# Stronger Together Phase 2 Policy Supplement

## Directions for adult onset disability services in NSW 2006-2016

**Version 1.0**

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# *The need for change – responding to the different needs of people with adult onset disabilities*

People who acquire a disability later in life which results from neurological degenerative conditions or trauma generally have established goals, lifestyles, interests, relationships and educational/vocational directions. After the onset of their disability they will try to re-claim their previous lifestyle and minimise the impact of their disability on their previous life situation and roles. This group generally experiences loss, shock, anxiety, depression and/or anger as well as managing the impact of their disability.

Assisting this client group requires consideration, collaboration and responses from client's families, friends and communities as well as across government and non-government agencies. Ageing, Disability and Home Care (ADHC), Department of Human Services has been working together with clients and their families, disability specific organisations, service providers and a number of government agencies to clarify roles, pathways and service responses.

Many individuals with an adult onset disability have been unable to access appropriate disability, health and community care services that meet their needs. This has resulted in some younger people being admitted to Residential Aged Care Facilities (RACFs) where they may cease to participate in age appropriate activities of their choice, lose contact with friends and family and have a reduced quality of life.

Others have fractured relationships with family and friends or family and friends who have developed health and stress problems and are not able to (or continue to) provide high levels of care. These clients may end up blocking hospital beds, in the criminal justice system beyond their first parole date, homeless, living alone with increasing need for support or in very expensive care and support options that have been individually developed as there is no suitable option available to them.

Within this group there are individuals with:

- mostly stable, non life threatening conditions (for example, multiple amputations, spinal cord injury, brain injury). These individuals need to adjust to their decreased level of functioning and limitations and incorporate them into their daily lives, receive assistance to complete basic everyday care tasks and adjust aspects of their lifestyle and role. They also need to learn new skills to sustain and improve their ability to both participate and increase independence;
- progressive and unstable conditions (such as Multiple Sclerosis, Huntington's Disease, Motor Neurone Disease, muscular dystrophy disorders and Parkinson's Disease). Due to the progressive deterioration and uncertainty inherent in these chronic conditions, people face threats to dignity and self esteem, disruption of normal relationships, decreasing resources for them and their carers, increasing dependence, and need for support on a continued basis.

People in these target groups will require access to services from a number of agencies at the same time and clear pathways to move sequentially back and forwards between collaborating agencies.

## *Achievements in the first phase of Stronger Together 2006/07 to 2010/11*

*Stronger Together Phase One* identified the need to improve the policy and service response for people with an adult acquired disability and clarify and improve the appropriate pathways and interagency intersections.

### Interagency partnerships and agreements were developed

- Key sector interagency stakeholders include NSW Health; Enable NSW; Housing NSW; Corrective Services; Lifetime Care and Support Authority; Justice Health; and the Agency for Clinical Innovation which includes NSW State Spinal Cord Injury Service; NSW Stroke Services and NSW Brain Injury Rehabilitation Directorate. Examples of collaboration follow.
- The ABI Interagency Agreement between ADHC, NSW Health, Housing NSW and Lifetime Care and Support Authority was signed in 2008. The *'Care and Support Pathways for People with an ABI: Referral and Service Options in NSW'* paper was developed by the interagency partners. This outlines agency roles and current prevision and highlights areas for joint collaboration.
- An Interagency ABI Steering Committee was established to oversee the implementation of the ABI Interagency Agreement. The ABI Steering Committee has developed a Work Plan that sets out and monitors the delivery of the tasks from the ABI Interagency Agreement. The Work Plan tasks cover pathways and protocols, standardised assessments, rehabilitation planning, sharing of client information, privacy and consent, case coordination, transition planning and access to other interventions such as mental health and/or drug and alcohol support and behaviour modification.
- *The Integrated Services Project* (ISP) is administered by the Office of the Senior Practitioner in ADHC. This is a partnership with Housing NSW and NSW Health which establishes coordinated cross-agency responses for adult clients who have complex needs and challenging behaviour. People with an ABI are eligible for this Program.
- An agreement between ADHC and NSW Health (Enable NSW) to jointly fund clients in the NSW Health Home Ventilation Program was implemented.
- ADHC is collaborating with the Lifetime Care and Support Authority to identify staff competencies required to work with people with Spinal Cord Injury and people with an ABI. This work will support further development of expertise across the service system.

