to imagine and plan changed opportunities.

- The policy seems to recognise the importance of informal support but pays little regard to what is involved in developing informal support. The mere naming of the issue without proper thought and planning will only lead to a misuse of the language and frustration by all concerned.
- The policy indicates that the resident might lead a planning meeting. This is unlikely to lead to changed vision or opportunities. Without real experience of something different, most residents will have no idea of what is or might be possible. For ADHC to suggest this as one of the limited number of examples, opens ADHC and services to the perception of a 'cop out'.

The way forward

In order to improve the effectiveness of client focused service delivery and demonstrate a genuine commitment to person centred planning and Lifestyle Support, ADHC must work:

- with services to develop multiple strategies to transform services from a service centred and congregate approaches to people centred and individualised approaches.
- to realign its processes with a person centred approach including understanding the implications for planning, commissioning, budgets, resource allocation and the purchase of service, infrastructure to support people to take a self directed approach, monitoring, accountability, quality assurance and whole of government considerations.

Many decisions made by ADHC as to the services it purchases limit the opportunities for people with disability and their families to have an ordinary life.

Examples include

After school and holiday support for teenagers with disability

ADHC funds *Teen Time – After School and Vacation Support for Working Parents, Leisure Link and Respite Camps for Teens with a Disability* all of which are options that congregate young people with disability and segregate them from the community.

There are many young people with the same profile of support needs who would prefer support to participate in regular after school and holiday activities.

It is inappropriate and perhaps discriminatory for a government funded program targeting a particular profile of person (teenagers with moderate to high support needs) to only make provision in segregated settings and make no provision to support young people who have no involvement in special schools.

The way forward

Government funded programs targeting teenagers with disability should include:

- support for young people who choose regular settings; and
- the availability of consultancy support to assist mainstream activities to be welcoming and supportive to young people of differing abilities.

Provision of case management over support coordination

There has been a significant growth in case management services either provided or funded by ADHC. Given the complexity of the current system, many people certainly require a guide to navigate the system to get the best for a person with disability. However, a case manager will ask the question "What services does this person need" to lead to a list of services.

Family Advocacy believes that helping people to navigate the system is best undertaken by a person with a developmental approach who asks *"What is a good life for this person?* This will lead to a different approach and outcome from the traditional case management approach.

DADHC has a small team of Local Support Coordinators (LSC) who use this developmental approach. Their aim is to:

- help people with disability achieve increased independence, self sufficiency and community participation;
- assist families to provide care and support for their family member with disability;
- increase the capacity of people with disability to lead valued and quality lives within their communities; and
- build more inclusive communities.

The ADHC Local Support Coordinator role has been built on the Local Area Coordination (LAC) approach, as implemented by the Disability Services Commission (DSC) in WA. This is a well-evaluated model on which to build a proactive, preventative approach to sustainable supports for people with disability.

The way forward

In order to improve the effectiveness of client focused service delivery and build the resilience of people with disability and their families the core navigation of the disability service system should be undertaken by a state wide team of LSCs rather than through a filter of case managers.

Inequities in the system

Differential funding for people according to the date on entry into a program

School leaver programs provide a clear example of the inequities in funding between people with identical profiles depending on the year in which they left school. The greatest inequity is seen in the fact that those who did not complete year 12 received NO post school support for many years!

School leavers:

- before 1994 moved into day programs with funding per head often less than $10,000;
- between 1992 and 1998 went into Post School Options Programs with approximately $16,000;
- between 1999 and 2003 attended ATLAS programs with slightly more money; and
- from 2003 participate in Community Participation Programs for whom funding for 2010/2011 is Moderate $21,901, High $25,408, Very High $39,153 and Exceptional $54,758.

The way forward

In order to improve the effectiveness of client focused service delivery ADAHC should upgrade the funding of people in day and Post School Options programs to the current level of Community Participation.

Children with autism and intellectual disability are eligible for ADHC support while children without intellectual disability are not

ADHC Behaviour Support teams provide valuable assistance in relation to children, young people and adults with challenging behaviour that should be available for all people with challenging behaviour whether or not they have an intellectual disability.

The way forward

In order to improve the equity in service delivery ADHC should offer behaviour support to all people with challenging behaviour.

Positive developments - New features of the NSW context

ADHC has promoted limited growth in individualised support that enable people with disability and their families to have significant influence and control over the government resources targeted to their support. This can be seen through the self managed options in the Community Participation, Life Choices and Active Ageing Programs and the trial of direct payments in the Attendant Care Program.

