

# **Submission to the Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme.**

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## **Introduction:**

### **Continuous Care for people with a progressive neurological disability.**

This submission addresses the particular needs of people living with increasing disability related to progressive neurological conditions. As a starting point, it targets a relatively small number of people with high needs. It advocates for a model of life-time care which includes health care and disability support under one authority. The need for integration of specialist and mainstream providers of health and community services is highlighted. It proposes a Specialist Care Coordinator role to promote comprehensive assessment, good communication and care planning which is responsive to the client's needs and wishes. The information sharing and support framework of the Continuous Care Program will better identify realistic options for meeting client needs and risk amelioration. Care and support will be better targeted, leading to more effective use of finite resources. Monitoring and review will allow for incremental support as the person's circumstances change.

The need for a coordinated approach and the delivery of timely services for this group has been well documented. The changing and degenerative nature of these conditions means that people need to draw from multiple service programs which, currently, may have no articulated relationship and conflicting eligibility criteria. A coordinated, 'Continuous Care' approach, operating within a Life-time Care Scheme would be an effective way of managing risks and allocating resources to individuals and providers.

The paper draws on work carried out between 2007 and 2010 by the Motor Neurone Disease Association of Victoria, MS Australia: ACT/NSW/Vic and Calvary Health Care Bethlehem, sponsored by the Departments of Health and Disability Services in Victoria. In particular, 3 projects; 'Palliative Care Pathway in MND', 'Collaborative Care in MND' and the 'Continuous Care Pilot', all explored better ways to integrate the health and community care of people with progressive neurological diseases and support them in their own communities.

## **Long-term disability care and support scheme:**

- **Continuous care for people with chronic progressive neurological disease and disability.**

This submission addresses the particular needs of people living with progressive neurological conditions, as well as the needs of their families and carers. A National Disability Strategy must recognise the different life-narratives and disease processes which underlie different forms of disability. For people with **progressive neurological conditions**, this is one of ever-changing needs, declining independence and future uncertainty. Many of these conditions are life-limiting.

Disability care options must be informed by a person's social context, health care plans and the prognosis of their disease. Disability support may need to be incremental and keep up with the changes in a person's health and social circumstances. High quality, responsive care can only be provided when there is a shared understanding of the client's goals and a framework which supports informed decisions, enables the implementation of plans and underpins the skill base of the relevant workforce. Health care and disability support need to work synergistically with the client and their family.

This paper aims to briefly describe:

- The nature of chronic progressive neurological diseases
  - Their impact on
    - people and families
    - services and the workforce
- The rationale for a Continuous Care model
  - Developing a synergy between health care and disability support
  - Transition to a continuous care program
  - How it works
- Developing the infrastructure for a Continuous Care Program
- Governance and funding of a Continuous Care Program

## **Chronic Progressive Neurological Diseases: What Are They?**

Progressive neurological conditions have a number of underlying pathologies; genetic (Friedreich's Ataxia, Muscular Dystrophy, Huntington's Disease), degenerative (Motor Neurone Disease, Parkinson's Disease), inflammatory (Multiple Sclerosis), metabolic (Mitochondrial Disease), malignant (brain tumours). Often the cause is still unclear. By definition, these progressive conditions are incurable, although some treatments and management strategies are useful in alleviating symptoms, improving quality of life and can be life-prolonging. Timely intervention can prevent physical or social breakdown.

The age of onset and timeframe of progression in these diseases can be quite variable. Most follow a relatively predictable path; others relapse and remit, and are harder to forecast. Most are uncommon, and therefore poorly understood in the wider community. Health professionals and community service providers working outside the neurological field are often unfamiliar with this group of disorders.

### ***The impact on the person and their family***

The nervous system controls our movements, communication, sensations, our thoughts, memory and emotional responses. Therefore, the impact of many of these diseases can leave the individual physically and cognitively and socially disadvantaged. Mood, behaviour, personality and judgment can all be disturbed. The individual has to cope with the relentless challenges to their sense of wholeness and to what is meaningful in their lives. Even when cognition is preserved; fearfulness, demoralisation and depression commonly impair the person's ability to face the future and plan ahead. Most of these diseases have life-threatening complications or are in themselves life-limiting. Decisions around medical interventions and end-of-life care are also challenging for the individual and their family, who may end up acting as surrogate decision-makers. Without a pro-active framework to support decision-making, such issues are often left unexplored until a crisis occurs. The client may miss a 'window of opportunity' for timely action or suffer adverse consequences of late or futile intervention.

This client group has a high rate of social and financial disadvantage. (When the disease is genetic, the domestic and financial integrity of families can be challenged across generations). These diseases often begin in young people or middle-age and result in the early loss of employment. The sustainability of friendships and partnering are threatened. The person's spouse or partner is required to juggle the roles of breadwinner and carer, restricting their own career development and earning power. Aging parents as carers become frail or ill themselves. Dependent children, by default, may become surrogate carers with sometimes profound effects on their own education and social development. Many relationships fail, further isolating and disadvantaging the person with the disease and increasing their reliance on social services. These people have a high risk of ending up, inappropriately, in residential aged care. Without help and understanding, people's lifestyle, autonomy and opportunities become increasingly constrained.