### Service models were identified, enhanced and implemented by ADHC

- An additional 500 Attendant Care Program (ACP) places were allocated from *Stronger Together* growth funds and other reform initiatives. The Attendant Care Program was enhanced and reformed to include greater flexibility and to broaden eligibility criteria.
- Initiatives to assist people with rapidly degenerative neurological conditions to access flexible services in a timely manner include a protocol facilitating early access to the Attendant Care Program and development of a time limited case management and brokerage model.
- Young people living in RACFs were assessed and a range of options were planned and implemented to address their needs and preferences. This included a variety of service models including 165 In-Reach Packages, 29 alternative accommodation

placements, 53 in-home support services and 19 day programs currently in place. Over 90% of clients accessing the services had an adult onset disability[1].

- Flexible support and respite packages were made available to support carers of people with adult onset disability, including initiatives to support young carers and older carers.
- The Disability, Housing and Support Initiative (DHASI) was established to provide long term appropriate accommodation and support for people with a disability who otherwise will be homeless or inappropriately placed. To date 12 people with an ABI access this service.
- New directions using flexible and person-centered approaches were developed in ADHC Community Participation services including the option for clients to self-manage their support. Of those who self manage 16% have an ABI, 4% have a neurological condition and 9% have a physical disability. The Life Choices and Active Ageing Programs are accessible to people with adult onset disabilities.

## Building the evidence base: pilot projects, evaluations and research

- New case management and brokerage services for people with an ABI, people with Muscular Dystrophy and people with Motor Neurone Disease (MND) were piloted tailoring individual solutions and identifying essential elements for services to these clients including a capacity to respond quickly to people with MND.
- Specialised assessments and short term interventions were developed and refined to address specific gaps in services and expertise required for these client groups.
- The equipment loan pool for people with MND was enhanced and monitored and negotiations were held with Enable NSW (NSW Health) to inform appropriate ongoing options.
- The ABI Attendant Care Pilot Project was implemented and evaluated for 20 clients to gain a better understanding of the needs of people in the community, the pathways and intersections across agencies, issues arising and possible solutions.
- Funding was allocated through Young People in Residential Aged Care Facilities (YPIRAC) to the Multiple Sclerosis Society to implement the Continuous Care Pilot for people with progressive neurological conditions.
- A literature review was completed which covered case classification and funding linked to functional need classifications and service models that respond to the needs of people with an ABI and/or physical disability.
- Research was completed to investigate current prevalence, level of unmet need and potential demand for services from people with an ABI in NSW and the cost/quantum of resources required to meet the need (2010). This work specifically referred to the need to work across agencies
- Progress and evaluation reports were completed for key pilot projects: the Flexi-Rest Project for people with neuromuscular disorders; time limited case management and brokerage model for people with rapidly degenerative conditions; the ACP ABI Pilot Project and the ABI Case Management Project.
- The ACP's Direct Funding Model was monitored and evaluated providing evidence of a service model that is flexible, person-centred and facilitates maximum choice for clients.

[1] YPIRAC figures from the October 2010 Parliamentary Brief

### Policy Development

- *Stronger Together Phase One* initiatives have informed policy development, planning, assessment and new service models in all ADHC program areas– including attendant care, supported accommodation, case management, community participation and respite.
- Work on ADHC's Eligibility, Intake and Assessment protocols is continuing to ensure responsiveness to people with adult onset disabilities.
- The ACP Guidelines and Procedures were revised to enhance an individualised, person-centred, flexible approach and to broaden eligibility criteria and model suitability.