In addition, ADHC has funded four pilot programs that enable participants to have greater control over the use of resources:

- One pilot enables 20 families of children 0-6 in metro south to use Early Start funds in a more flexible way.
- The second pilot targets families eligible for extended family support and enables flexible use of between $20,000 and $60,000 identified for their use.
- The third pilot targets people with unmet need for day programs offering them $15,999 for their own individually tailored supports as an alternative to centre based day programs; and
- The fourth pilot enables 30 older parent carers in the northern region of NSW to use up to $50,000 pa in planning for creative solutions for the future.

The way forward for the NSW disability service system – the implementation of a self directed approach

A self directed approach gives people with disability and their families greater choice and control over the government funding directed at their support. It puts people in the driver's seat of their own lives rather than requiring them to choose from the predetermined list of service options. A self directed approach recognises that some people need assistance to take control and puts systems in place so that everyone can have the option of directing their own support.

Key features of a self directed approach

- The person with disability is genuinely at the centre and their family is treated as allies.
- Planning is personalised to achieve real goals in a real life. The person with disability and their family are assisted to plan, implement and change supports by a person who is accountable to the person with disability and is independent of government and service providers.
- Resources are allocated to the individual and their family early in the process and are spent in accordance with the person's desires and requirements.

- Support is provided through a combination of formal and informal, public and privately provided avenues, which are coordinated to deliver the best outcomes in response to the individual's circumstance.
- Financial, legal and administrative responsibility can be delegated to an intermediary (which could be a disability service) that looks after the 'paper work' while the person and their family make decisions that are important to them.
- People with disability and their families have the opportunity to increase their knowledge and skills to direct their own support.

How would it work?

Self directed support already exists in Western Australia and Victoria where changes in government policy and procedures have given people much greater control over the services targeted at their support. In Victoria, for example, people with disability and their families can:

- Have their funds paid to their existing service provider or move to other service providers;
- Have control over the what, when, where and by whom of support while a financial intermediary looks after the legal and financial obligations of funding; and
- Receive the funds directly and manage the package themselves (or with the help of family or a support network).

Anticipated benefits

People with disability will have:

- control of the what, when, where and by whom of support enabling them to pursue the lifestyle of their choice;
- improved quality of life.

Families will have:

- control over their lives;
- paid support that compliments rather than pushes out informal support.

Government will see:

- services become more flexible and responsive;
- better utilisation and effectiveness of limited resources as they will be better targeted to make a difference in people's lives.

Recommendations

1. ADHC must implement a self directed approach in all areas of service provision. This will include:
    a. the amalgamation of all program areas into a single funding program similar to the approach adopted by the Victorian Government. This will result in a single set of guidelines and one set of planning and approval processes enabling people with disability and their families to have greater choice including choice to:
        i. continue to have their funds paid to their existing service provider or move to other service providers;
        ii. continue to have their funds paid to the service provider who provides the support or move to another service provider;
        iii. use a financial intermediary, an organisation that holds funds, makes payments at the direction of the person and keeps records of the funds for the person;
        iv. receive the funds directly and manage the package themselves (or with the help of family or a support network).
    b. The adoption of multiple strategies to enhance the capacity of people with disability and families to take advantage of the opportunities provided by a self directed approach. Some of the strategies include:
        i. building the knowledge and skills of people with disability and families to direct their own support. This may include information provision, workshops that help families build vision and help families to plan and imagine better, mentoring programs etc;
        ii. developing an independent, community based, statewide resource centre that supports people with disability and their families to manage their own supports;
        iii. developing a mechanisms that assists people with disability and families to plan, implement and change supports. Such mechanisms must be accountable to the person with disability and independent of government and service providers.
    c. Collaboration with services to develop multiple strategies to transform services from a service centred and congregate approaches to people centred and individualised approaches.
    d. Realignment of ADHC processes with an individualised approach including understanding the implications for planning, commissioning, budgets, resource allocation and the purchase of service, infrastructure to support people to take a self directed approach, monitoring, accountability, quality assurance and whole of government considerations.

2. ADHC must implement a Supported Living Fund as part of an identifiable strategy that rebuts the notion that the only way for people with disability to move out of the family home is for them to move into a government allocated place. Family Advocacy has developed a proposal for a Supported Living Fund to meet this need.

3. ADHC must implement specific immediate changes that will increase the flexibility of service provision including:

    a. Providing people in the crisis system with a unit cost of support and allow them to choose where it is spent and how (consistent with a self directed approach)
    b. Ensuring that teenagers with disability are able to use the government funded support in regular settings not just in segregated settings.
    c. The growth of Local Support Coordination as the core navigation mechanisms in the disability service system rather than case management.
    d. The upgrading of funding of people in day and Post School Options programs to the current level of Community Participation.
    e. The provision of behavior support to all people who require this specialist assistance.