It is tempting to speculate that small amounts of targeted financial and social supports, earlier in the disability may help to sustain these relationships better. In turn, the client retains all the benefits of informal care and the social enrichment of normal domestic life – a situation which, once lost, is hard to recapture as the disease progresses.

### ***The impact on the current service model and workforce***

People who incur a neurological disability as a result of a single insult, (e.g. stroke, trauma), will undergo rehabilitation and usually make some recovery of function. Their on-going health care and disability support needs are determined as part of multidisciplinary discharge planning, as they return to life in the community. Their support needs are likely to remain stable for long periods or indefinitely. In contrast, progressive neurological conditions often begin insidiously, and disability evolves over time. During the diagnostic and early phases of the illness, the person usually has significant contact with acute and rehabilitative health care services, but may not need, or indeed accept, much in the way of social supports at that stage. However as the disease progresses and disability advances, it is not uncommon, for many of the reasons discussed in this paper, that people and their families disengage from health care services and soldier on at home. This means that at the very time that early health and social interventions might be helpful; they are less likely to be offered.

The nature and severity of a person's disability, balanced by the availability of formal and informal supports, will determine how well an individual can manage within the current health and disability service model. People with progressive neurological conditions may seek services from a range of health care and community service providers, including case management. Often this engagement or re-engagement

with formal services occurs in an adhoc way. Peak bodies, Neurological Organisations and support groups also provide a range of information, services and advocacy.

Currently, however, many service providers work with the client in relative isolation and often in brief encounters. Outcomes may be counter-productive or unsustainable when viewed in the wider context, especially if the client's and family's needs and wishes have not been fully explored. The majority of generic health professionals and community service providers have limited knowledge of these diseases and their likely trajectory and impact on the affected individuals. They are therefore ill-equipped to anticipate problems and assist clients and families to plan their future needs. The 'Continuous Care Pilot'<sup>19</sup> showed that case managers needed considerable support to assist clients in their applications to the Disability Support Register in Victoria.

Existing government funding models for subacute health services commonly discourage long-term models of care, focusing on strict 'rehabilitation goals' and 'episodes of care' followed by discharge. In the case of people with long-term progressive neurological diseases this often results in exclusion from services or ineffectual, and therefore wasted interventions. Failure to receive the right care can lead to recurrent use of emergency and acute services for chronic issues better addressed in the community.

As disability advances, optimal disease management should have a multidisciplinary focus, to maximize independence, control symptoms, and promote care planning. Services need to be joined-up, provide monitoring and be able to meet contingencies. Disability and health care services need to work synergistically.

Even once the needs are recognised, the present application processes and waiting times for disability support packages commonly result in unacceptable delays in service delivery. The process of assessment and allocation of the many different funding packages is not transparent and often appears inequitable.

**A 'Continuous Care Program' would realign the goals of intervention with the expressed and mutually understood needs of the individual client and their family, within a realistic framework of available resources.**

### **Rationale for a Continuous Care Model:**

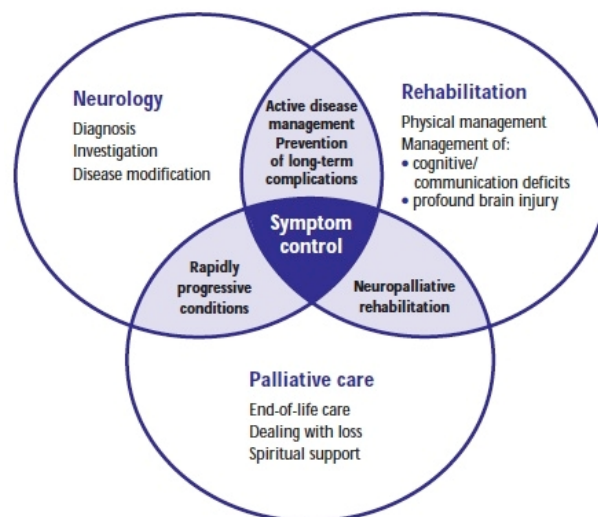
The aim of a 'continuous care model' would be to avoid the pitfalls of managing in part what needs to be addressed as a whole. The person with a progressive neurological condition should be able to access a program of care which reflects their views, their social context and the prognosis for their disease. Early exploration of future needs and timely, incremental allocation of resources, could help maintain the person in their residence of choice and support their formal and informal carers.

### ***Advantages of Continuous Care:***

- Defined entry point
- Client centred – collaborative model of care
- Specialist input to care and disability service planning
- Specialist input to coordination of care and services
- Realistic planning of future care
- Practical and emotional support for decision-making and implementation of plans
- Evidence-based education and training for carers, health professionals and service providers
- Research-driven policy and service development
- Effective use of resources

### ***Policy background and evidence from the literature***

People with chronic progressive neurological illness and disability want support and advice to help them and their families to continue to lead comfortable and purposeful lives, whenever possible in their own homes. The necessity to focus on models of continuous and client-centred care to meet the needs of people with chronic diseases is well established in the literature and government policy in Australia and overseas<sup>1-12</sup>. This team based approach has been termed ‘teams without walls’, ‘not bound by institutions’<sup>4</sup>. The United Kingdom National Service Framework for Long-term (Neurological) Conditions (2005)<sup>5</sup> advocates for ‘lifelong care...and the need for integrated care and joined-up services’. In 2008, The Royal College of Physicians (UK)<sup>6</sup> recommended greater collaboration and cross-referral between neurology, rehabilitation and palliative care services and proposed a model of ‘Neuropalliative Rehabilitation’ for the management of people with long-term neurological conditions. This was based on strong evidence (research grade A) that multidisciplinary care can improve the experience of living with a long-term neurological condition, both at the level of functional activity and societal participation. There is also evidence from the cancer literature that palliative care improves quality of life and is cost effective, and that palliative care principles can translate to non-malignant conditions such as chronic neurological conditions.