### Enhancing the capacity of the service system with information and expertise

- Training modules and resources were developed and face to face training sessions on ABI and MND have been commissioned for ADHC provided and funded front line staff to enhance capacity and expertise of services and staff. This work links with the work of the Brain Injury Rehabilitation Directorate of NSW Health who have also contributed significantly to this resource.
- A number of projects were implemented to enhance the specific expertise, competencies and skills of some ACP and other in-home support service providers.
- Funding was allocated to enhance disability specific organisations' capacity to provide information, referral and community education where the need was identified.

## *Your voice… what have we learned*

Consultations have taken place with clients, families and stakeholders throughout the implementation of *Stronger Together Phase One* and during the development of directions for *Stronger Together Phase Two* about the needs and appropriate supports and service responses required for people with adult onset disabilities.

### Key lessons learned

- Intervening early enhances positive outcomes for people with an adult onset disability and provides more effective use of resources.
- Variable funding approaches including transition models, step-up/step-down funding, and capacity to increase or decrease funding enable the tailoring and effective use of individualised funding to meet changing needs over time.
- Clearer service access pathways across ADHC, its funded agencies, disability specific agencies and across government agencies will improve access, collaborative solutions and the use of resources while meeting individual needs of clients with adult onset disabilities, many of whom have complex health and care needs.
- There is a need for integrated review processes involving the variable funding approaches and cross agency involvement and collaboration to ensure clients can re-engage with services from different agencies when their needs change.
- Disability specific organisations have reported that the use of consortiums and collaboration between agencies has led to improved client outcomes, more efficient practices, more innovation and reduced costs.

- Flexible individual approaches to community access and participation as part of a package of supports best meet the needs of individuals with adult onset disabilities living in the community.
- Effective case management practices are essential for achieving the best outcomes for people with complex care needs.
- Access to one-off and brokerage funds supports an individualised tailored response to access specialised intervention, flexible supports, equipment and technology and enables a cost effective way to address gaps in capacity and expertise.
- Equipment, home modifications and technology are essential components in facilitating enabling environments and greater independence, maintaining clients with degenerating conditions at home with families and reducing recurrent service costs.
- Key stakeholder organisations especially those that are disability specific have a key role in supporting their client groups. This includes specialist information and referral, community education and development, emotional support and advice for their client members and the mentoring and support of the general disability services sector. They have been key partners through *Stronger Together Phase One* assisting ADHC with pilot projects, research and the monitoring and evaluation of strategies to enhance some of the above functions.
- People with adult onset disability have strongly supported the increased choices, flexibility, individualised allocations and the timely response available in the ACP model.

## Service gaps identified through research, pilots and consultation

A need for:

- consistent information and referral advice about services to clients and their families/carers
- improved processes to access services that do not require multiple access points
- emotional support and wellbeing strategies for clients, families and carers following diagnosis of an adult acquired disability and for those who become palliative
- support, training and mentoring for service providers who need to respond to the unique needs of people with adult onset disabilities
- support for clients to develop, monitor and review lifelong planning that would assist them in returning to educational and vocational activities, maintaining and developing relationships and identifying and achieving personal goals.

In addition there is a need to research the support and service needs of people with a sensory disability as their primary disability who have complex needs.

## *Plans for the second phase of Stronger Together 2011/12 to 2015/16*

To further address and strengthen the service response for people with an adult onset disability we aim to continue improving the service response by focusing on the following:

- Person-centred approaches
- A lifespan approach
- A service system with the right capacity.

It is important to note that approaches to meeting the needs of individual clients with adult onset disabilities need to focus on broader lifestyle goals. This includes work towards assisting individuals to remain in their own homes, maintain family relationships and participate and integrate in their communities. Equally a service system with the right capacity must include integrated cross agency responsiveness. ADHC will continue to work with and enhance cross agency and stakeholder partnerships.

### Person-centred approaches

The need for person-centred and flexible approaches has been evidenced throughout the implementation of *Stronger Together Phase One*. This includes, ensuring that people with adult onset disabilities, their families and carers can determine and be involved in planning and decision-making, are offered flexibility and choice and that their allocation of resources is based on an individual assessment of need.

Throughout *Stronger Together Phase Two*, person-centred approaches will continue to be enhanced by:

**Training strategies**

- Investing funds to develop support and training resources for people with adult onset disabilities who want to directly manage their own funding.
- Enhancing the person-centered skills of in-home support providers through developing program procedures, conducting forums, peer supports and other training.

**Improving access, choice and self-determination**

- Investing funds to enhance and increase information, referral and education initiatives, especially those that assist clients themselves, informal supports and community involvement.
- Further clarifying referral pathways that can assist clients with adult onset disabilities to navigate the service system and to be involved in planning their care and support services.
- Funding specialised assessment, case management and intervention services that enhance the general disability sector with behaviour interventions, skills and support, quick response packages and pools of brokerage funds for equipment and individualised person-centred interventions.

## A lifespan approach

ADHC will continue to enhance support services for people with adult onset disabilities that respond to their changing and lifelong needs. Support will also be provided for broader lifestyle planning, integration into communities and packaged support.

### Improving access and further developing service models that respond to lifelong needs

- Creating long term pathways to access services.
- Improving equity of access to services.
- Continuing to develop appropriate service models that include flexibility and an early intervention approach such as step-up/step down funding models and transition services that are inclusive of specialist supports where necessary.
- Providing access to one-off enabling funds for essential items, equipment (not available through other equipment programs), technology, assessment and community participation supports.
- Piloting and evaluating an Attendant Care Program project that incorporates lifespan planning; monitoring and review of personal goals; flexibility to adjust to changing needs; a packaged approach to services in conjunction with other program areas; and, incorporates links to assist the individual to access educational and vocational goals.
- Funding specialist assessment and intervention services and seeking further clarification from our cross agency partners about specialist interventions for behaviour support and access to equipment and technology solutions.

### Interagency collaboration

- Increasing collaboration between ADHC and other agencies such as NSW Health, Housing NSW and Corrective Services NSW to clarify pathways and integrated care planning to improve access to appropriate services provided by a range of agencies. This includes continuing to implement the ABI Interagency Agreement Work Plan.

### Support for carers

- Funding initiatives to support carers including enhancement of flexible respite approaches. These approaches will also provide people with a disability with opportunities for life skill development and increased independence.

### Further research

- Researching the use of equipment, technology and innovation to increase independence and lower service costs.
- Researching prevalence, incidence, potential demand and unmet need for people with a sensory disability who may require supports from ADHC.
- Researching policy and service development initiatives across government agencies to assist those clients who are currently accessing low levels of Home and Community Care (HACC) services or no services whose needs are increasing and where an early intervention approach would maintain carer support, assist with pathways to community participation, further education and employment and halt a progression to high cost services.

## A service system with the right capacity

The service system will be required to expand to deliver growth in places required throughout *Stronger Together Phase Two* and to respond to the unique needs of people with adult onset disability. The right capacity will include joint initiatives and collaboration with other government agencies.

In ADHC this will include:

- initiatives to support the growth of services across ADHC program areas
- initiatives to increase capacity and expertise of the disability sector including:
    - education and training resources to enhance competencies of staff and service providers
    - guidance tools and referral directories to support best practice
    - mentoring role for general disability case managers to facilitate access by people with adult onset disabilities to these services over time
- policy changes to enhance the response to the service needs of people with adult onset disability
- continuing interagency collaboration to support development of referral, information and agreements for clients referred to ADHC from hospitals, specialist rehabilitation units (spinal, brain injury), Justice Health and Corrective Services
- inclusion of specialist providers in other pre-qualified panels of providers in ADHC service areas.