**Fig. 1.** The interaction between specialist neurology, rehabilitation and palliative care services in the management of patients with long-term neurological conditions.

Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care Copyright © 2008 Royal College of Physicians. *Reproduced by permission.*

## **A Continuous Care Model:**

- ***Developing a synergy between health care and disability support***

A Continuous Care Model for the progressive neurological sector will improve service outcomes and reduce the risk of unplanned and often inappropriate entry to aged care or acute hospitals. It will require systemic reform. The model proposes a structure inclusive of community & community services, disability and health sectors, clients, primary carers and families. Central to the model is a communication process, pathways and a coordination role that will facilitate collaboration, the transfer of knowledge and effective responses from all sectors to deliver an integrated approach to disease and disability management for the progressive neurological sector.

## **A Continuous Care Model:**

- ***Transition to a continuous care program***
- ***How it works***

**6 steps are critical for developing a model of continuous care –**

1. Transition to a Continuous Care Program
2. Specialist health and social assessment
3. Information-sharing and knowledge transfer
4. Decision-making and implementation of plans
5. Planning to meet contingencies, including brokerage funds
6. Monitoring and review

### **1. Transition: timely referral systems**

- a. Define 'transition criteria' for different diagnostic groups, to identify the point at which a person with a chronic neurological condition should be offered a 'continuous care' program.
- b. Identify 'red flags' for this 'at risk' group, and educate health and community providers to recognise risks
- c. Inform public and consumers (including consumer groups)

### **2. Specialist multidisciplinary team and specialist care coordination**

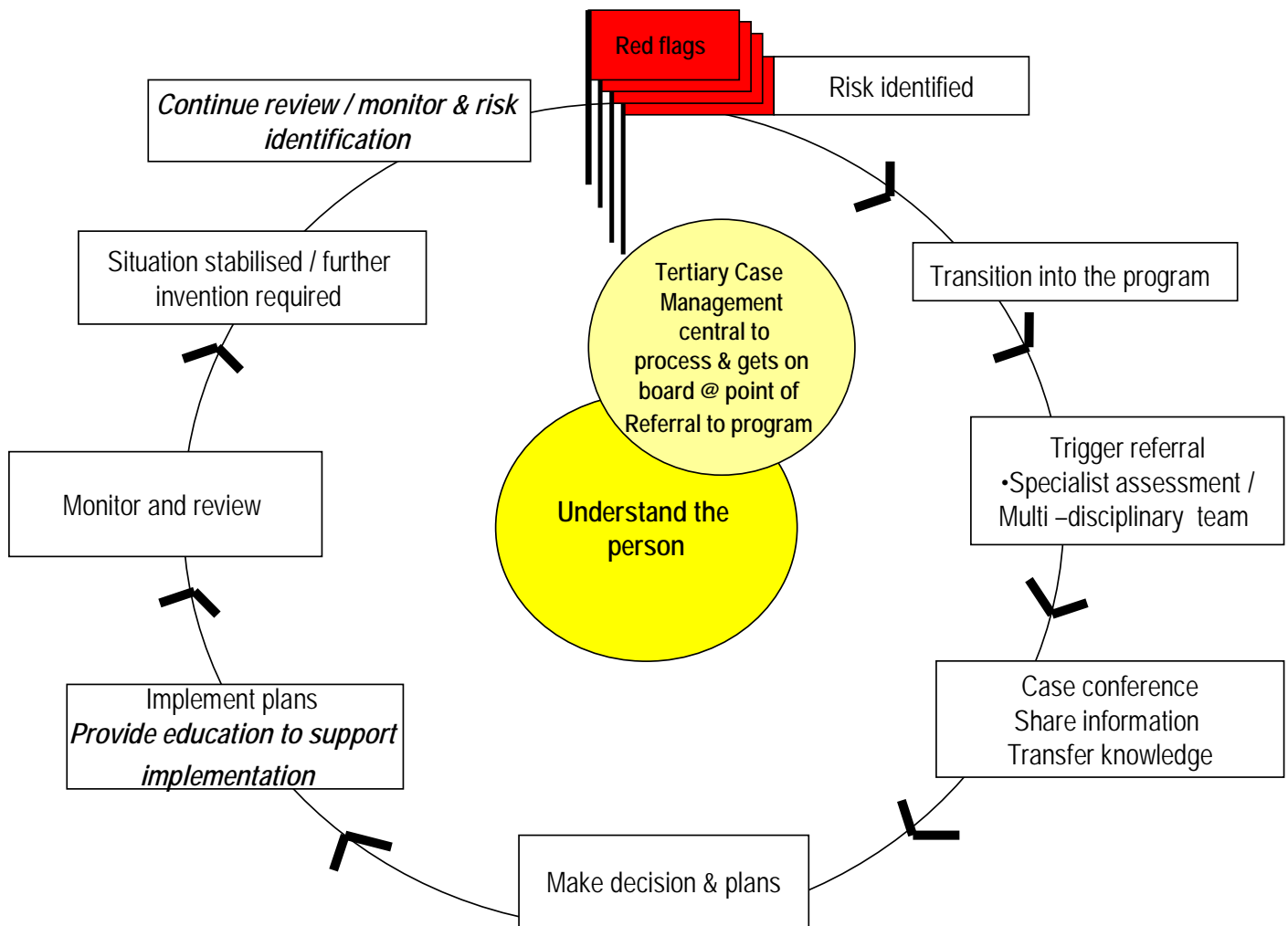
- a. Comprehensive assessment of needs / risks
- b. Specialist input to risk amelioration and care planning
- c. Support to local case managers, service providers and health professionals
- d. Planned review as required – step-up / step-down mechanisms for level of specialist involvement

### **3. Streamlined information-sharing and consent processes**

- a. Client-centred and confidentiality protected
- b. Case-conferencing
- c. Uniform documentation
- d. Shared electronic record

### **4. Decision-making support for client / family and professionals.**

- a. Information, advice and education
- b. Counselling and emotional support for client and family / carers
- c. Secondary consultation and peer support for health professionals and service providers



## Model of Continuous Care

### 5. Planning to meet contingencies

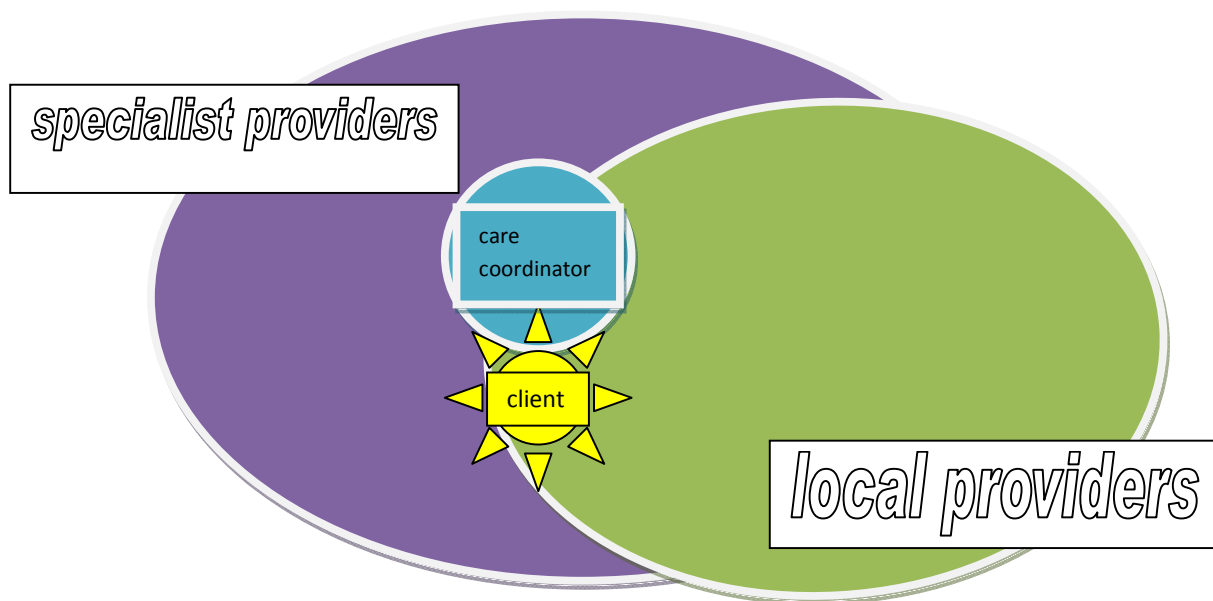
- a. Trouble-shooting mechanism for contingencies
- b. Protocols for access to brokerage funds

### 6. Monitoring and review

- a. To support continuing client engagement with services
- b. Follow-through action plans
- c. Troubleshoot problems
- d. Timely response to contingencies

The most important innovations of this model are the provisions for a

- Specialist care-coordination role
- decision-making support framework
- communication and information sharing framework for all parties.



**Specialist Care Coordinators with knowledge and expertise in health and community services would:**

- Understand the client and their family – needs and wishes
- Understand the natural history of the underlying disease process causing the disability
- Link client and family to appropriate health and community providers, if not already in place
- Link specialist health providers, local health providers and community services / case managers to better meet the needs of the client.
- Support clients and families to make decisions and realise their goals
- Drive the application process for **tailored** disability support packages





## **Decision-making support framework**

### *Client-centred support*

This client group is at increased risk of cognitive, emotional and behavioural disturbance. Impaired judgement and higher executive functioning can put the client at risk of poor decisions or impulsiveness, even before cognitive dysfunction is obvious to the layman or non-specialist health professional.

The impact of progressive neurological conditions on people and families can also undermine the resilience that people need to remain purposeful and in control of their lives. Financial and emotional burden and demoralisation are often just as incapacitating as physical disability and dependency. It is not uncommon for clients or families to fail to persist with agreed plans, and defer decisions that had seemed important to them initially. Many people acknowledge that discussions and decisions are confronting.

The support and encouragement offered by a knowledgeable care-coordinator can help many clients to move forward with their plans, which would otherwise stall<sup>19</sup>. The specialist advice and decision-making support which clients need ranges from legal, financial, emotional / relationship and health-related. However it is the 'continuous care' method, and not just the specialist advice, which helps people persist with planning and to accept change.

This suggests that people first need a support framework within which they can build the emotional strength to tackle some of these more confronting decisions and changes. The relationship and trust developed by more intensive and specialised care coordination, coupled to the availability of appropriate advice and counselling, go a long way to providing that framework. This is especially true for people who are socially isolated and cannot draw on the informal support of significant 'others' in their lives.

The current system fails when decisions are hurried or expected from individuals without taking into account the wider context of the person's health and social and emotional circumstances. A more biographical approach to decision-making takes into account the various domains of a person's life and experience. Early involvement with this support framework drawn from specialist and local providers in health and community services will allow time for this narrative and trust to develop. More tailored and sustainable decisions are likely to ensue. The framework then provides the support and monitoring to assist clients to bring their plans to fruition.

### **Communication and information-sharing framework**

Hub and spoke models of care and secondary consultation networks can link mainstream clinicians and community agencies to tertiary specialist providers<sup>18</sup>. While supporting the client to plan for the future, the Continuous Care Program would also provide peer-support and education to local health and community service providers, to assist them in delivering effective and timely care and services to their clients in their community. This can only be achieved if there is more reliable communication and information-sharing between all parties than currently occurs. Much of the usefulness of the work done by clients, families and individual providers is unrealised if other providers are left in the dark and there is no commonality of purpose to see agreed plans implemented or wishes respected.

The use of e-records, telehealth technology and case-conferencing will facilitate this model and provide equitable access to consumers living and working at a distance.

## **Developing the infrastructure for a Continuous Care Program**

In order to connect the current health and community services to deliver integrated care to clients with progressive neurological disease more effectively, there are 5 new pieces of work which first need to be completed:

### **1. Development of entry criteria (Red Flags) for clients entering the Program**

- set-up working party of senior clinicians and service providers, with consumer representation to
  - define entry criteria which are appropriate to the neurological diagnosis and the social context of the client
  - estimate numbers of potential clients requiring this Program in Victoria / Australia.

### **2. Development of a job description and training requirements for regional 'Specialist Care Coordinators'**

- a. Management and reporting structure
- b. Qualifications / skill base / training requirements
- c. Functions
  - i. initial point of contact with the program for client and family
  - ii. comprehensive assessment of needs / risks – in conjunction with case manager (if existing)
  - iii. initiates referrals (or supports case manager) to
    - 1. disability support funding / case management
    - 2. health service providers (see below)
    - 3. community services
    - 4. advisory and counselling support as required (see below)
  - iv. enhances care coordination by encouraging good information-sharing between all parties
  - v. improves outcomes by facilitating client's access to team-based care and specialist input to decision-making
  - vi. supports client / family / case manager to make decisions and implement plans

### **3. Identification of regional interdisciplinary health and community care providers**

- a. existing multi / interdisciplinary healthcare teams, case managers and community service providers; may need short to medium term direct support from specialist centres (shared care) to fill gaps in skill base or personnel
- b. responsible for on-going clinical and community care or referral to other local provider as appropriate
- c. required to provide a team-based, Neuropalliative rehabilitation approach
- d. required to offer 'continuous care' model, with the assistance of the Specialist Care Coordinator
  - i. information-sharing with client and other service providers
  - ii. regular case-conferencing with community and specialist providers
  - iii. care planning and implementation
  - iv. monitoring and review

### **4. Identification of specialist providers**

- a. tertiary level centres specialising in certain diagnostic groups are already established
  - i. drivers for undergraduate, post-graduate education, training programs and research
  - ii. development of clinical protocols and evidence-based practice
  - iii. development of Outreach tools and services to support clients and providers at a distance
  - iv. Neuropalliative rehabilitation approach

- v. required to offer 'continuous care' model (as above, but frequency of review and involvement in care planning and implementation as appropriate)

- b. individual specialist providers already involved in client's care.
- c. Neurological Organisations (e.g. MND Associations, MS Society, Parkinson's Australia, Huntington's Association, Muscular Dystrophy Association)
  - i. Client advocacy
  - ii. Client and family support programs
  - iii. Support and education to community and health providers
  - iv. Volunteer programs

**5. Development of a support framework for clients and providers within the Program (high-level coordination by tertiary centres), including**

- a. for clients and families
  - i. information and education about the Program and its aims
  - ii. access pathways for advice and counselling; health issues, emotional support, relationships, support for children, financial, legal etc. Some of these services would be integral to the Program, for others, e.g. legal and financial; the Program would offer linkage to other providers.
  - iii. Access pathway for respite services
  - iv. Access to non-recurrent, emergency brokerage funding
  - v. Volunteer services
- b. for case managers and community service providers
  - i. peer support and education
  - ii. secondary consultation service from specialist providers
  - iii. career pathways, training
  - iv. research involvement
- c. for health professionals
  - i. peer support and education
  - ii. secondary consultation service from specialist providers
  - iii. career pathways, training
  - iv. research involvement

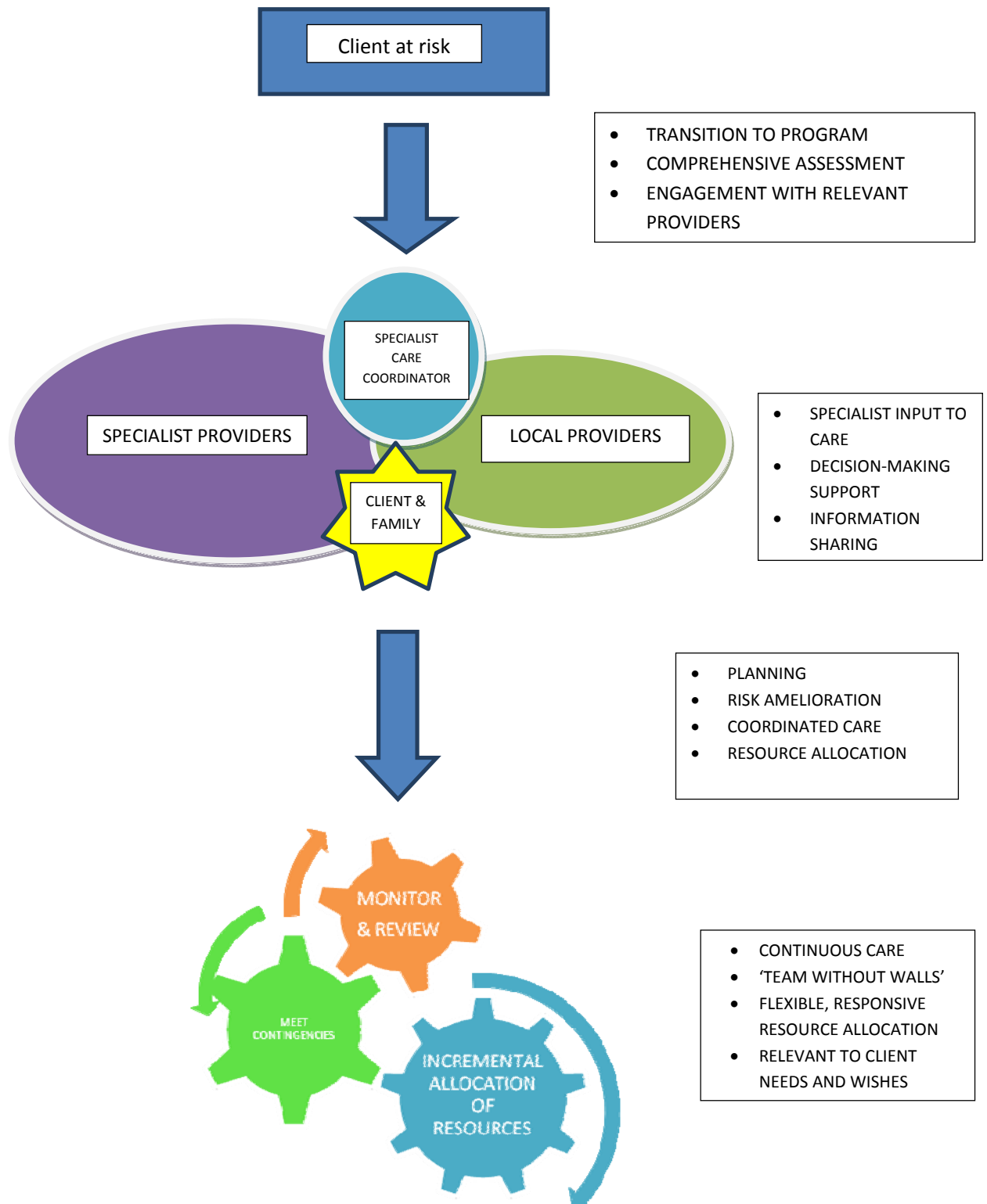
**Funding and governance of a Continuous Care Program.**

To be achievable this proposed model of Continuous Care will need to evolve and adapt from the current health care and disability service structures. By encouraging a synergy between clinical care and social service delivery, it aims to draw on the skills and deliverables of an existing diverse workforce, to improve not so much how people work, but how they work together, to the benefit of the client.

This level of care is not necessary for everyone with a neurological illness, but will streamline the care of people in the more advanced stages of these progressive illnesses and make the most efficient use of finite resources. Future developments of the model should look at increasing opportunities for earlier intervention.

The model offers a defined entry point to more intensive care coordination for people with progressive neurological disability once they reach a determined level of risk. The specialist care coordinator ensures that there is a comprehensive assessment of the client's needs and risks - drawing on the skills of other health and social service providers as appropriate. The Disability Support provision tracks alongside the client's progress.

# Continuous Care Program



***The role of the Specialist Care Coordinator:***

The role of the Specialist Care Coordinator is pivotal in facilitating the client's involvement in their care planning and the linking in with relevant service providers to explore realistic options. This team-based approach to problem solving and planning will best inform the level of funding support and services required from the new 'Long term care and disability support scheme'. The findings of the Continuous Care Pilot showed that this approach led to more effective interventions and more prudent use of resources.

Planned monitoring and review will also allow sensible, incremental increases to the client's support package and logical restructuring of care plans to best meet the evolving needs as the illness progresses or family circumstances change.

The Specialist Care Coordinator would be the point of entry to the Continuous Care Program and would oversee the application for Disability Support funding and the relevant care planning. Day-to-day supervision of an active care plan and acquittal of the funding would be the responsibility of the case manager (or the client / family). The Specialist Care Coordinator would step-up involvement with the client at agreed intervals of review or to address contingencies that cannot be met by the local team.

The Specialist Care Coordinator should have a health service background, but include experience in community care and the disability sector. Their role could be modelled on the Regional Advisor role developed by Motor Neurone Disease Association, Victoria to support their clients and families living with MND, a rapidly progressive neurological illness<sup>18</sup>. This role would be located in the community based Neurological Organisations, who could have a direct relationship with the Life-time Care Scheme for planning, coordination, service purchasing and tertiary consultancy for existing service providers.

### **A Life-time Care Authority – building a bridge between Health and Disability Services.**

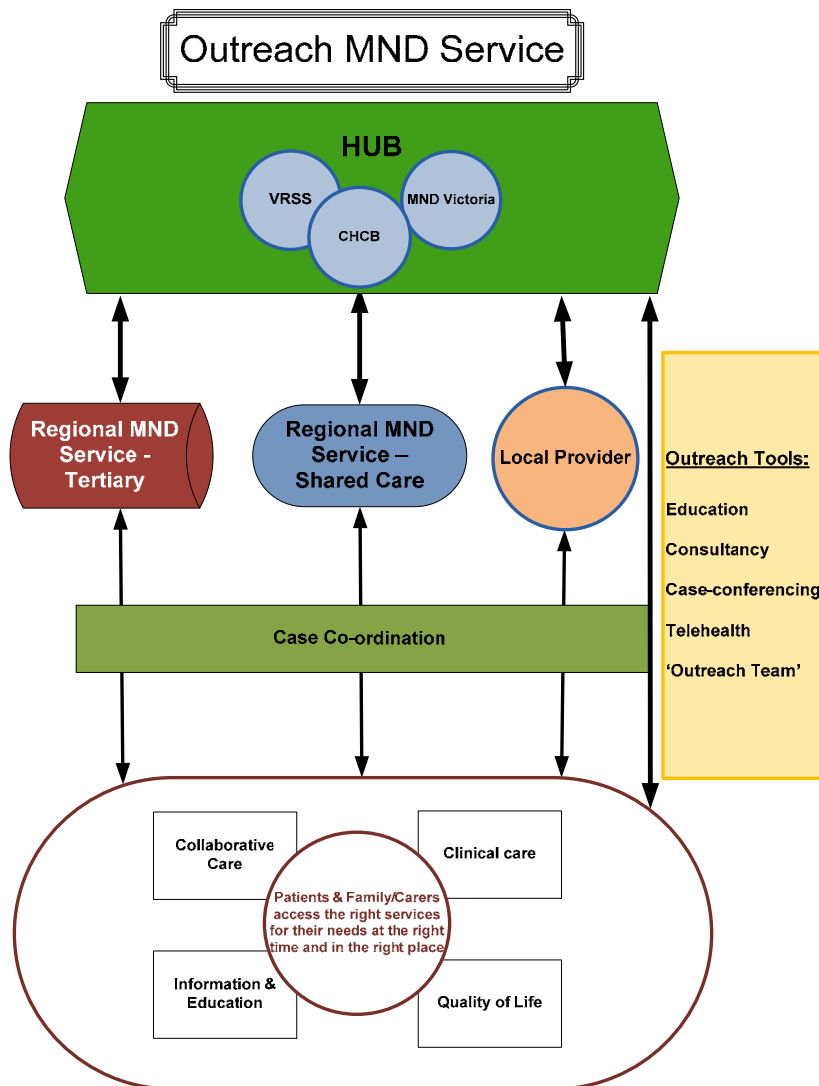
Equitable resourcing of care and support for people with progressive disabilities lies at the interface between health care and disability services. It makes sense to house the funding allocation for 'life-time care' services with a new authorising body, sponsored by government. To capitalise on existing infrastructure, a separate but complementary body would be most efficient.

A separate Lifetime Care Authority in each state and territory would create links across existing government programs that have eluded these programs, despite many fruitless attempts to build them. It would run a meaningful 'Disability Support Register' for this group of clients with high and increasing needs. The Authority could allocate funds directly, or through 'Continuous Care Program' provider networks. Distribution would be based on the comprehensive risk and needs assessments for each client, collated by the Specialist Care Coordinators. Brokerage funding held by these Programs would allow flexibility in meeting contingencies. Funding for Specialist Care Coordinators could also be provided through this Authority.

An accurate register of high-needs clients, whose support requirements are actively tracked by the Continuous Care model, would allow better strategic planning of future service delivery and the budget required.

The Life-time Care Authority would manage the budget and reporting requirements for 'Life-time Care Programs', one of which would be a Continuous Care Program for people with Progressive Neurological Disability. (Other Life-time Care Programs might be developed along similar lines for people with high needs due to other conditions; congenital disability, intellectual disability, trauma, stroke, etc.). The intensity of Care-Coordination and monitoring needed by people in these groups would be different.





#### Appendix 1.

Example of 'Collaborative Care' model proposed for people with Motor Neurone Disease<sup>18</sup>, incorporating:

- Client-centred care
- Care close to home
- Integrated health care and disability care and support
- Specialist care coordination
- The use of information technology and communication to benefit people

## **References.**

### **1. Chronic disease management: time for consultant physicians to take more leadership in system redesign.**

Brand C, Scott I, Greenberg and Sargious P. Internal Medicine Journal 2007;37 (9):653-659.

### **2. High quality care for people with chronic diseases**

Editorial BMJ 2005;330:609-10

### **3. Our health, our care, our say: a new direction for community services.**

London: DoH, 2006

### **4. Editorial – Teams without walls: the future of care closer to home**

Clin Med 2008;8:130-1

### **5. The National Service Framework for Long-term Conditions.**

Department of Health. London: DH, 2005.

### **6. National Guidelines No 10 Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care.**

Royal College of Physicians UK. March 2008

### **7. Prime Minister's announcement of a feasibility study into a life time care and support scheme, National Disability Awards, Parliament House Canberra, November 23 2009**

## **DHS Policy context**

**8. The Victorian Health Independence Guidelines (2008)** aim to ensure appropriate health care is delivered **at the right time and in the right place**. Based on the supporting principles of – person and family centred care, quality and evidenced based and timely services, equity of access, coordination and integration, interdisciplinary approach, appropriate setting – as close to the patients home as possible.

<http://www.dhs.vic.gov.au/subacute/hip-manual08.pdf>

**9. The Care in your community (2007) document** provides a framework for modernisation of the Victorian health care system to provide health care which is **integrated and coordinated to the needs of people**, with an emphasis on providing people with care in their community whenever it is safe and effective to do so.

<http://www.health.vic.gov.au/ambulatorycare/careinyourcommunity>

**10. The Sub-acute Ambulatory Care Services (SACS)** framework will provide guidance on the integrated provision of **community based** rehabilitation and specialist assessment and management services.

<http://www.health.vic.gov.au/subacute/sacs/index.htm>

**11. Victoria. A better state of health (2005)** articulates five principles for the development of a sustainable, high quality health system for Victoria. The five principles encompass the view that patients should receive care in the best place to treat them and by the systems elements working together, using the best technology available this will improve outcomes for both patients and health professionals.

<http://www.health.vic.gov.au/archive/archive2008/betterstate/index.htm>

**12. Strengthening Palliative Care Policy 2004-2009 A policy for health and community care providers** provides the new directions for improving access for all Victorians with life-threatening illness to palliative care appropriate to their needs.

<http://www.health.vic.gov.au/palliativecare/polfund.htm>

## **Service Models**

### **13. Victorian Paediatric Rehabilitation Service model of care**

proposes a model of care for children and families living with complex disabilities.

[http://www.dhs.vic.gov.au/health/subacute/vic\\_paed\\_rehab\\_service\\_model.pdf](http://www.dhs.vic.gov.au/health/subacute/vic_paed_rehab_service_model.pdf)

### **14. Victorian Paediatric Palliative Care**

[http://www.rch.org.au/rch\\_palliative/index.cfm?doc\\_id=1650](http://www.rch.org.au/rch_palliative/index.cfm?doc_id=1650)

**15. Integrated Service Model for the provision of HIV Services in Victoria** covers all parts of the health system, including acute care, non-acute health services, mental health services and home and community care.

<http://www.health.vic.gov.au/hivaids/>

### **16. Renal Dialysis: a revised service model**

<http://www.health.vic.gov.au/renaldialysis/improving.htm>

### **17. Motor Neurone Disease and Palliative Care: Interim report on the MND Pathway Project**

This report provides a framework to assist people living with Motor Neurone Disease (MND) to access palliative care services, It also assists palliative care services to manage and support people living with MND.

<http://www.health.vic.gov.au/palliativecare/mnd-report.pdf>

**18. Collaborative Care in Motor Neurone Disease, 2009.** Victorian State Government sponsored project to develop a statewide, integrated model of care for people with Motor Neurone Disease. Project team: Calvary Health Care Bethlehem, MND Victoria, Victorian Respiratory Support Services (Austin Health), Victoria.

**19. Continuous Care Pilot Project, 2010.** This project was funded through the 'My Future, My Choice' Initiative to investigate an intensive care-coordination approach to disease and risk management for young people with progressive neurological diseases. Project team: MS Australia: ACT/NSW/Vic and Calvary Health Care Bethlehem, Victoria.